

Welcome

It gives me great pleasure to welcome you to this Autumn edition of the HSE National Dementia Services (NDS) newsletter 2024. Across the National Dementia Services, our team have been busy progressing a wide range of projects to increase awareness, offer education, and improve access to services in relation to dementia.

September is World Alzheimer's month; the theme this year is 'Time to act on dementia, Time to act on Alzheimer's'. This will focus on raising awareness and on addressing the stigma and discrimination which still exists around dementia. It is also an opportunity to acknowledge the progress made by organisations and governments globally to develop a more dementia inclusive society. September will be a time for people across the world to come together to raise awareness and to challenge the stigma that persists around dementia. On September 21st, we mark World Alzheimer's day. We would encourage where possible to support and interact with any dementia related material that marks this important date.

I hope you enjoy this issue of our newsletter and as always, please contact us with any comments or suggestions at dementia.office@hse.ie

- Paul Maloney

Programme Manager, National Dementia Services

QUICK UPDATES

eLearning: Support Pathways for People with Non-cognitive Symptoms of Dementia

The National Dementia Services launched a new HSeLanD module "Support pathways for people with non-cognitive symptoms of dementia" in December 2022, targeted at all staff who provide care to people with dementia across all settings. This 30 minute module aims to help the learner to determine the best person-centred supports for a person with non-cognitive symptoms of dementia and to recognise the risks of unnecessarily prescribing a psychotropic medication. There are three core topics within the module:

- Topic 1 - Non-cognitive symptoms of dementia
- Topic 2 - Tailored, person-centred support
- Topic 3 - Risks of psychotropic medication

The module has been completed to date by more than 5,100 learners, and has been evaluated very positively, for example:

"A very comprehensive module with great overview of current guidelines and plenty of direction to follow on from this module"

Update on Special Interest Groups

Special Interest Groups (SIGs) for each of the following were set up in recent months by the National Dementia Services: Post Diagnostic Support; Brain Health; Cognitive Stimulation Therapy. The primary aim of the groups is to design nationally agreed, exemplar pathways across all Regional Specialist Memory Clinics (RSMC) and Memory Assessment and Support Services (MASS) in relation to Post Diagnostic Support, Brain Health and Cognitive Stimulation Therapy. All three SIGs have held a number of meetings as well as an in-person workshop in recent weeks in their initial work to develop pathways. The workshops were attended by staff from the HSE and voluntary sector, across a wide range of disciplines. The pathways developed by these SIGs will be implemented by existing and future RSMC and MASS to share locally developed programmes that could be utilised and scaled nationally across RSMC and MASS sites.

Brain Health

In July, members of the Brain Health Special Interest Group with representatives from the RSMCs, MASSs, the Alzheimer Society of Ireland and academia, came together in Dublin to design a detailed pathway of an exemplar Brain Health programme that links with phase 3 of the main clinical pathway "Post Diagnostic Support and Brain Health". Cathy McHale, ANP Tallaght University Hospital, and Joshi Dookhy, ANP Galway University Hospital RSMC presented their approach to Brain Health in their respective clinics, and the group shared learnings, resources and best practice for a standardised approach to Brain Health across RSMCs and MASSs. The work will continue this year to finalise the pathway, design resources and communication materials.

Dementia: Understand Together

World Alzheimer's Month

Marking World Alzheimer's month this September, the HSE's Dementia: Understand Together campaign is encouraging individuals, businesses and community organisations to learn more about dementia and help to create dementia inclusive communities that include people with dementia and help keep them and their families socially connected.

Every September, people come together from all around the world to raise awareness and to challenge any stigma around dementia. This year's theme, 'Time to act on dementia, Time to act on Alzheimer's', is highlighting the positive steps being undertaken by organisations and governments globally to develop a more dementia inclusive society.

In Ireland, the HSE's Dementia: Understand Together campaign is doing just that. National partners across retail, transport, banking, healthcare and community organisations and more, have signed up to the campaign. They are taking practical actions, such as training staff and volunteers, making their services and spaces more accessible and displaying the national dementia inclusive community symbol to show their

Cathy McHale brings us through a day in her life as an Advance Nurse Practitioner based in Tallaght University Hospital



