

## World Alzheimer Month September



### Welcome

September is World Alzheimer's Awareness Month and World Alzheimer's Day falls on September 21st. This year's international theme is 'Know Dementia, Know Alzheimer's,' and it builds on the 2021 campaign which focused on diagnosis, the warning signs of dementia, the continued effect of COVID-19 on the global dementia community and more. The HSE is raising awareness this month of dementia post-diagnostic supports and the growing number of supports available to people living with dementia and their families. You can read more about this below.

We said a fond farewell to Emer Begley in August who left the NDO to take up an external post. Emer was an important member of the NDO team for over five years, most recently as Interim General Manager. She will be missed by colleagues across the service and

we wish her every success. We also welcomed a number of new staff members, including Fiona Foley who joined as Senior Project Manager for the Dementia: Understand Together in Communities Programme and Grace Bergin who is providing support to the implementation programme for the National Clinical Guideline on appropriate prescribing of psychotropic medications for non-cognitive symptoms in people with dementia.

We 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).

Kind regards,  
The NDO Team

## QUICK UPDATES

### Palliative Care Model for Dementia

In June a consensus conference took place in Cork to discuss "Delivering Palliative Care to People with Dementia". The conference was held to support the further development of a model for dementia palliative care in Ireland which is in development by researchers in UCC. The consensus meeting had a range of representatives which included health and social care professionals, staff in dementia services, specialist palliative care services, community services and people living with dementia and there were good discussions on the day. Feedback from attendees will be compiled and considered to inform the final draft of the Model of Dementia Palliative Care, which complements the Dementia Model of Care (forthcoming). You can read more about the project [here](#).

### Older Persons Living with Dementia Quality Improvement Grant 2020

The NDO were delighted to be involved with the Nursing and Midwifery Planning and Development Unit (NMPDU) in the Midlands in supporting a quality improvement grant for dementia. The purpose of the initiative was to facilitate and support small quality improvement projects in dementia care for older persons in residential care facilities in the Laois/Offaly, Longford/Westmeath region. Six sites in total were awarded this grant and four sites have completed their projects. These are An Triú Aois Day Hospital, Laois who developed the programme 'Caring for the carers and improving quality of life for people with dementia'. St Vincent's Community Nursing Unit purchased a Laois Tovertafel 'Magic Table'. Ofalia House, Offaly developed Horticultural therapy for cognitive functioning of older people with dementia and St. Joseph's Care Centre, Longford created the programme 'Better Awareness and Understanding of Dementia'. The two remaining site projects are currently in development and will be completed later this year.

### Inclusive Design Workshop

As part of the Dementia: Understand Together campaign, dementia inclusive design workshops have been rolled-out to representatives of local county councils and community champions to raise awareness of dementia, and to ensure that we create accessible and supportive spaces and amenities. In June an Inclusive Design workshop was facilitated by the NDO for personnel from the Memory Assessment Support Services (MASS) and Regional Specialist Memory Clinic (RSMC) teams to enhance their knowledge of dementia inclusive design. The workshop focused on design elements that should be considered in any health buildings, waiting areas and consultation rooms to support the cognitive, sensory and physical abilities of any person attending the service. A further workshop will be hosted in the Autumn for both MASS and RSMC staff. You can contact [sinead.oreilly@hse.ie](mailto:sinead.oreilly@hse.ie) for further information.

### A Focus on Non-Cognitive Symptoms of Dementia: Promoting a Culture of Safety

The National Dementia Office together with the National Safeguarding Office will host a webinar on 21st September (10.00-11.30am) focusing on non-cognitive symptoms of dementia. The aim of the webinar is to promote a culture of safety in relation to supporting people with dementia who are experiencing non-cognitive symptoms of dementia. The webinar will provide information on non-pharmacological interventions and psychotropic medications for non-cognitive symptoms of dementia and will raise awareness of National Clinical Guideline No. 21 ("Appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia"). You can register for the webinar [here](#).

### Dementia Quality Improvement Posts

The National Service Plan 2022 approved funding for six Dementia Quality Improvements posts for the acute services. This new initiative is for Assistant Director of Nursing (ADON) posts to more efficiently implement dementia quality improvements within each hospital group.

The ADONs will facilitate group-level approaches to environmental change, staff training, and pathway implementation, reducing duplication of time/effort, ensuring dementia care receives adequate prioritisation within the hospital group and people living with dementia and their families have a positive experience when in acute care. The ADONs will work closely with the dementia Clinical Nurse Specialists (x10) who were funded under NSP 2021 & 2022.

