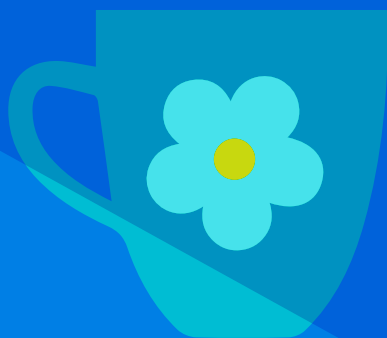


Proceedings of the Policy and Practice Forum on Dementia Post-diagnostic Supports: A Changing Landscape

4 November 2020



DEMENTIA RESEARCH NETWORK IRELAND
Prevention, Cure & Care for Neurodegenerative Diseases





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1.0

Introduction

Post-diagnostic support is incorporated into The Irish National Dementia Strategy (Dept of Health, 2014) through its priority action area 'Timely Diagnosis and Intervention'. Under this priority action area, the National Dementia Office (NDO) developed the Dementia Post-diagnostic Support Project in 2017 and established the Post-diagnostic Support Programme which ran in 2019.

A Policy and Practice Forum was hosted online by Dementia Research Network Ireland (DRNI) and the NDO on 4th November 2020, as part of the Engaging Dementia 12th International Dementia Conference. The aim of the forum was to examine the current post-diagnostic landscape in Ireland and explore how to build on recent progress made with regard to the implementation of post-diagnostic supports for people with dementia and their family carers. The Forum also provided an opportunity for practitioners to discuss best practice in this area, with a particular focus on ways of enabling provision for those who would most benefit from such supports, and overcoming challenges associated with implementing dementia post-diagnostic supports.

The forum was opened by **Dr. Carol Rogan**, Scientific Project Manager, DRNI who welcomed the attendees and outlined the aims of the forum. The welcome from DRNI was followed by an opening address given by Mary Butler, T.D., Minister of State Department of Health with responsibility for Mental Health and Older People. This was followed by a series of presentations and a panel discussion.

2.0

Key themes

2.1

Consensus on importance of post-diagnostic supports

An opinion shared by all of the presenters is that post-diagnostic supports for people with dementia and their family carers are an important part of the care landscape. They potentially offer important benefits for people with dementia and their care partners, especially in the earlier stages, as demonstrated by a growing body of evidence. Although the National Dementia Strategy makes no direct reference to post-diagnostic supports, Strategy commitments, especially under the priority action 'Timely Diagnosis and Intervention', are in line with the consensus view and have provided an important impetus for the development of post-diagnostic supports over the last five years. The NDO, which has responsibility for implementing the NDS, has picked up the baton and taken the lead in embedding post-diagnostic supports in the Dementia Care Model, which it is developing in consultation with a multidisciplinary Advisory Team. As well as being supported by the National Dementia Strategy, the development of post-diagnostic supports for people with dementia aligns well with Sláintecare. An important next step will be to optimise synergies between the National Dementia Strategy and Sláintecare, as well as other related policy such as the National Carers' Strategy, to ensure that people with dementia and their family carers are supported post-diagnosis. However, to develop post-diagnostic supports, resources are required. To date, reliance has largely been on once-off sources of funding such as Dormant Accounts Funds, but it is hoped that funding made available in Budget 2021 will enhance post-diagnostic services and supports for people with dementia and their family carers.

2.2

Framing post-diagnostic supports

There is no single definition of ‘post-diagnostic support’. In the UK, a formal definition has been provided by the Social Care Institute of Excellence (SCIE): “to help people continue living well in the community; provide information and support; help people to manage issues as a result of getting a diagnosis; and delay admission to long-term residential care” (SCIE, 2014: 2). However, this definition does not quite capture post-diagnostic supports and the way in which thinking about them is evolving in Ireland. The Policy and Practice Forum has helped to surface current thinking on post-diagnostic supports. The Post-diagnostic Support Pathway, one of three elements making up the Dementia Model of Care, provides a useful framework in this regard. According to the framework, post-diagnostic supports are designed to help people with dementia with understanding and planning, staying connected and staying healthy, to support people with dementia’s cognition and their emotional wellbeing. Post-diagnostic supports are for all people with dementia and their family carers, for people at all stages of dementia, following diagnosis through to end-of-life care. They are not restricted to people living in the community or delaying admission to long-stay residential care, but are relevant to people with dementia in all care settings.

