

Newsletter

Winter '20
Issue 7

Dear Colleagues,

Welcome to the winter edition of the National Dementia Office (NDO) Newsletter, 2020. Since our last newsletter, life has changed in many ways for all of us. We all have had to adapt and work in different ways; learn new skills and ways to continue day to day work. In this edition, we are delighted to share updates on recent national dementia events that were delivered virtually through webinars and the use of technology.

Over the past six months, the NDO have been working very closely with colleagues across the HSE services and voluntary organisations to support and enhance service delivery for people living with dementia in the community and in residential care. An example of some of this work included in this edition is the COVID-19 dementia resources. We were delighted that our poster submission 'Physical & mental wellbeing through the COVID-19 crisis' a collaborative project with colleagues in the NDO, DSiDC and ASI was presented at the recent virtual 30th Alzheimer Europe conference.

As we face into further restrictions and a period of uncertainty, we need to continue to work together to look after and be kind to each other and to stay safe. We hope you enjoy reading the NDO Newsletter. If you would like further information on any of the initiatives outlined in the newsletter or indeed would like to know about the on-going work of the office, please feel free to contact us at dementia.office@hse.ie

Mary Manning, NDO, General Manager

Dementia COVID-19 Resources

Weekly Activity Planner for people with dementia, families and carers

This Weekly Activity Planner developed in collaboration with the National Dementia Office, Dementia Understand Together, Alzheimer Society of Ireland and Dementia Services Information and Development Centre contains suggestions for a balanced plan of physical, cognitive and relaxing activities, to assist with creating new routines during COVID-19. Social distancing and restricted social activities introduced as a result of the pandemic can be challenging for people with dementia, their families and carers. Many supports have been curtailed or stopped, meaning people are now at home for longer hours. The Weekly Activity Planner is a guide to establishing new routines with an option to develop your own weekly schedule also based on what has worked well for both the carer and the person with dementia.



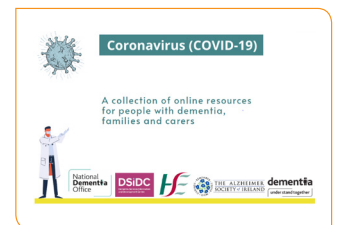
At Home Activities Booklet

This information booklet to support people with dementia, families and carers was compiled by Emma O'Brien, Occupational Therapist at the Memory Technology Resource Room (MTRR) in Clonmel. With COVID-19 people are spending more time at home and may become more dependent on in-home activities. Choosing meaningful activities enhances well-being and improves quality of life. This guide provides a selection of meaningful activities for people with dementia, families and carers to do at home. They support the person to remain engaged and active.



Resource Hub

The Dementia COVID-19 Resource Hub is a collection of resources compiled by the National Dementia Office, Dementia Understand Together, ASI & DSiDC. At present there is a lot of information available in the public domain on COVID-19 which has been provided by many organisations. Navigating this information can be quite difficult at times. The aim of the resource hub is to provide relevant resources compiled into one document. This information is separated into three themes - Medical, Practical and Emotional - and includes helplines and links to other helpful organisations. If you have a resource which has been helpful to you, do let us know by emailing dementia.office@hse.ie



COVID-19 Guidance Documents

The National Dementia Office in collaboration with partners in response to the COVID-19 crisis have developed a suite of one page dementia COVID-19 guidance documents. These documents are called

- COVID-19: Managing Isolation and NCS of People with Dementia in Residential Care Facilities,
- COVID-19: Related Hygiene & the Person Living with Dementia in Residential Care Facilities,
- COVID-19 and Dementia: Grieving in Exceptional Times,
- COVID-19: Testing & the Person Living with Dementia
- COVID-19: Providing Care to Community-Dwelling People Living with Dementia.

View these documents [here](#)

Older Persons Living with Dementia in Laois/Offaly, Longford/Westmeath Region Quality Improvement Initiative

The NDO are 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 this initiative is to facilitate and support small quality improvement projects to improve dementia care for older persons in residential care facilities in the Laois/Offaly, Longford/Westmeath region. We will provide an update on the successful applicants in our next newsletter.

