

## Welcome

Welcome to the Autumn 2023 edition of the HSE National Dementia Services newsletter.

September is World Alzheimer's month, the theme this year is "Never too early, never too late", which notes the value of Alzheimer's disease risk factors identification but also highlights the importance of proactive risk reduction measures to reduce, and if possible, prevent the onset of dementia. September will be a time for people across the world to come together to raise awareness and to challenge the stigma that surrounds dementia. On September 21st, we mark World Alzheimer's day. We would encourage you, where possible, to support and interact with any online 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](mailto:dementia.office@hse.ie)

- Paul Maloney

Programme Manager, National Dementia Services,  
Services for Older People, Change and Innovation

## QUICK UPDATES

### Community Champion "Welcome" Workshop

More than 200 new champions have joined Dementia: Understand Together since the launch of the dementia inclusive community symbol. All champions are invited to an initial workshop in which we explore the role we can all have in making our communities dementia inclusive, hear from other champions and connect with like-minded people in our community. 40 champions ranging from members of Tidy Towns, Libraries, local businesses, healthcare professional and volunteers joined the first workshop. Their feedback was overwhelmingly positive: "It is so helpful to know I can be part of a network. We are much stronger together and I'm really excited to get started". Additional workshops will take place on September 27th and November 8th from 12pm-1.30pm. To sign up please email [understandtogether@hse.ie](mailto:understandtogether@hse.ie)

### Dementia "Elevator" training relaunched

The Dementia "Elevator" training for financial services, retail and transport staff members is a free online dementia training module to increase awareness and understanding of dementia. The training videos include practical examples of how staff members can support a person with dementia to avail of their community services.

In addition to other free online trainings such as "Environmental Design" and "Dementia Awareness for individuals", bespoke training options for national organisations and community groups are also available. Visit [www.understandtogether.ie](http://www.understandtogether.ie) for a list of all dementia awareness training.

### Migration of Dementia Pathways website to HSE

The Dementia Pathways website was originally developed by the PREPARED project in UCC as a resource for primary care professionals, as part of the implementation of the National Dementia Strategy. In 2019, the National Dementia Services took on responsibility for maintaining and updating this website. Through the National Dementia Services, the Dementia Pathways website was expanded in scope to provide resources and information for health and social care professionals across all settings. The Dementia Pathways website is currently being migrated to the HSE website. This migration aims to improve the user experience for staff accessing the website to view information, publications or resources.

### Conferences and Events

The National Dementia Services team have attended and presented at a number of recent conferences and events.

On 14th March, Seán O'Dowd was a member of the discussant panel at a seminar entitled "Policy perspectives on the future of dementia care in Ireland". On May 10th, Seán chaired the Cognitive Neurology and Dementia Platform Presentation Session at the joint Association of British Neurologists - Irish Neurology Association Meeting in Belfast.

At the Engaging Dementia conference on 25th May, Fiona Foley presented with Kathleen Farrell, member of the Irish Dementia Working Group, on Dementia: Understand Together and the co-creation and implementation of the national dementia inclusive community symbol as a sign of solidarity and support. Seán spoke as part of day two of the Engaging Dementia conference programme on 26th May, providing information on the complexities of Lewy body dementia and related disorders.

On 26th May, TrinityHaus hosted a research symposium entitled "Ageing and Dementia in Healthcare Settings: Design, Evaluation and Beyond". Mairéad Bracken-Scally spoke at this event about the learning from the environmental audit of acute hospital wards conducted as part of the Second Irish National Audit of Dementia in acute hospitals (INAD-2).

The Understand Together campaign and dementia inclusive community symbol roll-out was Fiona's theme at this year's Health & Wellbeing Community Health Organisation Dublin North City and County Healthy Ireland Conference.

Dementia: Understand Together joined Irish Rail's Health & Wellbeing conference as well as Healthy Ireland's "The time is now" conference, held a lecture on Dementia Inclusive Communities as part of University College Cork's MSc on Dementia, and spoke about dementia and brain health to the Health Promotion & Improvement Officers in CHO Dublin North City & County.

The Enhanced Community Care (ECC) Conference took place on 7th September. The theme for the conference was "Integrated Care: Empowering People and Improving Experiences". Seán O'Dowd spoke about the Model of Care for Dementia as part of the conference agenda.

