

It gives me great pleasure to welcome you to this Autumn edition of the National Dementia Office (NDO) Newsletter, 2021.

As national restrictions continue to lessen, we hope that everyone is exercising, meeting others and recharging our social batteries. In the National Dementia Office, we are relishing our ongoing work across a range of projects including dementia awareness raising, prevention, diagnosis, disclosure, treatment, care and support, and community inclusion. Our newsletter gives a flavour of some of this work.

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 to contact us at dementia.office@hse.ie

Professor Suzanne Timmons, Clinical Lead, NDO



PUBLIC PERCEPTIONS OF PEOPLE WITH DEMENTIA CHANGING FOR THE BETTER

A new survey by the Dementia: Understand Together campaign has found improving public perceptions and attitudes towards people with dementia since the last time similar questions were asked in 2016 and 2018. The nationally representative survey of over 1,200 people was undertaken in July and found:

- **Circle of friends:** Almost half of those surveyed (48%) said that they know (or have known) at least one person with dementia, up from 44% in 2018.
- **Welcoming society:** Shift in public inclusivity from 56% (in 2016) to 68% believing most would treat a person with dementia as they would anyone.
- **Good company:** 71% of people are happy to spend time with a person with dementia, up from 66% in 2018. 72% are happy to be in a social group in the company of a person with dementia, up from 68% in 2018.
- **Active citizens:** More than nine in ten (92%) believe that people with dementia have the right to be active citizens in their communities.
- **Businesses:** More than eight in ten (81%) believe that there are things businesses and service providers can do to make their services accessible to people with dementia.
- **Understanding:** A third of adults (33%) feel that they have a reasonable understanding of dementia while almost nine in ten adults (88%) know something about dementia – just 12% say they know nothing at all. These figures have remained consistent with those reported in the previous surveys.
- **Early diagnosis:** 91% agreed that getting diagnosed at an early stage is good because it allows the person more of an opportunity to make decisions about their care – up from 78% in 2018.
- **Seeking attention:** 58% of people would react immediately if they felt they were concerned about their memory. Three in ten (31%) would probably delay a couple of months and “keep checking myself”. One in ten (9%) say they would be anxious about such a diagnosis and would probably try and cover it up for a while.

The survey findings will support the ongoing work of the Dementia Understand Together programme which is a campaign led by the HSE in partnership with The Alzheimer Society of Ireland, Age Friendly Ireland, Age and Opportunity, and the Dementia Services Information and Development Centre working to create communities that actively embrace and include those living with dementia and their families. You can find out more about the campaign at www.understandtogether.ie.

EVENTS

13th International Engaging Dementia Conference

The 13th International Engaging Dementia Conference is being held from the 4th to the 6th of October. The theme this year is "Opportunity out of Adversity". You can read the preliminary programme and register for the event [here](#).

Enhanced Home Supports for Person Living with Dementia

The National Dementia Office and the National Office, Services for Older People have developed an enhanced model of service delivery for home support for clients with a mild cognitive impairment (MCI) or clients with Dementia. Enhanced home support is available across the country, offering block hours of care and the delivery of psychosocial supports as well as personnel care to clients with cognitive impairment/dementia. Between March and May this year over 150 HSE personnel attended webinars to learn more about the enhanced home support model and to understand the implementation of this service which operates as part of general home support.

Gender and Dementia Care: Aspects in Family Caring

The NDO and Dementia Research Network Ireland are hosting a forum on the 6th of October to raise awareness of the inequity regarding female dementia carers as well as the lack of visibility, research and supports for male carers and carers from the LGBTQI+ community. You can register for this free event [here](#)

Older Persons Living with Dementia Quality Improvement Grant 2020

The NDO was delighted to be involved with the Nursing and Midwifery Planning and Development Unit (NMPDU) in the Midlands to support 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. Six grants were awarded to sites across the Laois/Offaly, Longford/Westmeath area.

PUBLICATIONS

Publication of Dementia Design Guidance

The Dementia Inclusive Community Guide from a Universal Design Approach was published by Dementia: Understand Together Community Campaign. This guide creates communities that include and support people with dementia. Design can aid greater dignity, independence and autonomy. You can download and read the report [here](#).