2nd National Audit of Dementia Care in Acute Hospitals (INAD-2) launched

The HSE National Dementia Office held a virtual launch of the 2nd National Audit of Dementia Care in Acute Hospitals (INAD-2) on 1st September 2020. The audit is extremely important in helping to improve the care of people living with dementia in acute hospitals. The audit shows improvements with dementia quality improvement teams and staff with a specific dementia role in many hospitals. There was also evidence of physical environment changes to enhance the experience and safety of a person living with dementia.

There are other areas like recording the type and severity of dementia, and gathering information to support person-centred care that need further work at national and local level to support improved practice.

You can download a copy of the INAD-2 report [here](#)

The recordings of the launch can be viewed [here](#)

Acute Hospital Quality Improvement Grant

Following an open competition to progress dementia care in acute hospitals, the NDO are funding 21 small quality improvement projects across 17 hospitals. The purpose of this grant was to facilitate small quality improvement projects to improve dementia care in acute hospitals.

View the successful hospitals and a summary of their projects [here](#)

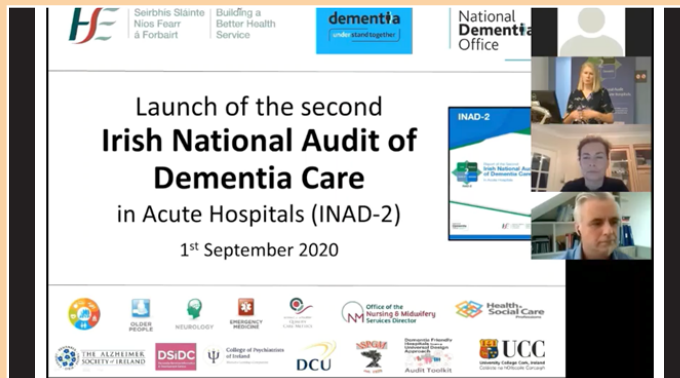
Dementia Pathways

A number of new resources have been added to the revised Dementia Pathways website. The [Information Portal](#) provides easy access to a range of information materials which healthcare staff can distribute to their clients who are living with dementia and to their families/carers, as appropriate.

The [Good Practice & Innovation Hub](#) showcases information on different projects and initiatives being delivered across a range of care settings. The hub provides an opportunity to learn more about what's happening across the country and to link in with colleagues.

Queries in relation to providing material for the Good Practice & Innovation Hub can be sent to dementia.office@hse.ie

This website will work in conjunction with our partner website www.understandtogether.ie



Dr Suzanne Timmons (Clinical lead for the National Dementia Office), Dr Vida Hamilton (National Clinical Advisors and Group Lead (NCAGL) Acute Strategy & Operations) and Tom Grey research fellow in Trinity Haus.

National Intellectual Disability Memory Service Clinic (NIDMC)

People with an intellectual disability need access to dementia diagnosis. This was the clear message from the inaugural webinar of the National Intellectual Disability Memory Clinic (NIDMC) in Tallaght University Hospital. The webinar was supported by the 'Dementia: Understand Together' campaign and was held to mark World Alzheimer's Day (September 21st).

The NIDMC aims to address some of those issues directly by providing diagnosis, post-diagnostic support and promoting prevention strategies and brain health. The clinic, which is a pilot service developed with the support of the HSE National Dementia Office and funded through the Dormant Accounts Disbursement Fund, is operating on a part-time basis from Tallaght Hospital.