Given the low base of post-diagnostic supports in Ireland, the importance of both increasing the level and expanding the range of post-diagnostic supports available to people with dementia and their family carers was highlighted at the Forum. A broad range of post-diagnostic supports were referred to and discussed. Traditionally, the most predominant post-diagnostic support for people with dementia and their family carers has been dementia-specific day care, however in recent years, the focus has been on broadening the range of supports. Presentations on Dementia Advisers, Dementia Cafés, and Maintenance Cognitive Stimulation Therapy (MCST) offered examples of post-diagnostic supports relatively new to the Irish care landscape that support dementia understanding and planning, that enable people with dementia and their family carers to stay connected and that support cognition. There are also many supports and interventions to help people with dementia and their family carers to stay healthy and support wellbeing.

While an eclectic mix is needed to best meet the needs of individuals with dementia and their family carers, the array of supports is not easily shoe-horned into a Dementia Post-diagnostic Pathway, presenting challenges for health professionals prescribing post-diagnostic supports and people with dementia and family carers seeking such supports. This is further complicated by the timing and quality of a dementia diagnosis and the progressive nature of the condition. Consideration of a number of dimensions may be helpful in this regard including the target beneficiary(ies), the modality, the setting and the intensity/level of supports as well as concepts such as tiered or stepped care. Because of the multiplicity of offerings, one solution may be to provide a core offering supplemented by other post-diagnostic supports based on needs and circumstances.

Post-diagnostic support also involves the creation of inclusive communities in which people with dementia are respected, supported and connected.

2.3

Personalising post-diagnostic supports

The centrality of a person-centred approach to post-diagnostic supports was stressed by several presenters. A person-centred approach has been identified as one of five supporting principles underpinning the Dementia Care Model. In person-centred post-diagnostic supports, the person is viewed, treated and valued as an individual with dignity and respect; personhood is at the centre of care provision and it requires that people with dementia are involved in treatment and support decisions. A person-centred approach can underpin specific post-diagnostic supports and interventions. For example, care planning can be focused on developing a personalised plan. Maintenance Cognitive Stimulation Therapy (MCST) offers another example. Adopting a person-centred approach is a guiding principle of this intervention and its delivery in a flexible manner and tailored to the preferences and needs of people with dementia exemplifies person-centred care in practice. Obtaining feedback from people with dementia participating in post-diagnostic supports and using outcomes that matter to people with dementia demonstrates a commitment to a person-centred approach. Having a range of post-diagnostic supports available makes it possible to present people with dementia with different offerings from which to choose, and giving consideration to different dimensions of post-diagnostic supports, allows health professionals to tailor supports to the wishes and needs of people with dementia and their family carers. Part of a person-centred approach is allowing people with dementia make their own decisions about if or when to participate in post-diagnostic supports and having established relationships and connections in place with health professionals ready to usher people into relevant post-diagnostic supports if and when they wish to take part. A named person or dedicated point of contact may be useful in this regard.

2.4

Including the voices of people with dementia and their family carers

The voices of people with dementia are often excluded. Professor Reilly's presentation provided an excellent example of how the voices of people with dementia were incorporated into a study aimed at developing an agreed set of outcomes that can be used to evaluate post-diagnostic supports. Importantly, the set of outcomes agreed are outcomes that matter to people with dementia, in contrast to the outcomes often used in studies to evaluate outcomes but which have excluded people with dementia from their development. Involving people with dementia in decisions that affect them is central to the principle of citizenship, a principle underpinning the Dementia Care Model. Feedback from people with dementia on their experience of Maintenance Cognitive Stimulation Therapy (MCST) adapted from face-to-face to phone calls during the Covid-19 pandemic provided insights into the value of this post-diagnostic support intervention during a tremendously difficult time. The voice of family carers of people with dementia was represented by Carly Duggan who spoke about her experience of attending a Dementia Café, a testimony of the value of this type of post-diagnostic support both for the person with dementia and their family carers.