## LAUNCH OF MODEL OF CARE FOR DEMENTIA

On 31st May, the HSE Enhanced Community Care Programme and National Dementia Services launched a [new Model of Care for Dementia](#). The Model sets out a range of targets and practice recommendations to advance the assessment and diagnosis of pre-dementia states (MCI) and dementia. The Model is underpinned by the following principles:

- people living with dementia are at the centre of considerations relating to service design and recommendations related to care practices
- they receive timely and equitable access to assessment, diagnosis and post-diagnostic support regardless of the location of a service, the type of dementia they have, their age, their ethnicity, any other disability or co-morbidity, or their gender.

The Model builds upon the work of the National Dementia Strategy (2014), the HSE Corporate Plan 2021-2024 and has been developed within the context of Sláintecare (2020-2023) and the health reform agenda, where delivering the right care, in the right place, at the right time, given by the right team.

The Model provides for a diagnostic framework utilising three levels of assessment:

- **Level 1: Primary Care GP delivered assessment:** This may include support and information from any community services, including any of the Enhanced Community Care (ECC) programme services; CHN/Primary Care Teams, Community Specialist Teams for older people, Community Specialist Teams for chronic disease and Community Intervention Teams (CIT).
- **Level 2: Memory Assessment and Support Service:** People 65 years or over with a typical and clear presentation of dementia will predominantly be assessed and supported in a Level 2 Memory Assessment and Support Service (MASS) (or/other specialist service). Ten MASSs have been funded to date, located in the Donegal, Sligo, Cavan/Monaghan, Mayo, Galway, Mullingar, Limerick, Kerry, Wexford and Waterford.
- **Level 3: Regional Specialist Memory Clinic (RSMC):** People 65 years or under with a suspected dementia or those with atypical or unclear presentations that require a more detailed assessment will predominantly be assessed and supported in a Level 3: Regional Specialist Memory Clinic (RSMC). Four RSMCs have been funded to date, they are located in the Mercy University Hospital, Cork, Galway University Hospital, Tallaght University Hospital (TUH) and St James's Hospital, Dublin.



Members of the National Dementia Services team with Minister Mary Butler TD at the launch of the Model of Care for Dementia

In addition, the National Intellectual Disability Memory Service (NIDMS) operates out of TUH and possess the MDT skill mix needed to assess, diagnose and support people with intellectual disabilities who present with memory concerns.

All of the above assessment services will not only be integrated with each other, but more importantly will be integrated with all dementia related services within the community. This is critical to ensure that the person living with dementia is signposted to the right service, in the right place and at the right time.

The Model of Care for Dementia is the culmination of significant engagement, investment and collaboration of a broad range of expert stakeholders across Community and Acute HSE service, Voluntary services, Third level education sector, Clinical and Executive Leadership within the HSE, Department of Health and Minister Mary Butler - Minister for Older People and Mental Health.

On 11th September, Kate Brennan represented the National Dementia Services at the report launch of "Living Well with Dementia in South Tipperary: Ten Years of Service Implementation, Sustainability into the Future". Kate spoke about how services like the Living Well with Dementia Service contribute to implementing the National Dementia Strategy.

At the upcoming Irish Gerontological Society Annual Scientific Meeting, Mairéad will provide a poster presentation on the development of education to implement National Clinical Guideline no. 21. In addition, we are delighted to have team members Mairéad and Kate attending the upcoming Alzheimer Europe conference in October to speak about their programmes of work within the National Dementia Services team.

### Dementia Care and Support Programme

The Dementia Care and Support Programme has been running in a pilot phase from 2021 to 2023. It has been implemented in three CHO areas; 1, 4 and 5. The programme was designed by the National Dementia Services team and DCU in consultation with people living with dementia, family carers and experienced healthcare staff from all levels of community care. This highly experienced team also previously developed and delivered the Dementia Skills Elevator empowerment programme between 2014 and 2017. The team then worked in partnership with Irish Times Training to accredit the programme as a QQI award. It is currently being delivered by Irish Times Training through the HSE and the Alzheimer's Society.