It runs in parallel with the mainstream Memory Clinic and uses the expertise of nurses from the Daughters of Charity Disability Support Services. The Clinic can take referrals from GPs or Psychiatrists who have a concern about someone with an intellectual disability. For further information contact Professor Mary Mc Carron, Trinity Centre for Ageing and Intellectual Disability (TCAID). [email: mccarrm@tcd.ie](mailto:mccarrm@tcd.ie)

Engaging Dementia's Virtual 12th International Dementia Conference

We were delighted to partner with Engaging Dementia on November 2nd and 3rd to host their Virtual 12th International Dementia Conference 'Transforming Care & Communities'. This conference is well established as the leading annual dementia event in Ireland. 2020 has been an extraordinarily challenging year for people living with dementia and those who care for them. COVID-19 has brought hardships and challenges, put pressure on the care infrastructure, and highlighted gaps in our support systems. However, it has also resulted in innovation, as well as new ways of providing supports to people in their own homes. To view the recordings from the event

[email: events@engagingdementia.ie](mailto:events@engagingdementia.ie)



Understand Together Champions Cafe event September 30th 2020

With COVID-19, recent months have been extremely challenging for many people living with dementia. It is vital to change the current culture around dementia and help create an Ireland that supports and includes people living with dementia, now more so than ever. Changing a culture takes time and cannot be done by one organisation; the Dementia Understand Together in Communities programme is working with over 40 national organisations and 340 community champions.

A key part of supporting dementia inclusive communities is training, education and building awareness as a first step. In the last number of months Boots Ireland has undertaken a significant step by providing training to all staff that will promote a dementia-inclusive environment across its 89 retail and pharmacy outlets. Irish Rail another National Partner have organised various dementia awareness initiatives including training for staff and workshops with people with dementia to explore their travel experience and how that can be enhanced.

Kevin Quaid, Vice Chair of the Irish Dementia Working Group (IDWG) and living with Lewy body dementia says "knowing staff have received training in dementia and seeing staff members wearing the Dementia: Understand Together badge makes me feel safe and enables me to travel alone. A little understanding can go a long way."

As many others during this time, the Dementia Understand Together in Communities Programme has also embraced technology to reach out to partner organisations and champions. At recent events more than 80 representatives from partner organisations and over 50 community champions have come together to listen to the experiences of people living with dementia. Technology also plays a part in creating better understanding of dementia and so three new online training programmes have been developed and went live in October. They include training on:

- **Dementia awareness**
- **Inclusive Design**
- **Azure programme**

The recent publication of the Evaluation report on the Framework of Dementia: Understand Together in Communities provides additional insights into actions taken by partners and champions and recommendations for the future development of the programme.

You can read this [report](#) and find out more about how you can get involved [here](#)

Young Onset Dementia Review

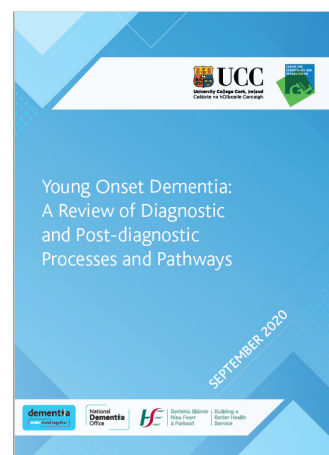
People who are diagnosed with dementia when they are aged under 65 years are said to have what is called Young Onset Dementia (YOD). Currently it is estimated that there are over 4,000 people living with YOD in Ireland. They can face additional challenges when diagnosed due to potential family care and financial responsibilities. It can also be a hugely unexpected diagnosis for them.

To learn more about the diagnostic and post-diagnostic experiences of people with YOD, the NDO commissioned a piece of research to inform the development of appropriate care pathways. The research was undertaken by a team from University College Cork and Trinity College Dublin, where they spoke to people with YOD, their families and a broad range of health and social care professionals.

The findings of the research were published by the NDO on World Alzheimer Awareness Day on the 21st of September, in the report *Young Onset Dementia: A Review of Diagnostic and Post-diagnostic Processes and Pathways*.

Findings from the qualitative interviews were consistent with the literature showing the complexities of making a diagnosis of YOD which can result in delays and there are limited postdiagnostic supports available; with many community-dementia specific supports not deemed appropriate.