After many years working across many care settings, a gerontological nursing focus evolved into work as a Registered Advanced Nurse Practitioner in the Institute of Memory & Cognition in Tallaght University Hospital. Our all age Regional Specialist Memory Clinic is affiliated with Neurology Colleagues and the National Intellectual Disability Memory Service. We deal with a wide spectrum of deficits from subjective memory complaints to the most complex atypical presentations. My caseload largely consists of urgently triaged complex and younger cases of cognitive impairment. I spend a number of hours with the person and their family and the journey begins with advanced history taking, physical assessment and a comprehensive holistic review of cognition (using neuropsychological testing), gait, mood and language. I identify the tempo of evolution of symptoms and cognitive domains involved in order to get an accurate baseline of cognition to share with our multidisciplinary team at consensus meeting. I am fascinated by dementia and continually discover new facets of it through meeting new cases and seeing it through the eyes of other disciplines. One lovely part of my role is meeting patients and their families after diagnosis when the dust has settled. Post-diagnostic care begins by ascertaining the insight level of the patient, preference for information and support needs. An individualised care plan signposts to community services e.g. 'Exwell' to increase exercise, social connectedness. This clinic allows me to reinforce the given diagnosis, dispel myths and discuss important topics such as delirium and brain health. My educational role expands to many groups across the year e.g. student nurses and formal groups for families. I participate in workshops and initiatives to enhance dementia care and pathways both nationally and locally - to deliver equity of access and embellish services for our patients. I enjoy a role as clinical rater within the research arm of our service as we cater for our patients' right to participate in a variety of studies. I have learnt so much down through the years from our patients and their families about the lived experience of dementia. This experience is vital to harness and understand because it will be the primary guidance that we need in order to shape our services in a responsive way and improve the landscape of dementia care. No matter where my work life leads me I feel very honoured to share the journeys of so many inspirational people.

solidarity and support for people living with dementia and their loved ones. In addition, over 1,200 Community Champions are making a difference in their local communities by creating dementia alliances, holding awareness events and setting up dementia cafes and inclusive events and activities.

Research suggests that attitudes are changing, with 96% of people across the country feeling it is important to talk about dementia and 97% agreeing it is important to support people with dementia to stay active and socially connected in the community, when asked in the HSE's Advertising Tracker in March 2024.

Dementia: Understand Together offers free information, training and marketing materials and you can contact the campaign team directly if you would like advice about how you or your organisation can become more aware of dementia and more inclusive for people with dementia and their families. Email the team on understandtogether@hse.ie or get involved at www.understandtogether.ie. Dementia inclusive community materials can be ordered free of charge through health promotion: www.healthpromotion.ie

Inclusive community support continues to thrive across the country, here are some dates for your diary

- The North Cork Dementia Alliance together with Kevin Quaid, member of the Irish Dementia Working Group are hosting a dementia awareness evening on September 25th from 6.30-9.00pm in the Charleville Park Hotel. You can register by phone on 021 492 8389 or email ciara.murphy36@hse.ie

- The Solstice Arts Centre hosts Azure: Dementia-Inclusive Gallery Tours on Friday 27 September, Friday 29 October, Friday 29 November and Friday 20 December at 11am (90 minutes). The tours are free, but booking is required. For more information or to book, please contact Deirdre on 046 9092300 or by email at deirdre.rogers@solsticeartscentre.ie
- Dementia Cafés continue to be opened up nationwide, keep an eye on our social pages where we share information upcoming activities and events.

RTÉ Today Show 2024

Watch our recent 'Meet the Medical Expert' features on RTÉ's Today Show where the HSE's National Dementia Services Clinical Lead, Dr Seán O'Dowd and Dr Rónán O'Caomh, Consultant Geriatrician at Mercy University Hospital discuss the importance of social inclusion for people with dementia, changes we can all make to help reduce our risk of developing dementia and improve our brain health.

As well as raising awareness for dementia and brain health, the interviews highlighted the many positive actions community champions and partners are taking across the country and use of the national dementia inclusive community symbol as a sign of solidarity.

You can watch the interviews here: <https://www.understandtogether.ie/lets-talk-dementia/>

IMPLEMENTATION OF A CLINICAL GUIDELINE

on psychotropic prescribing for non-cognitive symptoms of dementia in Bantry General Hospital

National Clinical Guideline no. 21 (Appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia) was published by the Department of Health in December 2019 to guide the appropriate use of psychotropic medication for non-cognitive symptoms in a person with dementia (in any setting). An Implementation Programme for National Clinical Guideline no. 21 is underway by the National Dementia Services. A key element of this implementation programme is the delivery of a Facilitator Education Programme. The Facilitator Programme was piloted in three sites and is currently undergoing national roll-out in acute hospitals and residential care settings.