Dementia Registry Report

The final report of the Dementia Registry Project was published earlier this year (Hopper and Bowen, 2021). The report outlines a feasible model for a national dementia registry and presents the minimum data that should be collected to support positive outcomes for people and to improve clinical practice. You can read the report [here](#).

Report Published on the Dementia Post-Diagnostic Support Policy and Practice Forum

Last year the NDO co-hosted an event with Dementia Research Network Ireland on dementia post-diagnostic support. A detailed report of the event is available [here](#) which outlines the presentations and discussion points raised during the event.

EDUCATION AND TRAINING

Dementia Care and Support: Homecare Education Programme

This QQI level 5 module has been designed for Health Care Supports Assistants, Homecare Organisers, Managers & Coordinators. The aim of this programme is to develop skilled, self-aware, and reflective 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. This module is being piloted in a number of CHO's in Q4 2021. For further information please contact sinead.oreilly@hse.ie

WORLD ALZHEIMER AWARENESS MONTH

This month is World Alzheimer Awareness Month and to mark the month the Dementia Understand Together Campaign have undertaken a number of initiatives:

Mens Shed Dementia Manual - Developed in partnership with the campaign and the Alzheimer Society of Ireland, the manual offers tools to help 'Shedders' recognise signs of dementia, as well as offering practical communication and listening tips on supporting a member with dementia. You can access the manual [here](#).

Media Campaign - To mark this month the campaign has undertaken a major awareness initiative, in partnership with local newspapers across the country. Local papers are featuring a series of four articles on different aspects of dementia throughout the month of September.

Healthy Ireland - The Healthy Ireland fund round for Local Community Development Committees (LCDC's) accepts/ includes projects promoting dementia inclusive communities. Applications for the fund begin Q4 2021 for projects commencing 2022. The primary aim of the Healthy Ireland Fund is to support innovative, cross-sectoral, evidence-based projects and initiatives that support the implementation of key national policies. Stakeholders can contact their local Healthy Ireland co-ordinator or their local LCDC to discuss dementia projects for their community and support the the LCDCs in putting forward their application.

IRISH DEMENTIA CAFÉ NETWORK LAUNCH 'HOW TO SET UP A DEMENTIA CAFÉ MANUAL'

In July 2021 the Irish Dementia Cafe Network launched the manual [How to set up a Dementia Café](#). The manual is a useful tool providing guidance on how to set up and run a dementia cafe.

The launch of the manual highlights the importance of dementia café's within the pathway of care for people who are living with dementia. It is a tool to enable everybody who wishes to set up a dementia cafe in their local community to do so.

The booklet contains information and guidance drawn from available national and international best practice and input from cafe co-ordinators as well as expert input from the Irish Dementia Cafe Network's Advisory Panel. The manual is part of a set of resources that have been developed to support existing café's and start-up café groups.

The manual is a useful tool to learn more about dementia cafes, how they work, where to find them and how to get involved, as well as signposting to organisations and websites for further information on dementia. It breaks down the process of setting up a dementia café into 5 easy steps and demystifies the idea that only people with professional experience of dementia can set up a dementia café. The engine of a dementia café is its voluntary steering committee, and while it is important to have a health and social care professional in the steering committee, having an expert by experience (person living with dementia or family carer) is equally important.

Dementia cafés are a community support service, and anyone with an interest in setting up a dementia café should read the 'How to set up a dementia café manual'.

The manual is available to request for free [here](#). The Irish Dementia Café Network is funded by Dormant Accounts through the Department of Health and the National Dementia Office. It is run and facilitated by Engaging Dementia.

SAFEGUARDING WEBINARS

Earlier this year the National Safeguarding Office and the National Dementia Office organised a number of education webinars entitled "Towards A Greater Understanding of Dementia" presented by Susan O'Reilly, ANP in Dementia Care, Connolly Hospital. These webinars were delivered to over 230 staff of the Safeguarding and Protection teams and to the wider audience of Designated Officers who have a safeguarding role in services funded by the HSE.

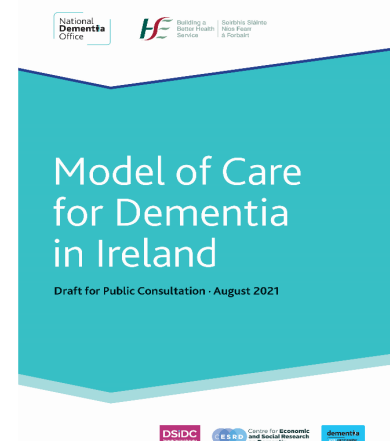
Personnel attending the webinars liaise and work with people living with dementia on a regular basis and the webinar focused on increasing their understanding of living with the condition. The webinar provided practical advice around communicating with people with dementia; focusing on enabling people rather than disabling this client group. Attendees were also directed to a range of resources available on www.dementiapathways.ie.