The report puts forward a number of recommendations to guide the development of policy and services to improve the quality of life for those living with Young Onset Dementia. You can read the full report [here](#)



Memory Technology Resource Room - Evaluation Report Published

There are currently 27 Memory Technology Resource Rooms (MTRR) operating across the country. The MTRRs provide advice and assistance around assistive technology for those with concerns about their memory and cognition. The majority of people accessing the service either live with dementia or care for someone with the condition. There is an Occupational Therapist working in each MTRR who undertakes a full assessment of the person before providing necessary advice. They often signpost and refer people to other supports as appropriate.

The MTRR network was officially launched in 2018 and to get a sense of the impact of the programme an independent evaluation was commissioned. In September this year The National Office for Services for Older People and Palliative Care Strategy and the National Dementia Office published the Evaluation Report. The evaluation, completed by the Work Research Centre,

demonstrates the benefits of the service including supporting people dementia to better manage the condition. It indicates that the MTRRs are a source of empowerment, education and support to people living with dementia and other memory difficulties and their family members, and also for health and social care workers and members of the public who visit. In this way it is an integral part of the emerging dementia post-diagnostic pathway.

The report contains recommendations to ensure the sustainability and development of the service including building on the learning from COVID-19 and the use of virtual visiting technologies to support people with dementia in their homes. You can read the Evaluation Report [here](#) or access an MTRR [here](#)

Education Updates

Education and training is a priority area for the National Dementia office, with a number of education programmes now revised and updated. Dementia education programmes continue to be made available across the country. The national dementia education programmes:

Enhancing and Enabling Well Being for the Person Living with Dementia - 2 Day Programme and Enhancing and Enabling Quality of Care with the Person with Dementia -Acute Care Programme have been revised and updated.

The philosophy underpinning the programmes is based on the values and beliefs that personhood is central to the well-being of people living with dementia. In person centred care all behaviour has meaning and the language/words we use can strongly influence how others treat or view people living with dementia.

Workshops for facilitators on the updated National 2 day Dementia Programme were held in Cork and Dublin in January and February 2020. Due to COVID-19 the final facilitator's workshop was delivered via webinar in early September. In addition, a webinar for facilitators of the updated National Dementia acute care programme was held in late September. This coincided with the recent launch of the 2nd Irish National Audit of Dementia Care in Acute Hospitals (INAD-2). Now more than ever dementia education and awareness is paramount when dealing with people living with dementia and their families. The Office of the Nursing and Midwifery Services Director (ONMSD) and NDO acknowledge the expertise and support of the stakeholder groups, programme reviewers, facilitators and organisations delivering these important education programmes. For course(s) details and dates contact Centres of Nurse and Midwifery Education/Education Departments. For further information on the two programmes [email: lorraine.mcnamee@hse.ie](mailto:lorraine.mcnamee@hse.ie)



Dementia Care in Primary Care

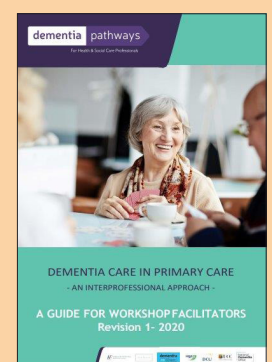
An Interdisciplinary programme for the Primary Care Team. To date over 500 primary care team members have attended this training. The programme was originally developed to ensure a general basic knowledge of dementia across the disciplines working in a primary care setting. The programme has recently been reviewed and updated. A workshop for current facilitators on the new revised programme was facilitated on line in October. If you are interested in knowing more about the programme or wish to become a facilitator [email: Sinead.oreilly@hse.ie](mailto:Sinead.oreilly@hse.ie)

The Early Identification of Memory Problems in Older Persons

This is an E-Learning programme on HSEland. This short online course introduces participants to the experience of those with memory problems. The programme looks at memory problems within a broader social and personal context. It also differentiates between different types of memory problems including Dementia and Delirium. It is available through www.hseland.ie

Dementia Services and Information Development Centre (DSiDC)

The DSiDC's education and training programmes are directed mainly at Health and Social Care professionals. A suite of Dementia education programmes have been developed and further information is available at www.dementia.ie



Living with Dementia during COVID-19 Times

Kathleen Quinlan tells us about her experiences as someone under 65 living with dementia during COVID-19; how keeping active has been key to helping her over the past few months.

