# National **Dementia** Services



# Newsletter | Spring 2025 ISSUE 16

# Welcome

It gives me great pleasure to welcome you to this Spring edition of the HSE National Dementia Services (NDS) newsletter 2025. We recently marked International Brain Awareness Week (10th March -16th March 2025), the Understand Together campaign urged people across the country to think more about brain health and to take steps to protect their brain health and reduce their risk of developing dementia. This is an area we are actively developing.

Across the National Dementia Services team we are working on a wide range of projects to increase awareness with our partners through the Understand Together Campaign, offer education through our eLearning modules and the Dementia Care and Support Education Programme for Health Care Assistants, and improve access to diagnostic services. I am delighted to say that the Regional Specialist Memory Clinic (RSMC) in the Mercy University Hospital, Cork recently became fully operational. All four RSMCs, Tallaght University Hospital, St. James hospital, University Hospital Galway are now operational. RSMCs offer assessment, diagnosis and post diagnostic support of younger, atypical or unclear presentations.

I hope you enjoy reading this edition of the Newsletter which will give an overview of this work to date and future plans. If you would like further information on any of the topics outlined in the newsletter or indeed would like to know about the on-going work of the office, please feel to contact us at dementia.office@hse.ie

> - Paul Maloney Programme Manager, National Dementia Services

# **QUICK UPDATES**

#### eLearning: Support Pathways for People with Noncognitive 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 and supporting resources across all Regional Specialist Memory Clinics (RSMC) and Memory Assessment & 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 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 2024, 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 & 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**

The HSE's Dementia: Understand Together campaign is a public support, awareness and information campaign that aims to inspire people from all sections of society to stand together with the 500,000 Irish people whose



families have been affected by dementia. Marking International Brain Awareness Week (10th March - 16th March 2024), the campaign urged people across the country to think more about brain health and to take steps to protect their brain health and reduce their risk of dementia. A Brain Health partner pack with information and social media messages was created.

This year the campaign is placing a focus on story-telling and growing the network of community champions. Your stories are making a difference, they are reaching people, changing behaviours, increasing empathy and enabling a dementia culture change. With many national partners and local community champions and alliances taken actions the national dementia inclusive community symbol is connecting all the work as an overarching symbol of solidarity and support. Campaign partner's parkrun and Men's Sheds spoke about the importance of community engagement and how their organisations reach out to all members in society including people with dementia to join their local parkrun and Men's Sheds on RTE's Today show. A "Your parkrun and dementia" and "Your Men's Shed and dementia" manual is available to order free of charge from www.healthpromotion.ie. You can view the segments here

Men's Sheds: A dementia inclusive community: https://youtu.be/NBXUIqu6l5A

#### parkrun: A dementia inclusive community: https://www.youtube.com/watch?v=kZPrXFR2BI4





#### **Community Champions**

As the network of champions grows, we can connect people locally to share ideas, and support one another. Champion actions can be as simple as wearing a dementia inclusive community badge, considering whether a family member, friend or neighbour might need support, or talking to local organisations and businesses about the dementia training that is available to them.

#### Please sign up to join the network of champions here

https://www.understandtogether.ie/get-involved/getinvolved.html

If you would like us to share your stories please contact understandtogether@hse.ie

Dementia: Understand Together community champions are making a difference in their local communities. As well as displaying and using the dementia inclusive community symbol on websites, newsletters and on social media, they encourage local organisations and businesses to take part in free dementia awareness training.

North Cork Dementia Alliance is supporting Kanturk & Charleville to learn more about dementia inclusive communities. Free on line training was delivered on February 19th 2025. The approach to this training was slightly different in that it was held by Kevin Quaid who is living with Lewy body Dementia and who is the chair of the Irish Dementia Working Group, and Amy Murphy,



dementia advisor. There were 34 attendees in total with an overwhelmingly positive reception. The cohort was composed primarily of people working in the community (e.g. Garda, HSE employees, ALONE support coordinators, Cork County/City Council employees). Dementia Inclusive community window stickers are in the post for every library in Cork, as well as the Cork North Community Work department.