As part of the pilot phase, the Facilitator Education Programme was delivered by the National Dementia Services in Bantry General Hospital in November 2023. Six staff working in the hospital attended this one day programme of education, as well as five staff working in other locally linked community services. The day encompassed a range of interactive activities, group work and knowledge exchange with the overall goal of planning the implementation of National Clinical Guideline no. 21 in the attendees' settings. Feedback from attendees of the Facilitator Education Programme in Bantry General Hospital was very positive, for example:

"Enjoyed the mix of acute and community staff"

"A very enjoyable day - group work was beneficial"

"Great education programme, great discussions and brainstorming"



Image of Attendees at the Facilitator Education Programme in Bantry General Hospital

Staff who attended this education programme became Local Facilitators for the Implementation of NCG no. 21. A number of education sessions have been delivered by Local Facilitators in Bantry General Hospital, as outlined below:

- Delivering person-centred care for non-cognitive symptoms of dementia: This 90 minute education session was delivered on a twice weekly basis over an approximate four month period to 87% of all nursing staff and 65% of all non-nursing staff. Following this intensive delivery phase, monthly delivery of this education session will continue until the end of 2024, and quarterly delivery is planned following this.
- Prescriber education: Implementation of NCG no. 21. This 60 minute education is targeted at staff prescribing or administering psychotropic medication. As at May 2024, this session had been delivered to 66% of all staff in the hospital who are prescribers of psychotropic medications. It is planned to continue delivery of this education session on a less regular basis until all relevant staff have completed this.
- Using quality improvement methodology to support the implementation of NCG no. 21. This education session was

delivered once in order to facilitate an audit of psychotropic prescribing to be conducted. This audit will be repeated in the future in order to assess the impact of the education programme on psychotropic prescribing.

The implementation of NCG no. 21 in Bantry General Hospital has been led by Teresa Bohane (ANP Dementia) and Annette Collins (CNS Dementia). They have been supported by the Dementia Quality Improvement Assistant Director of Nursing for the area, Noreen Galvin. Speaking about the process of implementation in their setting, Teresa outlined "It was fantastic to be involved in the pilot roll-out of the Facilitator Education Programme for the implementation of National Clinical Guideline no. 21. We are very lucky here in Bantry to have had strong clinical and non-clinical management support for this work and for the release of staff to attend education sessions. Release of staff is an ongoing challenge and what we found worked well was to run the education sessions before or after mandatory education such as manual handling, as this made staff release easier." Speaking about their involvement in the audit of psychotropic prescribing, Teresa outlined "Taking part in the audit and receiving our audit findings has been very helpful to highlight areas where things are working well and other areas where practice needs to improve."

Noreen Galvin has liaised closely with the team in Bantry throughout their implementation journey: "Teresa, Annette and their team have worked incredibly hard to make this project a success in their setting. I will continue to support them as they deliver education sessions, now on a less frequent basis, endeavouring to reach all relevant staff. This education programme is crucial to ensure we are providing optimum care to people living with dementia, to ensure the focus remains on delivery of person-centred care, and to reduce inappropriate prescribing of psychotropic medications."

Where can I find out more or access relevant resources?

- Complete a 30 minute HSeLanD module "Support pathways for people with non-cognitive symptoms of dementia". This is available on hseland.ie.
- Read [National Clinical Guideline No. 21](#) and access the [algorithm to guide appropriate prescribing of psychotropic medication for non-cognitive symptoms in a person with dementia](#).
- Get [more information](#) about the Implementation Programme for National Clinical Guideline no. 21.
- Learn more about [non-pharmacological interventions to support those experiencing non-cognitive symptoms of dementia](#).
- Download this [document which answers a number of frequently asked questions](#) in relation to the comprehensive assessment of a person with dementia experiencing non-cognitive symptoms.
- Read the [prescriber information leaflet](#) which outlines the recommendations and good practice points of National Clinical Guideline no. 21, as well as providing information on comprehensive assessment and signposting to additional information. You can request a print copy of this by emailing dementia.office@hse.ie
- Download the information guide for people with dementia and their family carers and supporters in relation to prescribing psychotropic medication for non-cognitive symptoms of dementia. This is available in [Plain English](#) and [Easy Read](#) versions.
- Print and display these [infographics](#) in areas of your workplace which people with dementia and their family carers and supporters access.

The Online Family Carer Support Project, an initiative of Care Alliance Ireland, offers peer-to-peer support to family carers all around the country. Originally founded as a response to the sudden shut-down of services during the early days of COVID-19, thanks to the support of the HSE this project has now grown into an online community supporting over 8,500 family carers from every corner in Ireland.



The support group is moderated by a mix of professionals and family carers, offering a safe space to discuss all aspects of the life of a family carer, to ask and receive advice, and learn from other members' experiences. Family carers are proven to be at a greater risk of isolation, loneliness and depression than the general public, and one of the main objectives of this project is to reduce the negative impacts often associated with caring for a family member. Being a part of a community that understands what your life is like and the challenges you face on a daily basis can make such a difference. Along with answering queries around income supports and discussing the challenges of caring, we also offer a range of social activities for family carers. All of their activities are delivered online, making it much more accessible for family carers to take part and connect with others – they don't need to leave the house or worry about replacement care; everything is accessible from home. Some of their activities include an online book club, garden club, weekly Zoom coffee mornings, online art classes, monthly Zoom quiz nights as well as regular competitions, so there is something for everyone!

