# National **Dementia** Office





# Newsletter

Spring 2023 SSUE 11

# Welcome from the Assistant National Director

Welcome to the spring 2023 edition of the HSE National Dementia Services newsletter. We are delighted to welcome our new team members - Paul Maloney took up post as Programme Manager in February 2023. Rachel Ward and Sheena Farrell also joined the team to support the Implementation Programme for the National Clinical Guideline on appropriate prescribing of psychotropic medications for non-cognitive symptoms in people with dementia.

March is Brain Awareness Week which is 13th to the 19th of March 2023. The theme for this year is 'Invest in Neurology'.

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.

- Janette Dwyer

### **QUICK UPDATES**

### **AOTI conference Poster**

Annette Burke, Senior OT, Wicklow Memory Technology Resource Room, recently presented a poster entitled Evidence Based Cognitive Stimulation Therapy Group Programme in a Primary Care Dementia Service. "Stimulating, connecting and revealing the person" at the Association of Occupational Therapists of Ireland Annual Conference in Athlone.



Annette's well received poster demonstrated the benefits of a locally accessible group for person with dementia, using cognitive stimulation therapy as an evidence based intervention. Contact annette.burke2@hse.ie or Wicklow.mtrr@hse.ie

### **Irish Gerontological Society Podcast**

To mark World Alzheimer's Day, Edel McDaid from the Irish Gerontological Society recorded a podcast with Mairéad Bracken-Scally, Kate Brennan and Fiona Foley from the National Dementia Office. This podcast provides an update on recent activities within the National Dementia Office

#### **National Brain Awareness Week**

National Brain Awareness Week runs from March 13th to 19th and is the global campaign to foster public enthusiasm and support for brain science.

A Lancet study in 2020 identified 12 modifiable risk factors that could account for 40% of dementia worldwide and we are highlighting a number of these factors, creating awareness of the link with dementia and how people in their midlife can reduce their risk.

Proactive steps people can take include

- being physically active
- eating a healthy balanced diet
- quitting smoking
- managing blood pressure
- making time for social connection and interaction

It's always a good time to improve brain health and reduce your risk of Dementia and adopting these habits in adulthood can play an important part in reducing risk, as well as developing good routines for life.

### Hot Topics in Dementia: TeamUp for Dementia Research webinar

In December 2022, DRNI and the Alzheimer Society of Ireland (ASI) were delighted to present a webinar entitled TeamUp for Dementia Research. The webinar focused on what this ASI service is, what it entails, and how it has developed since its inception 18 months ago. Contributors included Ciara O'Reilly of the ASI, Coordinator for TeamUp for Dementia Research; Brenda Buckley, a member of TeamUp for Dementia Research who spoke captivatingly about why she joined up and her experience of taking part in research; Dr Louise Hopper from DCU who outlined benefits to the research community from the service. DRNI Chair professor Sean Kennelly spoke about Dementia Trials Ireland and Dr Laura O'Philbin from the ASI rounded off the webinar with summarising the exciting developments in the dementia research landscape in Ireland. Watch full webinar here.

Visit TeamUp for Dementia Research Service website and Dementia Trials Ireland website.

### **Dementia: Understand Together launches new** dementia inclusive community symbol

In consultation with people with dementia, carers, community champions and national partners, the Dementia: Understand Together campaign will be launching a community symbol nationally this March. The campaign is encouraging all organisations and services in communities to display the symbol, to raise awareness for dementia and show their solidarity with the 64,000 people living with the condition in Ireland.

Some 40 partners, ranging from voluntary and community groups, academia and health to retail, transport and financial services, and more than 500 community champions are backing the campaign and taking action to help support people with dementia and their families and friends.

As well as displaying and using the symbol on websites, newsletters and on social media, partners and champions are encouraged to take part in free dementia awareness training. Staff and volunteers will explore how simple actions can make a real difference to making their services and businesses more accessible, not just to people living with dementia, but to everybody living in our diverse communities.

By understanding together, we can all make a difference and help people in our communities to stay connected and included.