Leitrim: The Mohill Town Team are aiming to make their town dementia inclusive. As part of this initiative they invited their local community to join a dementia inclusive community awareness evening on Thursday 27th February. Speakers included Fiona Foley, National Dementia Services, HSE, Marina Devaney, Dementia Advisor for Sligo/Leitrim, The Alzheimer Society of Ireland, and Sharon Richardson, HSE who facilitated an interview with Laura Dunlop, a Leitrim woman who is living with dementia. Mary Carleton Reynolds, Interim Chair Mohill Town Team said, "We are very aware that there are many people quietly living in our communities with dementia. Mohill is already designated as an Age Friendly Town and this dementia awareness evening provided very practical advice on the 6 actions we can all take to consider people living with dementia in our community. Whether it's a family member, friend, neighbour, or customer in our business, we can all play our part in supporting people with dementia to continue living well in their own community."



Picture from the night include members of the local community along with Dementia: Understand Together campaign partners from the HSE's National Dementia Services, The Alzheimer Society of Ireland, Age Friendly Ireland and Alone.



Ask how you

can help





touch

See the person, not the dementia



Stay in



Support the person to keep up hobbies and interests

Make sure your service or space is easy to use

#### Bantry Dementia Inclusive Community

Initiated by Age Friendly Bantry, a cross sectoral group which includes HSE Community Work, Bantry General Hospital, Alzheimer's Society of Ireland, West Cork Development Partnership, Dementia and Older Person Service Co-Ordinators and volunteers with the support of the National Dementia Service have been working to develop a dementia inclusive community in Bantry. The goal is a community which supports people living with dementia to participate in the economic and social life of the local area, availing of local shops and services, and taking part in community, leisure and faith activities. Free dementia awareness training has been delivered to staff in Bantry businesses to enable them to support a person living with dementia within their community. This was over two 90 minute sessions. Businesses and services where more than half of their staff have attended this awareness training, were presented with the National Inclusive Communities toolkit from Fiona Foley, National Dementia Services, HSE at a public information evening.

These businesses are finding that not only are they more responsive to people living with dementia but that all of their customers have benefited from the insights gained into better communication. One business owner stated "I am more conscious of the need to take time with people, to relax, go back over things again. Sometimes if I am not fully sure what they mean, I check if they have a photo of what they are looking for and often they will have one on the phone". - Vincent Cronin

This dementia awareness training has also been extended to community and sports groups and most recently to Transition Year students in the local secondary school.

Other elements in building a Dementia Inclusive Community, include a Memory Café which has just celebrated it second anniversary and memory Cafes are now being established in other towns in west cork. Weekly Singing for the Brain sessions are very popular. 100% of staff in Bantry Library have now completed dementia awareness training. Bantry Library are commencing a reading group for people experiencing concentration issues. We are continuing to work with Bantry Day Care Centre and West Cork Arts

Action plan to continue to develop a Dementia Inclusive Community in Bantry and to extend this approach to other parts of west cork is nearing conclusion.

The work done to date has increased the awareness locally about dementia and encouraged people to talk about their experiences with family members and friends living with this condition. All parts of the community express more confidence in their ability to support people living with dementia.



Staff at Organico displaying the dementia inclusive community badge.



Staff at Drinagh hardware displaying the dementia inclusive community badge



Staff at Bantry library

#### Conferences and webinars

The year started off with the Let's Talk Dementia Webinar with more than 820 participants, and over 1,100 people viewing the recording. The webinar was organised by HSE Healthy Ireland Office and the HSE National Dementia Services, with information on the signs and symptoms of various types of dementia and the importance of understanding these, supports and services that are available, the Dementia Model of Care in the HSE, the impact of social inclusion on people living with dementia, and the lived experience.

If you wish to view the recorded webinar it is available here.

#### Genetic Testing in Dementia

There is growing public awareness and concern regarding dementia risk. In addition, genetic testing is increasingly accessible and is at the point of being integrated into routine clinical practice. As a result, there is a pressing need for treating clinicians to have the appropriate knowledge base to request and consent for diagnostic genetic testing in cognitive clinics. Dr. Sean O'Dowd (Clinical Lead, National Dementia Services) was involved in below publication which outlines the group's approach to genetic testing in patients with Alzheimer's disease, frontotemporal dementia, dementia with Lewy bodies and vascular cognitive impairment. The publication also describes when to consider testing, the consenting process, and the interpretation and communication of genetic test results.

O'Connor A, Ryan NS, Belder CRS, Lynch DS, Lahiri N, Houlden H, Rohrer JD, Fox NC, O'Dowd S. Genetic testing in dementia. Pract Neurol. 2024 Sep 17:pn-2024-004241. doi: 10.1136/pn-2024-004241. Epub ahead of print. PMID: 39288984.