2.5

Integrating post-diagnostic supports

Integration was a recurring theme in the Policy and Practice Forum. The National Dementia Strategy is explicit in its policy commitment to planned and integrated care for people living with dementia and integration is at the heart of Sláintecare. Dr Begley from the National Dementia Office (NDO) highlighted that integration is about bringing together health and social care services for people with dementia, including services and supports provided by community and voluntary organisations, and extends to linking these supports with mainstream supports and broader social services. The importance of integrating newly introduced post-diagnostic supports and interventions with existing services was stressed. In developing the Dementia Model of Care, integration has been identified as one of the five supporting principles by the project team: 'dementia care is delivered in a coordinated, integrated way that focuses on the needs of the individual'. Integration was identified by Samantha Taylor of The Alzheimer Society of Ireland as the most important element of the post-diagnostic pathway.

Various dimensions of integration were referred to in the presentations and panel discussion. The value of linking dementia diagnostic services with post-diagnostic supports, particularly professional integration between staff implementing post-diagnostic supports and those making and disclosing the diagnosis, was exemplified by the approach taken in one area to embed the Dementia Advisor service in a memory clinic service. It also provides an example of the integration of medical and social care and integration at a vertical level. This innovative approach needs to be replicated in other areas. Programmes such as the Integrated Care Programme for Older People offer a potential vehicle to bring about integration and there are plans to improve links between newly established Memory Technology Resource Rooms (MTRRs) and diagnostic services. However, further developments are needed with regard to integration. For example, participants stressed the importance of integrating GPs and Public Health Nurses (PHNs) in these processes, highlighting the work that is still needed to bring about better horizontal integration across primary and community services, with respect to both diagnostic services and post-diagnostic support, as well as medical and social care. Integration across the continuum of dementia and integration of post-diagnostic supports across settings were also identified as important.

Network building, one of three implementation streams identified in the Sláintecare report, is another way of bringing about integration. The formation of national, regional and local networks was referred to several times including the establishment of national networks of Memory Technology Resource Rooms (MTRRs) and Dementia Cafés. Dementia Understand Together has brought together a network of over 40 national partner organisations, taking action and inspiring others to get involved in creating dementia-inclusive communities.

Integration is clearly a strong theme in the area of post-diagnostic supports and has been incorporated as a key principle underpinning the framework for the Dementia Care Model. However, integration is a multi-dimensional concept, and inherently complex. Work in this area might benefit from a greater conceptual understanding of integration and its application to dementia post-diagnostic supports such as how can different perspectives of integration, different dimensions of integration, different models of components of integration be used to inform the development of dementia post-diagnostic supports? What are the methodological approaches and evaluation frameworks that can be used to evaluate if and how post-diagnostic supports are being implemented in an integrated way and what is the impact?

2.6

Implementing post-diagnostic supports

As Minister Butler asserted, implementation of post-diagnostic supports, a key focus of the Forum, is vital. As well as ensuring implementation of the National Dementia Strategy, the NDO has been heavily involved in facilitating the implementation of post-diagnostic supports. The presentations on Dementia Advisers, Dementia Cafés, and Maintenance Cognitive Stimulation Therapy offered concrete examples of the implementation of post-diagnostic supports in practice. However, implementing post-diagnostic supports is complex, resource intensive and takes time. For example, it is often underestimated how much time it takes to raise awareness about the existence of services and supports, reach the right audience, explain what the services or supports are about and establish referral pathways. Evaluations can provide valuable information not only about outcomes of post-diagnostic supports but also general important evidence to inform implementation.

2.7

Lessons from the delivery of post-diagnostic supports during the Covid-19 pandemic

The Covid-19 pandemic has left in its wake the closure of day care services and suspension of respite services, which has had a profound impact on people with dementia and their family carers. To provide continuity of care and maintain social contact with people with dementia, many post-diagnostic supports have been forced to adapt, and successfully so, shifting to phone-based supports in the case of MCST, operating virtually as demonstrated by the move to virtual cafés by Dementia Cafés or the reconfiguration of day care away from centre-based to an in-home format. New possibilities have undoubtedly opened up: the possibility of reaching a greater number of people through online supports, the possibility of including people with dementia who ordinarily may be confined to home due to mobility problems or advanced dementia, the possibility of including family carers unable to attend face-to-face supports due to demands of caring or lack of substitute care. Nevertheless, the pandemic has underscored that person-to-person interaction and connections are irreplaceable, and the great value of group-based and peer-to-peer support for people with dementia cannot be under-estimated. It has also highlighted the importance to people with dementia and their family carers of supports such as day care and respite services, the loss of which has impacted significantly on them. It reminds us that at a time when new and an expanding range of post-diagnostic supports are being introduced, we must not lose sight of the role played by the more traditional post-diagnostic supports such as day care and respite services.