# LAUNCH OF THE SUPPORTIVE MEMORY GUIDE EBOOK



The Supportive Memory Guide eBook has been created by occupational therapists to provide useful tips and practical strategies to empower people with early stages of dementia to create protective routines and systems. It began as part of the mPower project which provided a focus on eHealth and Self-Management. Senior Occupational Therapists Orla McDonnell, Kerri Malone and Emma O'Brien have many years' experience in dementia and offering post diagnostic support. They worked with Kate Hanlon, digital

designer from HSE eHealth to create an accessible eBook which includes downloads, active links and videos to further resources.

The eBook provides a range of advice covering topics on scheduling and planning, developing helpful routines and creating supportive environments to engage optimally. One objective of the eBook was to demonstrate how assistive technologies can support a person with early stages of dementia. The eBook suggests easy ways to adapt smart phones, tips on managing medication, and potential uses of smart home technologies along with information on simple home technologies. These can make participation in everyday activities easier and compensate where memory and cognitive changes have impacted on the person.

Further information and tips for staying active and engaged are provided as well as links to national and local support services and activity groups. The Supportive Memory Guide can also be used by healthcare professionals as a resource, providing them with key areas to work and support their client group. A webinar launch of the eBook was held on the 20th of February with a successful turnout and very positive feedback. The eBook is available for download and print on the eHealth website here. A feedback form is available which will help the creators on future developments of the eBook.

# NEW HSELAND MODULE: "SUPPORT PATHWAYS FOR PEOPLE WITH NON-COGNITIVE SYMPTOMS OF DEMENTIA"

The National Clinical Guideline on "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 being experienced by people living with dementia. The National Dementia Office is now rolling out the clinical guideline through a comprehensive implementation programme.

As part of the implementation programme, a HSeLanD module has been developed. This module, called "Support pathways for people with non-cognitive symptoms of dementia" is targeted at all healthcare professionals who provide care to people with dementia across all settings. The module aims to help the learner to determine the best person-centred supports for a person with noncognitive symptoms of dementia and to recognise the risks of unnecessarily prescribing a psychotropic medication.

There are three core topics within the 30 minute module:

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

By the end of this module, you will be able to:

- Explain the steps you must take to determine the best supports for a person with non-cognitive symptoms of dementia.
- Describe how you can deliver a person-centred approach to dementia care.
- Summarise the types of non-pharmacological interventions that can support a person who is experiencing non-cognitive symptoms of dementia.
- Outline the risks you associate with psychotropic prescribing.



The module includes recorded scenarios, audio excerpts and an animated explainer. This module, which is now available on HSeLanD, forms part of a broader training and education programme which includes Facilitator education which will be rolled out in 2023.

Keep up to date with progress of the implementation programme here.

### A FOCUS ON NON-COGNITIVE SYMPTOMS OF DEMENTIA: PROMOTING A CULTURE OF SAFETY

In September 2022, to coincide with World Alzheimer's Day, the National Dementia Office together with the National Safeguarding Office hosted a webinar on non-cognitive symptoms of dementia. This webinar, entitled "A focus on non-cognitive symptoms of dementia: Promoting a culture of safety", was targeted at staff within and outside the HSE, as well as people living with dementia and family carers of people living with dementia.

The webinar had almost 700 participants on the day and you can watch it on the Dementia Pathways website here. Speakers included:

- Mr Matthew Gibb, Director of the Dementia Services Information and Development Centre (DSiDC) who spoke about responsive behaviours and non-pharmacological approaches for noncognitive symptoms of dementia
- Mr Kevin Quaid, Representative of the Irish Dementia Working Group (IDWG) who spoke about the lived experience of the person with dementia
- Prof Suzanne Timmons, Co-Chair of the Guideline Development Group for National Clinical Guideline No. 21, who spoke about the impact of inappropriate prescribing and National Clinical Guideline No. 21
- Ms Susan Crampton, Representative of the Dementia Carers Campaign Network (DCCN), who spoke about the lived experience of a family carer of a person with dementia.



Kevin Quaid, Chair of the Irish Dementia Working Group, speaking at the webinar about the lived experience of the person with dementia

Speaker presentations were followed by a moderated question and answer session with speakers where attendees were afforded the opportunity to raise questions with the panel of speakers. This facilitated an interesting discussion.

The majority of attendees were HSE staff but there were many from other backgrounds including private nursing homes and care providers, intellectual disability services, Alzheimer's Society of Ireland, academia, people with dementia, and family carers of people with dementia.