To date over 120 home care support workers in Donegal, Cork, Bantry, Kerry, Sligo, Cavan/Monaghan and Kilkenny have completed this programme and secured their level 5 QQI accreditation. A process evaluation of the programme will be conducted by a research team in UCD. We look forward to working with Maria Pierce and her team in UCD on the process evaluation.

### 'Living Well with Dementia in South Tipperary' project marks 10 years of service

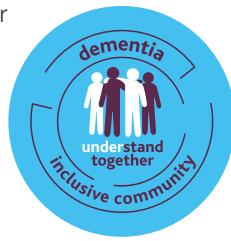
Supported by the HSE and run in cooperation with Family Carers Ireland, the 'Living Well with Dementia in South Tipperary' project marked 10 years of service recently. Established in 2012, 'Living Well with Dementia in South Tipperary' provides a broad range of supports and services which are designed to help people live as well and as independently as they can at home in their own community. An Evaluation Report, focused on this service's implementation and sustainability into the future, was launched this month. Funded by the HSE and Family Carers Ireland and carried out by Dr. Maria Pierce and Jeremy Golden of University College Dublin, the Evaluation Report looks at a wide range of practical, personalised, post-diagnostic, psychosocial supports and interventions provided by the project, in addition to contributions to national policy and programme development. More information available on the "Living Well in South Tipperary Project" at [www.SouthTipperaryDementia.ie](http://www.SouthTipperaryDementia.ie)



Dr Seán O'Dowd, Clinical Lead for National Dementia Services, speaking at the launch of the Model of Care for Dementia.

## LAUNCH OF NEW DEMENTIA INCLUSIVE COMMUNITY SYMBOL

In a celebratory event, Minister Butler together with people with dementia launched the new dementia inclusive community symbol. The symbol, which was created in consultation with people with dementia, carers, community champions and national partners, acts as an overarching symbol of solidarity, inclusivity and support for people living with dementia. Dementia: Understand Together is encouraging all organisations and services in communities to display the symbol, to raise awareness for dementia and to show that we are all working together to being dementia inclusive.



Some 40 partners, ranging from voluntary and community groups, academia and health to retail, transport and financial services, as well as local champions are backing the campaign, and are exploring how simple actions can make a real difference to making their services and businesses more accessible to everybody living in our diverse communities.

Kathleen Farrell, who is living with Lewy Body Dementia and is a member of the Dementia: Understand Together working group says: "I got involved in making the poster for the symbol campaign and it was the most incredible day. It is so important for me to be part of my community and I am very active in it. This symbol will enable people to engage in their own communities safely and as we all know, being part of our community is essential to our wellbeing."

If you'd like to join the campaign or find out more about dementia awareness training for your organisation or group visit [understandtogether.ie](http://understandtogether.ie)

All campaign resources such as the symbol guidance document, window stickers, posters and badges, can be ordered free of charge from [www.healthpromotion.ie](http://www.healthpromotion.ie)



Members of the Understand Together Working Group with members of the Irish Dementia Working Group

## UPDATE ON IMPLEMENTATION PROGRAMME FOR NCG NO. 21

The Implementation Programme for National Clinical Guideline No. 21 ("Appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia") is progressing at pace since its commencement in 2022. The HSeLanD module "Support pathways for people with non-cognitive symptoms of dementia", launched in December 2022 has been completed by over 2100 learners to date.

The Implementation Programme team will commence roll-out of the Facilitator Education Programme in the coming weeks. This one day programme will be attended by staff who will become Local Facilitators and go on to roll out three education sessions within their settings:

- **Delivering Person-Centred Care for Non-cognitive Symptoms of Dementia:** This session is targeted at all staff who provide care to people with dementia across all settings and provides relevant information on person-centred care and non-pharmacological approaches to support people experiencing non-cognitive symptoms of dementia.
- **Prescriber Education:** This session is targeted at the prescribers of psychotropic medication, namely doctors, nurse prescribers and pharmacists. It provides detailed information and guidance in relation to implementing the recommendations of National Clinical Guideline No. 21.
- **Using Quality Improvement Methodology to Support the Implementation of NCG no. 21:** This session is targeted at staff who will conduct an audit of psychotropic prescribing within their setting and provides detailed guidance on the audit process and audit tool, as well as relevant information on clinical audit and quality improvement more broadly.