3.0

Summary of Presentations

3.1

Mary Butler, T.D., Minister of State Department of Health with responsibility for Mental Health and Older People

Opening Address

Minister Butler expressed her pleasure at attending and speaking at the Forum and commended DRNI and the NDO for organising what promised to be an interesting Forum. The Minister has been passionate about improving the situation for people with dementia and family carers, exemplified by the key role she played in co-chairing the All-Party Oireachtas Committee on Dementia.

Dementia is front and centre in the Programme for Government (Department of An Taoiseach, 2020) and a financial package of support has been secured, including in Budget 2021. With the rising number of people with dementia, we have a duty to put post-diagnostic supports in place early on and implementation of these supports is vital, the Minister stated. Early intervention has many benefits including symptom management and behavioural change, enhancing social contact and reducing social isolation, and helping people come to terms with a dementia diagnosis. There is much work to be done to enhance services and enable people with dementia to live at home. While the COVID-19 pandemic has hampered the provision of community supports for people with dementia, the HSE and the community and voluntary sector have worked hard to provide some continuity of care through their service provision. For example, The Alzheimer Society of Ireland (ASI) is still supporting people with dementia and their families through services and supports that are operating, primary care teams are working collaboratively with Dementia Advisers, and volunteering is being facilitated through the Community Response Forum. While COVID-19 presents many challenges, it also creates an opportunity to provide services in new ways.

An additional €12.9 million of funding allocated to older persons in Budget 2021 will be dedicated to enhancing services and supports for people with dementia and their families. Funding has been approved for the provision of an additional 11 Dementia Adviser posts. This will mean that there will be a total of 29 Dementia Advisers in Ireland by the end of 2021, in addition to a National Coordinator post which received funding through the Sláintecare Enhanced Community Care Fund in 2020. A mapping of community-based public and voluntary dementia-specific services showed that access by people with dementia and their family carers is based on a postcode lottery and changes are needed to bring about equality of access. Dementia Advisers across more areas of the country will facilitate this (see Samantha Taylor's presentation for more details on the development of the National Dementia Advisor Service).

The Government's commitment to expand Home Supports, supported by Budget 2021, means that there will be at least an additional 250,000 home support hours for older people, including people with dementia. Funding of €5m will be allocated to increase access to community-based supports for people with dementia around the country. Inequality of access to memory clinics in Ireland has led to calls for specialist memory clinics to

be established throughout the country, and access to timely diagnosis of dementia will be improved with the establishment of a specialist memory clinic in Cork, as well as four additional memory assessment and support services in Mayo, Sligo, Wexford and Waterford. There are plans to improve the national network of Memory Technology Resource Rooms (MTRRs), which will link in with diagnostic services. The increased funding will also increase access to in-home day care, which will benefit those who cannot access day care outside the home due to COVID-19 and public health restrictions. Work to build on Dementia Understand Together will continue and grow in 2021 and subsequent years, and funding has been secured to do this. Dementia awareness raising campaigns have been successful in reducing stigma associated with dementia. With a view to improving care pathways and outcomes for people in acute care settings, funding secured in Budget 2021 will facilitate the delivery of an Acute Hospital Dementia and Delirium Care Pathway and ensure the effective implementation of the National Clinical Guideline on the Appropriate Use of Psychotropic Medication in people with dementia launched in December 2019.

These measures are wide-ranging and ambitious, and they will offer a greater level of support to our family members, neighbours and friends with dementia, and their families and carers. The Government is committed to building on this progress and moving forward with the implementation of the National Dementia Strategy. As a long-time advocate for people with dementia, Minister Butler affirmed that she will work to ensure that dementia remains a key focus of Government in the future. Finally, the Minister acknowledged the hard work of the National Dementia Office, its partners and the many other stakeholders who work tirelessly to improve services and supports for people with dementia and their families.