DEMENTIA MODEL OF CARE

Thanks to everyone who provided feedback on the Draft Dementia Model of Care which was recently out for public consultation. The model is a culmination of a number of years work and is informed by an expert advisory group and consultations with key stakeholders and interest groups.

It is developed by the NDO in partnership with the Centre for Economic and Social Research on Dementia (NUI Galway) and the Dementia Services Information and Development Centre (DSiDC).

You can read more about the model of care [here](#). The draft model is currently being updated and will be published shortly.





SUZANNA DOOLEY TELLS US ABOUT AN EXCITING INITIATIVE RUNNING IN ST.COLUMCILLES HOSPITAL

Caring Conversation Training
Project Update

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The Speech and Language Therapy (SLT) Care Pathway for people with dementia in St. Columcille's Hospital (SCH) is constantly evolving. There has been an increasing demand for SLT involvement across the wide range of services for people with dementia accessing MAU, acute care, day hospital, reablement service, memory clinics and community outreach.

Caring conversation training has been running over the past months co-ordinated by Dr. Suzanna Dooley & Sophie Furey, Speech and Language Therapists with funding from the National Dementia Office. Project targets have been to improve staff knowledge on the impact of dementia on communication, to reduce communication barriers, to provide education on the principles of supported communication and to enhance the health care experience for the person with dementia.

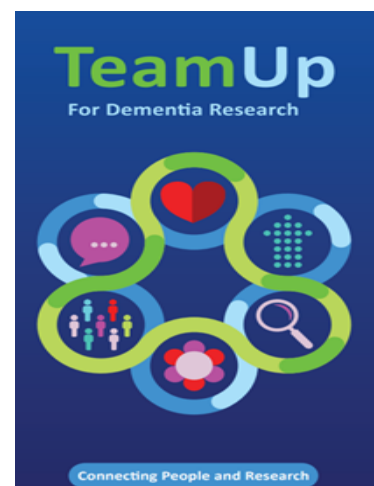
On completion of the training session, staff commit to improving one aspect of their own communication to support conversations with people with dementia. These changes may involve: being a better listener, slowing down the conversation or using specific communication aids. Everyone chooses their own goal. Two months later they receive a postcard reminder of their commitment to change. On the acute care wards, a little violet is put above the patient's bed and is a cue to staff to communicate in a dementia friendly manner, to check out the 5 things about me, the persons' communication profile and to link in with the speech and language therapist. The use of the little violet identifier on a pilot basis on the wards has been successful in improving communication access through the provision of communication support for people with dementia. The plan now is that the violet will be used hospital wide as a caring conversation identifier.

Staff feedback has been positive and 150 members of staff from across all hospital departments and disciplines have enthusiastically participated in the caring conversations project.

TEAM UP FOR DEMENTIA RESEARCH

The Alzheimer Society of Ireland (ASI) has launched a new service in collaboration with Dementia Research Network Ireland - TeamUp for Dementia Research.

TeamUp For Dementia Research is a service where people living with dementia and their families can register their interest to participate in dementia research. It connects the person with researchers who are conducting studies in the area of dementia (e.g. prevention, diagnosis, treatment, care, cure). This might be of interest to people with dementia, their families and carers who you are working with. You can find out more [here](#).





EXPANSION OF DEMENTIA ADVISER SERVICE

The Dementia Adviser Service (DAS) has been operating since 2014, initially as a pilot initiative led by the Alzheimer Society of Ireland (ASI). Following an independent evaluation (Coffey et al, 2018) commissioned by the HSE the service has gone from strength to strength. With funding made to the ASI from the HSE and SláinteCare, the DAS now comprises a national coordinator and a team of Dementia Advisers, with a presence in every county.