An independent evaluation of the Implementation Programme is being undertaken by a research team in Trinity College Dublin, and is an important part of the process of determining the effectiveness and impact of the Implementation Programme.

## DISEASE-MODIFYING TREATMENTS

Up until recently, standard drug therapy for Alzheimer's disease (AD) treated symptoms only, with no ability to alter the relentless course of the disease. However, a ground-breaking new class of medications, targeting beta-amyloid protein (which accumulates abnormally in brains of people with AD) has now, for the first time, demonstrated a disease-modifying effect: the ability to slow progression of disease in those treated in the early phase.

In January 2023, the New England Journal of Medicine published the results of a large clinical trial (1800 participants) of the anti-amyloid therapy lecanemab. The drug slowed the rate of progression of cognitive decline in early AD by 27%. After initial accelerated approval by the US regulator, the FDA, in January 2023, full "traditional" approval was granted in July 2023. Lecanemab is currently undergoing regulatory review in Europe, with a decision regarding approval expected in early 2024. In July 2023, similarly encouraging results were published in JAMA, of another large clinical trial involving a second anti-amyloid antibody, donanemab, which also demonstrated a significant disease-modifying effect.

This is a huge breakthrough in the field of neurodegenerative disease. However, availability of anti-amyloid disease-modifying therapies (DMTs) will bring huge complexity regarding patient selection/eligibility, administration (by intravenous infusion fortnightly or monthly) and safety monitoring (frequent MRIs mandatory whilst on treatment).

Notably, biomarker confirmation of the diagnosis of AD by demonstrating 'β-amyloid positivity' is necessary; most frequently secured via lumbar puncture, or alternatively by the use of amyloid-PET scanning. Use of these treatments is associated with potentially high-risk side effects such as brain oedema or microhaemorrhages (known as amyloid-associated imaging abnormalities; ARIA) which require serial monitoring with brain MRIs and close clinical follow-up during treatment.

NDS are actively leading a DMT Preparedness group which is tasked with identifying the resource implications of these medicines for dementia services.

## WORLD ALZHEIMER'S MONTH AND BRAIN HEALTH

World Alzheimer's Month is the international campaign from Alzheimer's Disease International that takes place every September. This year's theme "Never too early, never too late" - focuses on risk factors and risk reduction, emphasizing their crucial role in potentially delaying or even preventing the onset of dementia.

A growing body of evidence supports the 12 potentially modifiable risk factors for dementia modelled by the 2020 Lancet Commission on dementia prevention, intervention, and care. These are less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, low social contact, as well as excessive alcohol consumption, traumatic brain injury, and air pollution. Together they account for around 40% of worldwide dementias, which consequently could theoretically be prevented or delayed. You can read the full Lancet report [here](#).

The Brain Health Working Group, chaired by the National Dementia Service's Clinical Lead Dr. Sean O'Dowd, together with colleagues, national partners and local communities, aims to raise awareness for the dementia risk factors, and the things we can do to promote brain health.

## NEWS FROM ACROSS THE COUNTRY

Dementia: Understand Together is supported by community champions and local partners who are taking actions to create dementia inclusive communities. These are just some of the many examples of the work that is taking place across the country. The Understand Together team continue to work closely and support communities in their actions. Community champions in Listowel held their first alliance meeting in February. Since then the group has organised several dementia awareness workshops for businesses and retailers which were attended by more than 100 people. The Bantry Alliance have continued with their sessions for businesses with further sessions planned for Autumn. Another Dementia awareness evening will take place on October 12th, at which local businesses will receive their Dementia Inclusive Community symbol. Our community champions & Wexford alliance hosted a sporting memories event with Wexford GAA in association with Wexford County Council. This event had a large turnout with a feature in Alzheimer Europe's newsletter. Age Friendly Wexford have developed an information guide to Services for Older People in County Wexford for further information **\*\*\*View the 2023 Wexford Directory of Services for Older Persons here\*\*\*** This was officially launched by Minister Butler.