### New Clinical Lead for the National Dementia Office



Dr. Seán O'Dowd has been appointed as the new Clinical Lead for the National Dementia Office. Seán is a Consultant Neurologist at Tallaght University Hospital (TUH). His subspecialty interest is neurodegenerative disorders including young - and later-onset dementias, Parkinson's disease and atypical parkinsonian disorders, including Lewy Body dementia. He trained in Ireland and the UK and worked in specialist services in Newcastle-upon-Tyne and Cambridge before commencing a weekly specialist clinic in TUH for these patients in 2017. Seán will bring a wealth of knowledge and experience to the office and will join the team in October.

### Engaging Dementia Annual Conference

Engaging Dementia are delighted to be hosting their 14th International Dementia Conference with the theme of "Fostering a Dementia Inclusive Ireland". The conference will be held in person in Croke Park as well as online, on the 15th and 16th of November.

Specialist guest speakers from around the world will present on a wide variety of topics such as:

- People with Intellectual Disability and Dementia
- Person Centred Training
- Young Onset Dementia
- Dementia Inclusion in the Community
- LGBT+ and Dementia
- Environmental & Technological Design and Dementia

The conference will include presentations from those living with dementia, family carers and supporters, as well as industry-leading researchers, professors and healthcare professionals. The fantastic Forget Me Nots Choir will be performing on stage to close the ceremonies.

All in-person tickets include access to:

- Talks, panel discussions and demonstrations across two stages
- Post-event access to digital recording of the plenary stage
- Two light refreshment breaks
- A catered lunch
- Access to exhibitor hall
- Use of a dedicated relaxation room
- Networking opportunities

All virtual attendance tickets will include access to a live stream of the event as well as a recorded copy after. Tickets can be purchased from [www.engagingdementia.ie](http://www.engagingdementia.ie) and there is a special discounted rate of just €40 per day for those living with dementia, and family carers.



## DEMENTIA: UNDERSTAND TOGETHER

Dementia: Understand Together is an innovative social movement model bringing about a dementia culture change in local communities. The campaign is supported by over 400 community champions and more than 40 national partner organisations ranging from retail, transport, banking, health, voluntary and community sectors who are taking actions to make our communities dementia inclusive. We feel now is the time to develop our dementia inclusive symbol that connects all that is happening across the country and visually represent the culture change we are seeing.

The design of the symbol is informed by feedback from people with dementia, carers, community champions and national partners. Its extensive roll-out will take place at the end of 2022 and will be accompanied by practical campaign resources such as window stickers, flyers and posters, lanyards and social media assets.

The goal is that our national network of partner organisations, local branches, community groups and public bodies will embrace the symbol and support its display across communities in Ireland to;

- Increase visibility and awareness of the Dementia: Understand Together campaign and its aims
- Act as an overarching symbol of solidarity and inclusivity
- Act as a symbol of support for people living with dementia
- Be a cue that their community, business, service or group is working towards being dementia inclusive and supportive of a person's needs
- Visually connect the actions of champions, partners and communities across the country.

To continue supporting national partners and community champions in the actions they are taking, the campaign is re-designing its online training offering, community champion toolkit and developing a more people centred social media approach. This includes the introduction in Q4 2022 of;

- An updated DCU Dementia Elevator Training Programme for retailers, financial services and transport providers and
- A community champion induction programme for new and existing champions.

## NEW SERVICES ARE DEVELOPING ACROSS THE COUNTRY

**These include Memory Assessment and Support Services and Regional Specialist Memory Clinics**

The Memory Assessment Support Services (MASS) is a new and innovative development for dementia care in Ireland. The MASS provides not only assessment and diagnosis of dementia but importantly dementia post-diagnostic support as well as a brain health service. It includes an expert multi-disciplinary team including nursing personnel, Occupational Therapist, Speech and Language Therapist, social work, psychology, neuro-radiology and a consultant. People attending the MASS will undergo a comprehensive assessment and work with the team on developing a care and support plan. They will receive information tailored to them and start on a care pathway, working with the MASS team to manage symptoms and adapt to the condition.

The MASS concept was first outlined in the dementia model of care and is based on best available international evidence and consultation with a wide range of key stakeholders.

Currently funding has been received through NSP 2021 and 2022 for nine MASS and work is underway across these sites to recruit expert personnel and they will be operational shortly. The aim is to build on the number of MASS across the country, to ensure the service is accessible to people in each region.

## UPDATE ON THE IMPLEMENTATION OF "APPROPRIATE PRESCRIBING OF PSYCHOTROPIC MEDICATION FOR NON-COGNITIVE SYMPTOMS IN PEOPLE WITH DEMENTIA" (NCG NO. 21)

The two year implementation programme for National Clinical Guideline No. 21 ("Appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia") commenced in January 2022. The primary aim of the programme is to implement the guideline on a phased basis across settings, including acute care, mental health settings, residential care for older people, and within community settings.

An expert multi-disciplinary Steering Committee has been convened and two meetings have been held to date. The project will be rolled out through three work packages: (i) communication and engagement; (ii) education and training; and (iii) evaluation.