#### LINK: https://doi.org/10.1136/pn-2024-004241

#### Brain Health - what's your take on it?

A recent HSE study, conducted by Empathy research, is aimed at understanding the public's awareness and knowledge of dementia risk factors and the importance of maintaining a healthy brain in order to reduce the risk. 1500 adults over the age of 18 with a focus on women (sample size 1000) participated in the research.

Our brain is more powerful, more complex and much smarter than any computer ever built, and it has more connections than there are stars in the universe. Our brain thinks, remembers, solves problems and coordinates all actions at the same time, even when we're asleep.

#### But many of us take our brains for granted

The research findings show that only 1 in 10 are familiar with the term "Brain Health" and that while participants tend to understand in general that a healthy lifestyle reduces the risk of health issues, 77% don't know that they can take steps to reduce their risk of developing dementia.

This, despite 1 in 5 saying they are most concerned about developing dementia in the future, ranking second overall behind cancer.

Asked about what may impact the risk of developing dementia, 3 in 4 feel that a lack of engagement in mentally stimulating activities may increase the risk of memory decline and dementia. However the impact of vaccines, hearing loss, blood sugar levels and blood pressure are not as clear.

Positive news is, almost 7 in 10 of study participants believe they can improve their brain health, with high levels feeling it is never too late to take action. Together we can build on the 'BELIEF IN THE POTENTIAL OF POSITIVE CHANGE'.

Although we can't prevent all types of dementia, small lifestyle changes can help reduce the risk, while also helping a person with dementia to live well.

You can find more information on Brain Health here https://www.hse.ie/eng/dementia-pathways/resources-forpractice/brain-health-risk-reduction/ and below are some impactful examples of Brain Health initiatives across the country.

#### 'Try it for your Brain Groups'

The North Cork Dementia Alliance has recently begun facilitating six week 'Try it for your Brain' groups. Aimed at those in the early stages of dementia these groups give participants the opportunity to undertake new challenges in a supportive and understanding environment. The first of these groups was a six week 'Ukulele for the Brain' group, facilitated in the summer of 2024. Six people took part in the group and though some found the instrument a challenge to play, all reported enjoying the opportunity to try it, along with the social aspects of the group.

Now a 'Writing for your Brain' group is being launched. This will be facilitated by Mecca Barrett, chair of Mallow Scribes and will incorporate creative writing and poetry. Five participants have signed up with the hope that the group provides an opportunity for self-expression and creativity.

#### Supportive Saturdays

Keeping clients socially active is a key target of the HSE dementia care coordinator service. As a response to service user feedback, Supportive Saturdays was developed to facilitate weekday working families/care partners by arranging these information days at the weekend. West Cork was chosen as the pilot area with rural isolation being a prevalent issue. Supportive Saturdays will be once a month in seven locations in West Cork, with various health professionals joining the team for informative sessions on aspects of dementia and brain health with a different theme each month Open to Everyone. Please contact 0214923998 or email







upportive Saturdays– Love your Brain

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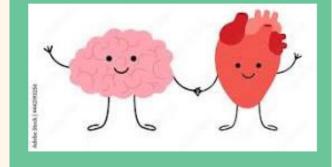
Want to find out more about Brain Health?

Are you living with Dementia? Or are you a care partner?

Come meet some of the HSE Dementia Care Coordinator team and Public Health Nurse from Diabetes and Cardio Vascular Prevention and get to know your risk factors and how to stay healthy and well

# All welcome

Location: Skibbereen Day Care Centre is adjacent to Skibbereen Community Hospital. Address: Coolnagarrane, Skibbereen, P81 PY82 Date: 15th February Time: 11pm - 13.00pm For more information Call : (021) 4923998





# Dementia Services Information and Development (DSiDC) updates

The DSIDC have had a busy start to 2025 with the launch of the updated version of the popular 'Dementia Awareness' eLearning course. It has a fresh new look, updated information and automatic certification on completion. The updated 'Communication' eLearning course also is scheduled to become available in the next few weeks so keep your eyes open! In other eLearning news there is now a webpage dedicated to Micro learning. Short, focused learnings that can be done on your mobile. See www.dementia.ie/education for all online offerings and contact us at dsidc@stjames.ie for inperson training.