Our community champions in Mayo held their annual dementia awareness campaign "Come Walk a Mile and Make Me Smile" in Castlebar on 21st June with a large turnout. Tipperary Together have a monthly newsletter which promotes community events. There are plans for the ASI mobile unit to visit towns in Tipperary later in the year to raise awareness and disseminate information.

North Cork Dementia Alliance held a Cork GAA afternoon of memories on Monday 18th September in Mallow GAA Complex along with a number of planned activities.

We focus on key elements to support our community champions, these are Building a network of champions, forming Dementia Alliances, Dementia Awareness and Design Training, Inclusive Services and Resources. If you are interested in joining the growing community of champions across the country to take actions for dementia, network and share best practice, please contact [Sinead.oreilly@hse.ie](mailto:Sinead.oreilly@hse.ie)

## GET TO KNOW THE NATIONAL DEMENTIA SERVICES TEAM

### Clinical Lead, National Dementia Services

Dr Seán O'Dowd became Clinical Lead at the HSE National Dementia Services in October 2022. Dr O'Dowd is a Consultant Neurologist with a special interest in cognitive disorders. He has almost fifteen years' experience in the field, commencing his higher specialist training in Neurology in 2009 by completing an MD on CSF biomarkers in neurodegenerative diseases-the primary tauopathies (Progressive Supranuclear Palsy (PSP) and Corticobasal Syndrome (CBS)), and Alzheimer's disease. He subsequently completed further subspecialty training in neurodegenerative diseases, in particular Dementia with Lewy Bodies (DLB) in Newcastle-upon-Tyne. In Newcastle he was involved in a number of clinical trials and epidemiological studies in Alzheimer's disease, DLB, and atypical parkinsonian disorders.

Seán took his first consultant role in Norwich in 2016, with a commitment at the Cambridge Memory Clinic. In 2017 he established a specialist Cognitive Clinic in Tallaght University Hospital, now part of the Regional Specialist Memory Centre, which he co-directs with gerontologist Professor Sean Kennelly. His clinic serves as a tertiary referral centre for patients with atypical and young-onset dementia and incorporates dedicated interdisciplinary services for patients with DLB; PSP/CBS; Huntington's Disease and Frontotemporal Dementia.

Prior to Seán's appointment as Clinical Lead he had a close working relationship with the National Dementia Services, representing the National Clinical Programme for Neurology (NCPN) in stakeholder meetings on the Dementia Model of Care and contributed to the Model's approach to atypical (non-amnesic) dementia presentations, as well as guidance on use of Cerebrospinal Fluid (CSF) and Genetic testing in dementia. Since becoming Clinical Lead, he has chaired the Dementia Workstream, which completed and launched the Model in May 2023. He provides clinical guidance on the Implementation Programme for National Clinical Guideline 21 (appropriate prescribing of psychotropic medication in non-cognitive symptoms of dementia) as well as the National Dementia Services Brain Health Programme, and chairs the Disease-Modifying Treatment Preparedness group.

### Programme Manager, National Dementia Services

Paul Maloney qualified from University of Salford, Greater Manchester in 2006 as an Occupational Therapist. In October 2006, he joined Beaumont Hospital as a Staff Grade Occupational Therapist. In 2010 he commenced his role as Senior Occupational Therapist in Care of the Elderly at St Joseph's Rehabilitation Unit. In 2013 he co-developed Hear Me Think! "A cognitive screen that is accessible for patients with communication impairment". This was a joint initiative with Beaumont's Speech and Language Therapy Department. In 2014 he became NDT certified for working with adults with hemiplegia. He has worked in all areas under the Care of the Elderly umbrella at Beaumont Hospital including the acute setting, rehabilitation and day hospital. He was the Clinical Specialist Occupational Therapist in Care of the Elderly between 2015 and 2017 and was primarily based in Beaumont Hospital's Emergency Department as part of the award winning Frail Intervention Therapy Team (FIT Team). He has been a member of the National Health and Social Care Professions (HSCP) Unscheduled Care group, the National Clinical Programme for Older Persons (NCPOP) and a member of the Association of Occupational Therapists, Ireland (AOTI). He worked as the Occupational Therapy Manager at Beaumont Hospital between October 2017 and February 2023. In February 2023, Paul joined the National Dementia Services team as Programme Manager.