The DAS is a responsive service, providing locally based and individualised information, signposting, and emotional support to people worried about their memory, awaiting a diagnosis or diagnosed with dementia, and their carers/supporters. The type of work they do includes:

- Increasing understanding of dementia and its impacts;
- Providing guidance to families on how best they can help support their loved one living with dementia; Supporting clients to identify strategies to manage day-to-day life with a focus on maintaining wellbeing, activity, participation and inclusion in their local communities;
- Providing assistance and support to navigate the health and social care systems;
- Encouraging clients to plan for the future.

As part of the development of an integrated care pathway for people living with dementia DA's liaise with health and social care professionals/teams that work with people with dementia, including hospital and community based teams, Memory Assessment Services, Memory Technology Resource Rooms, GP's and Public Health Nurses.

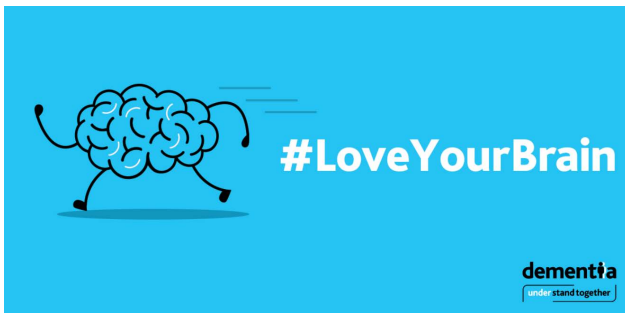
In addition, to raise awareness of dementia and reduce stigma the DA team engage locally with the Dementia Understand Together in Communities programme and the Irish Dementia Café Network.

The DAS welcomes referrals from health and social care professionals and accepts self-referral from people living with dementia, carers and family members. For information about the service and contact details of local dementia advisers see the Alzheimer Society of Ireland [website](#) or contact the National Helpline 1800 341 341 or helpline@alzheimer.ie.

DEMENTIA BRAIN IMAGING WORKING GROUP

The NDO has convened a national working group to look at brain imaging as part of an accurate and timely dementia diagnosis. The remit of the group is to:

- Examine the appropriate scans for different presentations of dementia (e.g. those with sensory, language or behaviour problems and those with memory or cognitive impairment);
- Map existing scanning capacity within the health system
- Identify future demand for neuroimaging to guide investment in this area and ensure waiting times can be minimised;
- Examine educational need for clinicians.



While the NDO has a remit to improve the diagnosis, treatment and support of people with dementia, and their families, it goes without saying that we need to also try to prevent or delay dementia, or slow its progression, wherever possible. In fact, 40% of dementia is potentially modifiable - that is that it could be prevented or delayed. The same good lifestyle habits that reduce the risk of heart disease and stroke can reduce the risk of developing cognitive impairment or dementia. Not smoking, avoiding high blood pressure and diabetes, and regular physical exercise are very important. There is particularly strong evidence that exercise reduces the risk of dementia. This can be any exercise that a person enjoys, including walking, swimming, dancing, golf, etc. A healthy diet, such as the Mediterranean diet, may also help. This contains lots of fresh vegetables and fruit and wholemeal foods, as well as oily fish (like mackerel and salmon). Alcohol is toxic to brain cells so only drinking in moderation is important too.

There are also some risk factors that are unique to dementia. One of these is hearing loss. People with mild hearing loss are almost twice as likely to develop dementia. With severe hearing loss, the risk of dementia is five-fold. To protect hearing, people need to avoid excessive noise exposure and, where not possible, wear proper ear protection. Anyone concerned about their hearing should seek attention via their GP, who can refer to audiology services as needed. Anyone assessing a person with suspected dementia should make sure they are hearing all questions properly, but moreover should screen for hearing loss, and refer onwards as needed. Finally, anyone needing a hearing aid should be encouraged and supported to wear it. This helps a person to maintain social contacts and keep engaged, hence exercising their brain and supporting good mental health. See [here](#) for more details.

GENERAL MANAGER RETIREMENT

In July the National Dementia Office bid farewell to Mary Manning who retired after many years with the HSE. Mary has led the NDO team since 2016 as General Manager.

Prior to taking up this National Post, Mary was Director of the Nursing & Midwifery Planning & Development Unit in the midlands region in the ROI. She also held the post of National Nursing Lead for Dementia for the Office for Nursing & Midwifery Directorate (ONMSD).

Mary will be missed by her colleagues in the NDO, HSE and beyond and wish her congratulations and the very best for her retirement.