Friday 23rd May, 'Memory Assessment Services Conference'. Back for its 10th anniversary. All Memory assessment staff welcome. Register at https://MASConference2025.eventbrite.ie

Bernadette.HorganEdmead@hse.ie

# Dementia Care and Support Programme for Health Care Support Assistants

National Dementia Services secured funding through the National Service Plan for the rollout of the Dementia Care and Support Programme. In 2024, eight areas completed this training. They are Tuam, Claremorris, Offaly, Lifford, Letterkenny, Buncranna, and groups from across Cork and Kerry. There has been continued interest in the training and other Regional Health Authorities (RHA) areas are hoping to commence training for health care support assistants in 2025.

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

The overall approach is that the learner is not only learning about the illness but also about themselves, their ability to recognise stress, practice self-care, establish and maintain boundaries, to build relationships of trust, develop ethical approaches and fundamentally take a strength-based, rather than loss-based approach to Dementia care.

We would like to thank Irish Times Training, Leadership Learning and Talent Management, tutors, Home Support Managers and all the participants who have attended the training for their ongoing commitment and support of this programme.

**Engaging Dementia: The 17th International Dementia Conference** takes place in the Athlone Springs Hotel, Co. Roscommon, on the 7th & 8th of May.

Topics cover Dementia Inclusion in the Community, Late-Stage Dementia and End of Life, Person-Centred Training and Therapeutic Interventions, Young Onset Dementia, and many more!

Hear from those living with dementia and family carers, as well as industry-leading researchers, professors and healthcare professionals.

17th International Dementia Conference Bridging Worlds in Dementia Care: Connecting Global Perspectives and Local Solutions' 7th and 8th May | 2025

Welcoming those living with dementia, family carers, volunteers, industry-leading researchers, professors and healthcare professionals













### A DAY IN THE LIFE

Catherine Dolan brings us through a day in her working Life in the Sligo Memory Assessment and Support Service (MASS)



Sligo MASS provides a service for people with symptoms of cognitive impairment and dementia, along with their families. in Sligo, Leitrim, West Cavan and South Donegal since 2022. It is one of three operational MASS services across Ireland to date, and the first dedicated memory service in the North West of Ireland. With a Sligo town community team base, it is co-located with other local specialist HSE Older Persons services, including the ICTOP team.

Sligo MASS is an integrated memory service with multidisciplinary clinicians from across the acute hospital and community services. Clinicians come together to provide person centred care for people with cognitive impairment and dementia, including those with young onset dementia. The service is consultant-led collaboratively by Neurology, Psychiatry of Old Age, Geriatric Medicine, Radiology and Older Persons Service clinicians. The expertise of the multidisciplinary team, consisting of administrative, medical, nursing, occupational therapy, dietician, social work and psychology professionals, reflects the diverse care needs of our service users.

Sligo MASS serves the population of a predominantly rural, and geographically dispersed, catchment area in community based clinics, outreach to people's homes, as well as in-reach to a Geriatric Medicine Clinic in Sligo University Hospital. Through doing this we aim to deliver the right care, at the right time, by the right team in line with HSE policy.

When a person with a cognitive complaint is assessed in Sligo MASS they get a comprehensive assessment to try and determine the cause. If they receive a diagnosis of dementia they can avail of Sligo MASS post diagnostic service (PDS) with a keyworker allocated. As part of PDS, a support plan is made collaboratively with the patient and family aiming to meet their individualised needs, along with emotional support for the person with dementia and their family.

MASS Sligo team members also run groups jointly with other local dementia care related services including Alzheimer's Society of Ireland and Sligo Memory Technology Resource Room Service. These close links between MASS and related services helps strengthen the support network for people with dementia while acknowledging their changing needs over time.

Given the breadth of the service and the unique needs of service users, no two days are similar in Sligo MASS. My role includes assessing, and diagnosing patients and meeting with families, leading a weekly MASS clinical consensus meeting where assessments are discussed and next steps planned, reviewing patient brain imaging in a monthly MASS radiology meeting, monthly integrated Cognitive Clinical meetings with hospital colleagues, and disclosure and follow up clinical reviews with service users and families.

Linked with clinical care are my administrative tasks and operational and management duties. They include triage of new referrals to the service, correspondence with other clinicians involved in shared patient care, supervision and support for team members, monthly MASS and wider operational meetings, service activity reviews and planning. Active membership of National Dementia Service working groups, research work, audit, education, supervision and training of fellow professionals are also an important part of my role.