You can find more information about the Online Family Carer Support Project on their website, including a recent detailed presentation about the project:

<https://www.carealliance.ie/OnlineFamilyCarerSupportGroup>

The Online Family Carer Support Group is run through a private group on Facebook. There are no waiting lists and no requirement for formal referrals. Family carers can join at:

<https://www.facebook.com/groups/FamilyCarerOnlineSupportGroupIreland>

Hard copy fliers detailing the project are available on request by emailing tara@carealliance.ie



and recommendation of the Dementia Care and Support Home Care Worker Education Programme

The number of people living with dementia in Ireland today is 64,000; this number is expected to double by 2045. Two thirds of the current figure are living at home, and approximately 45% of all home care services in Ireland are provided to people living with dementia. There is an emerging consensus on the need to realign care with the kind of support that matches the wishes of people with dementia and their families. The Dementia Care and Support programme has been designed to address this need.

This programme is the official HSE training standard for Health Care Support Assistants. The Dementia Care and Support: Home Care Education programme is a QQI Level 5 Accredited programme. It achieved accreditation in 2020, following partnership with Irish Times Training and a robust accreditation process.

The programme aims to develop skilled, reflective and self-aware Health Care Support Assistants who are equipped to care for people with dementia with humanity, empathy, and dignity, so that they may live well for longer in their own homes and communities. The target learners for the programme are Health Care Support Assistants working with people living with dementia.

The programme has been designed by the National Dementia Services and Dublin City University in consultation with people living with dementia, family carers and experienced healthcare staff from all levels of community care.

The NDS piloted the education programme in three areas, i.e., CHO1, CHO4 and CHO5, between November 2020 to May 2023. After completion of the pilot phase the NDS commissioned an independent process evaluation by University College Dublin to capture impact and process of this training programme.

The evaluation has identified process issues to enable expansion and streamlining of the delivery of the Dementia Care and Support Programme and provided evidence on the effectiveness and impact of the programme on (i) learners, (ii) managers and (iii) care recipients.

It has also provided recommendations to assist with a national roll-out of the programme.

With respect to the future of the programme, there was strong support for the roll-out of the programme to other areas across the country. While stakeholders and learners would like to see the programme become mandatory for all Health Care Support Assistants.

Key Recommendations

- Develop an overarching implementation plan and monitor programme delivery.
- State and clearly define the role and responsibilities of all organisations involved in the implementation of the programme
- Better prepare Health Care Support Assistants or participation in the programme
- Monitor and evaluate changes to supervisory element of the programme.

The NDS would like to thank Dr Maria Pierce, UCD for her work on this evaluation and all those who contributed to this evaluation and who contributed to the overall success of the pilot phase. Funding has now been secured by the NDS from the Department of Health for national roll-out of this programme.

HSE SOUTH WEST HOST DEMENTIA WEBINAR

On 5 September, the HSE South West region hosted a webinar/seminar event entitled “Enhancing care for the person with dementia in hospital and going home” and was organised by the Regional Dementia Quality Improvement Steering Group as part of World Alzheimer’s Month. It was a very successful event with attendees from across the country including primary care, secondary care, residential care, community and dementia organisations such as the Alzheimer Society of Ireland and the National Dementia Services. A hybrid approach was used to access a wide audience with excellent attendance on line and in person.

Speakers and topics covered included

- Prof Suzanne Timmons, MUH/UCC, delivered the welcome and opening address
- Noreen Galvin, Dementia Quality Improvement ADON for the South West Region, presented on the Strategic Vision for the South West Region
- Sandra O’Sullivan, CNS Older Persons in SIVUH, presented on assessing for delirium using the 4AT tool
- Sharon Maher, ANP Dementia in MUH, spoke about management of delirium and identifying reversible causes
- Dr Kevin Quaid, Chair of the Irish Dementia Working Group, described his experience as a service user
- Mary Hickey, ANP Dementia in Kilkenny/Carlow, presented on adopting a person-centred approach
- Teresa Bohane, ANP Dementia in BGH, described her hospital’s journey in implementing National Clinical Guideline no. 21 in Bantry General Hospital
- Bernadette Horgan Edmead, Dementia Care Coordinator in CHO4, spoke about returning home and the range community services available
- Bridie O’Sullivan, Chief Director of Nursing and Midwifery, South-South West Hospital Group delivered the closing address

Feedback was very positive on the content and topics covered indicating that sessions were most practical, informative and a very enjoyable, worthwhile afternoon with attendees looking forward to the next seminar in the series. The Regional Dementia Quality Improvement Steering Group welcomes suggestions on future topics that staff would wish to hear about and topics can be forwarded to james.regan@hse.ie



Noreen Galvin speaking at the seminar