Feedback from the webinar was very positive. Almost all of those who completed the post-event survey reported that the webinar was relevant to their area of work/day-to-day living. Below is a selection of feedback from attendees:

"Knowledge gained will allow me to better inform those I work with living with dementia and their family care givers. Also, it strengthens my resolve to try any and all alternative therapies in an effort to support those living with dementia while on the journey."

"Great to hear from people with a lived experience of dementia as well as professionals. A really good balance of speakers. Powerful and emotive as well as being very informative."

"I especially found the personal stories inspiring - hearing from a person with dementia and a carer."

This webinar formed part of the communication and engagement work package of the Implementation Programme for National Clinical Guideline No. 21. You can keep up to date with progress of the implementation programme here.

### **NEWS FROM AROUND THE COUNTRY**

The Dementia: Understand Together campaign continues to work closely with our community champions across the country who are continuing their local activities to make their communities' dementia inclusive. Working closely with 7 communities, The Dementia: Understand Together is supporting and learning more about their initiatives, and in turn sharing best practice. 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

Bantry Dementia Alliance continue on their journey of making their town more dementia inclusive and there was a great turnout at the first Bantry Memory Café launch on 1st February in the Library in the Maritime



Bantry Memory Café

Hotel. Attendees felt it was very welcoming stating 'I am here to make connections to explore what is happening and what facilities are available' and 'I have been diagnosed with dementia and meetings like this are essential'. The Café will continue on the first Wednesday of each month, to know more chat to Juliette on 087 9103036.



Minister for Education, Norma Foley at ASI launch

The Tipperary Alliance recently developed a website to signpost for dementia support, Information and events within the county.

In Tralee the ASI officially launched a new Transition year programme "Creating a Dementia Inclusive Generation" with the presence of the Minister for Education, Norma Foley. This programme was developed in collaboration with Dementia Services Information and Development Centre in St. James Hospital. The program aims to take away the fear, to empower young people to be able to cope with the situation and ultimately to take away the stigma associated with Dementia.

Our communities are getting involved in this programme. If you wish to know more on how your community or school can get involved contact:

community engagement@alzheimer.ie

Sporting Memories - a workshop was recently held in Chadwicks Wexford Park on 6th February in association with Wexford County council, Wexford GAA, Sláinte Care and the ASI.





Attendees at the Sporting Memories event in Wexford GAA

with over 80 people in attendance, including people who are living with Dementia, included Community guards, Community Nurses and Dr Harkin Consultant Geriatrician at Wexford Hospital. Derek Kent the incoming chair of Leinster

There was a large turnout

Council GAA also attended. The response was very positive from families and carers. If you are interested in knowing more about Sporting memories which can be done for any sport including Golf, Tennis, Soccer please contact

communityengagement@alzheimer.ie

# DEMENTIA SERVICES INFORMATION AND DEVELOPMENT CENTRE (DSIDC) INFORMATION BOOKLETS



### Vascular dementia booklet

This booklet on vascular dementia is for those who have been recently diagnosed, their family and friends. It will help you to understand more about the condition, symptoms, treatment options, support and tips for living well with vascular dementia.

### PPA booklet

This booklet provides an insight into Primary progressive aphasia (PPA). PPA is a progressive illness because symptoms get worse over time. This booklet covers areas including symptoms, progression, types, treatment, speech and language support and tips for living well with PPA.

### **Dementia with Lewy Bodies booklet**

This booklet on Dementia with Lewy Bodies (DLB) is for those who have been recently diagnosed, their family and friends. The booklet covers areas such as symptoms, progression, treatment, support and tips for living well with DLB.

### Alzheimer disease booklet

This booklet on Alzheimer's disease is for those who have been recently diagnosed, their family and friends. It will help you to understand more about the condition, symptoms, progression, treatment options, support and tips for living well with Alzheimer's disease.

### Pills, bills and wills booklet

This booklet is helpful following a diagnosis of dementia. Information includes advice on medications for memory loss, lifestyle advice, Enduring Power of Attorney (EPA) and tips on how to manage personal finances.

### Mild Cognitive Impairment (MCI) booklet

This booklet is to help people who find their memory is not what it used to be beyond what is normal for a persons' age and education level. It will also explain what mild cognitive impairment is, changes that may happen and what you can do to live with it and have a full life.

National **Dementia** Office





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

dementia.office@hse.ie