"After caring for both my parents who had dementia, I was diagnosed myself. Initially we thought it was stress as caring could be hard. I started forgetting things I should know; leaving a pot on the cooker and not just leaving the room but going into town for hours. When I went to a new GP they were concerned and sent me to a specialist where I got my diagnosis.

I've lived in Cork all my life and have a busy home, with my husband and son. My daughter and grand-daughter live in the granny flat where my parents were when I cared for them. Some days are hard living with dementia during COVID-19. I find it difficult going into the shops, you have to walk this way and it's a one way system, wearing the mask and gloves, so I don't go to the shop much at all. It has restricted my movements. I'm not so much worried about getting COVID-19 but I'm worried about breaking the rules. You have to stay 2 metres back and I worry that I'm not doing it right. There's added anxiety around it all. I just forget. Someone said to me one day I was going the wrong way and I thought I won't be able to come here again. It's a worry.

I keep busy. Myself and my daughter go for a walk but there's no stops for coffee. I haven't been out to a café or restaurant since March. To pass the time I've taken up diamond painting; where you



stick little crystals onto pictures. I took it up two months; it passes the time in the evening. I used to love baking but the oven was becoming a problem; even with the timer. I found a lady on-line who does simple bakes and I bake with her, following what she does and that has been brilliant. There's great satisfaction taking something, like an apple tart, out of the oven. I can't read anymore; I get frustrated and annoyed when I can't remember what I've just read. So I set up a portable library on our wall outside. My husband built it for me. You can come and leave a book and then take a book. It was an opportunity to chat to people; neighbours telling me they had wiped down books to leave in the library.

I do bits with the Irish Dementia Working Group supported by The Alzheimer Society of Ireland and that's great. When I do projects with them I feel a sense of achievement, it's a good feeling. I was going to go to the dementia cafe to help out with the teas and wipe down tables but then COVID-19 came and we can't meet. My parents when they were alive had the day centre but that's closed now too. I worry about people who live alone and don't have anyone.

I would like to meet others who are in the same stage of life as I am but there's no one here locally who has dementia and is aged under 65 like I am. There's nothing there for people under 65. I'd like to talk to people and get information from others about how they are dealing with things, everyday living, to know their experiences.

While COVID-19 has been a big part of my life; I've always been a positive person. You have to be especially now".

Kathleen Quinlan

Launch of the Irish Dementia Café Network

The development of the Irish Dementia Café Network was commissioned by the NDO and established by Engaging Dementia during 2020. On the 17th of September the Café Network was officially launched by RTE's Miriam O'Callaghan; with the newly appointed Minister for Mental Health and Older People, Mary Butler TD, also speaking at the on-line event.

Dementia cafés are an important community resource for people living with dementia and family carers. They are a key part of the dementia post-diagnostic pathway, providing information in an informal welcoming and social environment. They are often a first step for people into more formal services and an opportunity to meet other people living with dementia in the community.

Due to public health restrictions as a result of COVID-19 cafés cannot meet face-to-face and many cafés have responded by going on-line, running virtual cafés under the same dementia café ethos of information sharing and peer support. The Irish Dementia Café Network includes 21 cafés across 15 counties. Launching the official model for the café network and the website www.dementiacafe.ie, will encourage other communities to set up a dementia café.