After the Minister's opening address, there were presentations from five speakers from Ireland focusing on key developments in relation to post-diagnostic supports. Outcomes are used to measure the effectiveness of post-diagnostic supports in research and the international speaker from the UK presented on outcomes that matter to people with dementia. The formal presentations were followed by a panel discussion.

3.2

Dr Emer Begley, Senior Project Manager,
National Dementia Office, HSE

Overview of the current post-diagnostic landscape

Dr Emer Begley gave an overview of the current dementia post-diagnostic landscape in Ireland. Emer explained that the availability of post-diagnostic supports for people with dementia and their family carers was at a low base in Ireland, but that this has changed in recent years and is continuing to change in a positive direction. The Irish National Dementia Strategy and, in particular, the priority action on Timely Diagnosis and Intervention is a useful starting point. It commits the HSE to developing a National and Local Dementia Care Pathway to describe and clearly signpost the optimal journey through the system from initial presentation with worrying symptoms, through to diagnosis, including levels of intervention appropriate to need at any given time. The following two objectives, set out in the National Dementia Strategy, are of particular relevance:

- Following a diagnosis, people with dementia and their carers know where to seek help or support, who to talk to about accessing services or entitlements and where to go for information.
- Availability of a range of flexible, community-based supports that draw on and integrate community and voluntary organisations and mainstream services as well as health and social care services.

In 2017, the NDO embarked on an exercise in collaboration with the ASI to map out community-based public and voluntary dementia-specific services. This mapping exercise showed that there were significant gaps in the provision of dementia-specific services. Examining service provision by both county and Community Healthcare Organisation (CHO) level showed that the geographical availability of different dementia-specific services was inconsistent. Of all dementia-specific services, dementia day care was most frequently provided across the country.

However, services focusing specifically on early intervention for people with dementia were at a low level, as were dementia inclusive activities, although more activities were available in some areas compared to others. Dementia-inclusive activities were absent in other areas. The community and voluntary sector were identified as being the main provider of community-based dementia-specific services (ASI and NDO, 2017).

To address the identified low level of services for people with dementia and inconsistency

across the country, a first phase of work was commenced by the NDO in June 2017. It involved two projects, a Dementia Diagnostic Project and the Dementia Post-diagnostic Support Project (2017-2019). The latter was concerned with obtaining additional evidence to inform the development of a post-diagnostic care pathway and identify best practice. Bringing these two projects together in 2020, the NDO is now leading a second phase of work, aimed at developing a Dementia Model of Care. The model comprises a number of elements: a diagnostic pathway; guidance on disclosure; care planning and post-diagnostic support. The model is being developed with partners from the Dementia Services and Information Development Centre (DSiDC), the Centre for Economic and Social Research on Dementia (CESRD) at the National University of Ireland, Galway (NUIG) and an expert clinical consultant who is supporting the development of the diagnostic pathway. The project is also informed by a cross-disciplinary Advisory Group.

Evidence generated as part of the diagnostic and post-diagnostic projects underpin this model of care and inform practices, supports and services. Between 2018 and 2020, for example, a range of reviews have been published by the NDO, including reviews of dementia diagnostic services (Revez, Timmons, Fox, Murphy & O'Shea, 2018), memory clinics (Gibb & Begley, 2018), dementia post-diagnostic supports (O'Shea, Keogh, & Heneghan, 2018) and young onset dementia (Fox, Cahill, McGown & Kilty, 2020). A survey of clinicians to better understand dementia diagnostic processes and practices in Ireland was also conducted (NDO, 2019). Several evaluations have been conducted including an evaluation of the Dementia Advisor Service (Coffey, Cornally, Hegarty, O'Caomh, O'Reilly, O'Loughlin et al., 2018), an evaluation of the Dementia Post-diagnostic Supports Grant Scheme

(Pierce, Keogh, Teahan & O'Shea, 2019) and an evaluation of MTRRs (Cullen, 2020). A full list of NDO publications can be found on the dementiaphways.ie website.