A number of activities have been completed to date as part of work package one including development of a project webpage on the Dementia Pathways website and engagements with a range of stakeholders.

An Education Working Group has also been convened to provide guidance in relation to the development and delivery of the education and training programme, and activity is underway to progress the development of the education and training programme. Currently, a key focus of this work package is the development of a HSeLanD module for all staff who provide care to people with dementia to raise awareness of the guideline and promote best practice in support people who experience non-cognitive symptoms of dementia.

The primary focus of work package three is to evaluate the impact of the implementation of NCG No. 21 in acute and residential settings. This evaluation is commissioned by the National Dementia Office and will be conducted by an external evaluation team. You can find further information on the guideline implementation [here](#).

If you would like more information about the implementation programme please contact Dr Mairéad Bracken-Scally: [Mairead.bracken@hse.ie](mailto:Mairead.bracken@hse.ie)

You can read more about the MASS [here](#). The current nine sites are located in Sligo, Castlebar, Limerick, Tralee, Mullingar, Waterford, Wexford, Cavan/Monaghan and Donegal.

### Regional Specialist Memory Clinic (RSMC)

In addition to the nine MASS, funding was received for the development of four RSMC sites under the National Service Plan 2021 and 2022.

The RSMC includes a highly skilled multi-disciplinary team to provide an assessment and diagnostic service for atypical, unclear suspected dementia and suspected young-onset dementia, or where the person wishes to participate in a more detailed and specific aetiological evaluation. For people in these categories the diagnostic process can be long and complex. The RSMC are addressing the need for a diagnostic pathway to ensure that people receive a timely diagnosis. You can find out more about RSMC [here](#).

## NEWS FROM AROUND THE COUNTRY

Under the umbrella of the Dementia: Understand Together campaign, community champions across the country are continuing their local activities to make their communities dementia inclusive. The Dementia: Understand Together team is working closely with seven counties to learn more about their initiatives, share best practice and see how we can best support their actions. These counties are Meath, Wexford, Tipperary, Mayo, Kerry, Cork and Sligo. 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)

Bantry Dementia Alliance are on the journey of making their town more inclusive and organised a recent Dementia Awareness evening which had an attendance of over 130 participants. Following on from this, Bantry Dementia Alliance including local council members, town planners and architects participated in the Dementia Inclusive Design training. This was the foundation for a town walkability audit which took place on July 5th.

The Tipperary Alliance recently held an Age Friendly Dementia Inclusive expo in Thurles with 60 exhibitors including Dementia Advisers and Memory Technology Resource rooms with two auditorium with talks over the day. Over 250 people visited the different stands, networked and looked at ways to support people living with dementia.

Tralee Dementia Friendly Inter-agency Group in collaboration with the HSE and with support from Kerry GAA held a Brain Health Awareness evening on Thursday 21st July. Key Speaker - Professor Iracema Leroi, discussed the importance of brain health and what we can do to promote brain health and maintain memory. Panel discussion included experts on the Fair Deal process and Enduring Power of Attorney, dementia advisers and Kerry Memory Technology Resource Room. There was a variety of community support and information stands available on the night. All our communities continue to raise awareness and plan activities to ensure their community is becoming inclusive.



Bantry Dementia Awareness evening



Panel speakers at the recent Tralee Dementia Friendly Brain Health Awareness

## DEMENTIA CARE AND SUPPORT/SUPERVISOR TRAINING

The Dementia Care and Support programme for home care support workers is continuing in its pilot phase in CHO 1, 4 and 5. Congratulations to our 28 learners who completed the training in Kilkenny and Cork and received their QQI level 5 certificates. Four courses are running at the moment in Bantry and Cork City and also in Letterkenny and Buncrana. These programmes have recently been completed. The Dementia Care and Support Home Care Education 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. In September we are hoping to progress with more training programmes in Sligo, Kerry, Cavan/Monaghan and Kilkenny.

As part of the training programme we need to recruit more supervisors/mentors to assist the learners as they progress through the programme. Supervision training is booked for 12 and 13th September. If you would be interested in becoming a supervisor/mentor on this programme please contact [dementia.office@hse.ie](mailto:dementia.office@hse.ie)

The NDO is proceeding with an evaluation of the programme and it is hoped that this will lead to the national rollout of the programme in all CHO areas.

Feedback from learners on the programme, those living with Dementia and their family carers has been very positive. One learner who has completed the programme said:

***“As a Healthcare Assistant the Dementia Care and Support Course challenged my thinking on the lived experience of dementia for my clients. Before the course I just saw the diagnosis and failed to see the person behind. Now after completing the course I actively seek the person first through meaningful engagement, empathy and connection.”***

- Jackie



Staff from CHO1 who recently completed the Dementia Care and Support Programme in Letterkenny

To keep up-to-date on NDO and related dementia news follow us on



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