If you are interested in establishing such a cafe in your own community please [email: events@engagingdementia.ie](mailto:events@engagingdementia.ie). You can also find out about virtual cafés, when they are running, by visiting <https://dementiacafe.ie/>



News from around the Country

During the restricted months of COVID-19 almost all of the National Memory Technology Resource Rooms (MTRRS) suspended their services. The MTRRs offer valuable hands on experience where people can engage with and trial assistive technologies to better understand how they work, and how they can support a person with dementia. The Memory Technology Library (MTL) in Clonmel became the central contact for the MTRRs nationally, offering families, carers and persons with dementia phone consultations with the occupational therapist, who provided advice on supportive technologies, practical strategies and meaningful activities.



In response to the disruption of daily occupations and social activities, the MTL and Dementia Understand together campaign produced the At Home Activities Booklet. This booklet provides ideas for families to support meaningful participation, stimulation and to promote routine, which can have a positive impact on the person with dementia's well-being and help reduce anxiety and boredom.

As time progressed and restrictions lifted we adapted our service at the MTL to ensure face to face appointments were offered safely and that people could get the practical experience of using assistive technologies. Spaced appointments were offered, and compliance with guidelines was ensured. Our post diagnostic groups have not yet resumed, however the content of the 4 week programme will be adapted to offer individual sessions.

In preparedness for another possible lock down, the MTL can now offer virtual appointments; this will provide clients with online face to face consultation and demonstration of assistive technologies. We plan also to resume our social group to online and are working on ways to support people with dementia and carers engage in online platforms through simple guides on how to use and tech terms explained.

Emma O'Brien, Occupational Therapist at the Memory Technology Resource Room. For further information [email: EmmaM.O'Brien@hse.ie](mailto:emma.m.obrien@hse.ie)

NDO publications

NDO publications

The NDO have compiled a comprehensive list of their current publications. Included in this list are other publications related to the National Dementia Strategy (NDS).

This resource is available [here](#)

National Dementia Office Publications

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Evaluation of the Role, Contribution and Value of the Memory Technology Resource Rooms (MTRR) Programme (2020)

The evaluation which was completed by the Work Research Centre, commissioned by the NDO highlights the benefits of the service which support people with dementia and their families and carers to live independent lives in the community.



Young Onset Dementia: A Review of Diagnostic and Post-diagnostic Processes and Pathways (2020)

This review investigates the diagnostic and post-diagnostic support needs of people with Young Onset Dementia, those aged under 65. Commissioned by the NDO, it was undertaken by researchers from UCC and TCD.



Appropriate Prescribing of Psychotropic Medication for Non-Cognitive Symptoms in People with Dementia. National Clinical Guideline No. 21 (2019)

The National Clinical Guidelines sets out recommendations for appropriate prescribing of psychotropic medications for non-cognitive symptoms in a person with dementia and is relevant to all doctors, nurses, pharmacists and health and social care professionals working in acute, community or residential care settings in Ireland who provide care to people with dementia.



Non-Cognitive Symptoms of Dementia (NCSd) (2019)

This guidance was developed to complement the National Clinical Guidelines on appropriate prescribing of psychotropic medications for non-cognitive symptoms of dementia.



Clinician Survey: Dementia Diagnostic Processes and Practices in Ireland (2019)

This report includes the findings of a 2019 survey of clinicians involved in the diagnosis of dementia. It also provides details of dementia post diagnostic practices.



INAD-2: Report of the Second Irish National Audit of Dementia Care in Acute Hospitals (2019)

The NDO published the 2nd Irish National Audit of Dementia Care in Acute Hospitals (INAD-2). The audit is extremely important in helping to improve the care of people living with dementia in acute hospitals.



The Continuum of Care for People with Dementia in Ireland (2019)

This report explores the potential of alternative models of long-term care for people living with dementia. Providing a review of national and international practice.



An Evaluation of the HSE's National Dementia Post-Diagnostic Support Grant Scheme (2019)

This is a report of the evaluation of the Post Diagnostic support scheme which forms part of the implementation of the Irish National Dementia Strategy.



If you have any queries please contact the National Dementia Office at: dementia.office@hse.ie or on: (057) 931 8451

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