As a psychiatrist, when meeting with service users and families and disclosing a diagnosis of dementia, including those with young onset dementia, my focus is on identifying the strengths and preferences of the person, as well as the current challenges for the person and their family. Getting to know a person's background and life story is key to helping identify appropriate interventions and supports to promote independence, enhance their ability to live well in the community for as long as possible.

Learning how each person's unique cognitive and non-cognitive symptoms of dementia, impact on the quality of their daily life, relationships with loved ones or carers, as well as their physical and mental health is a humbling experience. Hearing and supporting family carers in their unique carer journey, identifying carer burden and helping carers access timely interventions and support is a vital part of our roles as MASS team members.

I learn something new every day from the patients and families that we work with in Sligo MASS, as I have from my own experiences with family members with dementia.

Dr. Catherine Dolan is a Consultant in Psychiatry of Old Age, Sligo Leitrim Mental Health Service (SLMHS) and Co-Consultant lead in Sligo Memory Assessment and Support Service (MASS) along with Geriatric Medicine, Neurology, Radiology and Older Persons Service colleagues.

As part of her post graduate training she completed two year clinical fellowship in the National Memory Clinic with an MD in Clinical Research through Trinity College Dublin in the area of diabetes and brain health in conjunction with Public Health Medicine colleagues. She is also Honorary Senior Lecturer, University of Galway and NCHD Clinical Tutor in SLMHS.

### YELLOW DAYS POETRY COLLECTION

HSE's Memory Harbour service and Dún Laoghaire-Rathdown County Council are delighted to announce the launch of Yellow Days a new poetry booklet by the Harbour Poets.

The poets overcame the challenges of brain health, including planning, organizing, meeting new people, and testing their language skills, to reflect upon and write this remarkable collection of poetry. They collaborated with poet Grace Wilentz and Catherine Keogh, Senior Occupational Therapist, to bring this collection to life.

The Memory Harbour is part of a national network of HSE Memory Technology Resource Rooms. If you'd like to receive a copy of Yellow Days or would like more information about the project, please reach out to the Arts Office at arts@dlrcoco.ie or call (01) 236 2759.



### We are delighted to showcase some poems written by the Harbour poets:

#### Yellow

As the sun was rising over the sea Yellow turning gradually to orange Shining on the yellow sail of my boat And reflecting yellow onto the blue sea I though how lucky I was To be able to enjoy my time sailing My yellow boat on the blue sea

(By Roger)

#### Hands old and worn

Hands old and worn But musical in movement Playing the organ for a service. She is a constant in this gallery. How can she live like this for so long? There is no problem, it is her way.

(By Anne)

#### The Ballad of Alzheimer

I know a guy Alzheimer But Al is not my friend. Sometimes I think he is trying to send me Right around the bend. He bothers and bewilders me And makes me feel a fool. Hes really not a nice guy In fact, he's very cruel. But I shall have the last laugh When they can find a cure. Then nasty Al can take a hike. He'll bother me no more. (By David)

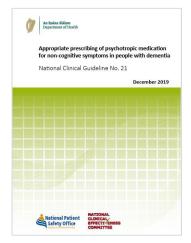
# THE IMPLEMENTATION OF NATIONAL CLINICAL GUIDELINE NO. 21 (NCG NO. 21)

#### "Appropriate prescribing of psychotropic medication for noncognitive symptoms in people with dementia"

The implementation programme continues nationally, with the Project Facilitators delivering a Facilitator Education Programme across Acute, Residential Care, Community Nursing Units, and Mental Health settings.

In recent months staff at sites in Cavan, Cork, Drogheda, Dublin, Kerry, Kildare, Limerick, Laois, Meath, Roscommon, Waterford and Wexford, have attended the Local Facilitator Education Programme. Once staff have attended this, they can plan and implement the rollout of NCG no, 21 in their setting.

Following on from their training, staff at Midlands Regional Hospital Portlaoise held an awareness day in January for the Implementation of NCG no. 21. There was an overwhelming turn out with over 100 staff visiting the stand on the day. Fantastic to see the progression of the roll-out being embraced so enthusiastically by staff.





Smitha Joy, CNS Dementia Care MRHP at the promotion of NCG no. 21



Staff from MRHP at the promotional stand

To keep up-to-date on National **Dementia Services and related** dementia news follow us on



dementia.office@hse.ie