Dr Begley outlined the range of supports and services currently available for people with dementia and their family carers. By the end of 2020, there will be 18 Dementia Advisers in place around the country and 27 MTRRs have been established. There are 21 Dementia Cafés, many of which are moving to virtual cafés due to COVID-19, and a network of Dementia Cafés has been established (the subject of a presentation later in the forum by Sinead Grennan). An increasing number of cognitive therapies and psychosocial programmes and interventions are being integrated into existing services. The community and voluntary sector are continuing to provide a wide range of services and supports including day care, social clubs, befriending, peer support and carer support, training and education. The development of community-based services for people with dementia aligns well with government policy, such as Sláintecare (Oireachtas Committee on the Future of Healthcare, 2017), aimed at reforming health services.

Awareness of dementia is being raised through Understand Together in Communities. Understand Together is described by Emer as a growing movement of people taking action to create understanding and inclusive communities where people with dementia and their families are respected, supported and connected. Across Ireland, a network of over 40 national partner organisations and more than 340 community champions are involved in taking action and inspiring others to get involved. A range of resources have been developed and are available at the understandtogether.ie and the dementiaphways.ie websites.

3.3

Professor Siobhan Reilly, Director of the Centre for Applied Dementia Studies, University of Bradford, UK

What matters most to people living with dementia – what does the evidence tell us?

Professor Reilly's presentation focused on a study led by her, which involved developing a core set of outcomes for use in evaluating non-pharmacological health and social care interventions for people living with dementia at home (Reilly, Harding, Morbey, Ahmed, Williamson, Swarbrikc, et al., 2020).

In her presentation, Professor Reilly explained that the questions posed stemmed from a growing interest in studies demonstrating effectiveness of care and services, including post-diagnostic support for people living with dementia. However, measuring effectiveness is fraught with challenges. A consensus has emerged that a set of core outcomes should be measured and reported in all clinical trials of a specific condition. COMET (Core Outcomes Measures in Effectiveness Trials) defines a core outcome set (COS) as 'an agreed standardised set of outcomes that should be measured and reported, as a minimum, in all clinical trials in specific areas of health or health care'.¹ The voices of people living with dementia, however, are often excluded in the development of core outcome sets for use in effectiveness trials in the area of dementia, or when included it is often in a tokenistic way.

Professor Reilly described a recent study she led to address this gap by exploring outcomes that matter to people living with dementia, with the voices of people living with dementia incorporated into the study. The study was funded by the Economic and Social Research Council (ESRC) and the National Institute of Health Research (NIHR) in the UK, and was undertaken as part of the Neighbourhoods and Dementia study.² The aims of the study were to: (i) establish consensus from key stakeholders on what outcomes are the most important, and (ii) recommend a minimum set of outcomes and outcome measures. The study had two research questions: (1) which outcomes should be measured from the perspective of people living with dementia, care partners, health & social care professionals and policy makers, service commissioners, and research leaders?; and (2) how should these outcomes be measured?

1 COMET Initiative | Home (comet-initiative.org)

2 The Neighbourhoods and Dementia study, led by Professor John Keady at The University of Manchester in collaboration with researchers at the University of Liverpool and Lancaster University, aimed to explore how people living with dementia understood and interacted with the people, spaces and places in their everyday lives.

The study adopted a mixed-methods design with three phases. Altogether, over 350 participants (including people living with dementia, care partners, health and social care professionals, policymakers and researchers) took part in the study. Involving people living with dementia as co-researchers was a key feature of the study. People living with dementia also co-presented the findings. In total, there was 62 instances of people living with dementia being involved in the study. Tony Husband, a cartoonist took part and provided a visual record of the study, to add fun and humour to it.

The first phase of the study involved focus groups and interviews. A total of 55 key stakeholders participated, including 17 people living with dementia. A review of studies was also undertaken during this phase. From this phase, a total of 170 outcomes were identified. For the second phase, Delphi surveys and a consensus meeting were conducted with a view to agreeing a list of outcomes important to people living with dementia. Some 300 people participated in this phase. People living with dementia were among the participants: 18 people living with dementia were consulted as co-researchers to help design an accessible Delphi process; 21 people living with dementia participated in the Delphi survey; and six in the consensus meeting. In this phase, the 170 outcomes identified from phase 1 were narrowed down to 54 outcomes through the Delphi surveys and the consensus meeting led to a final core set of 13 outcomes.

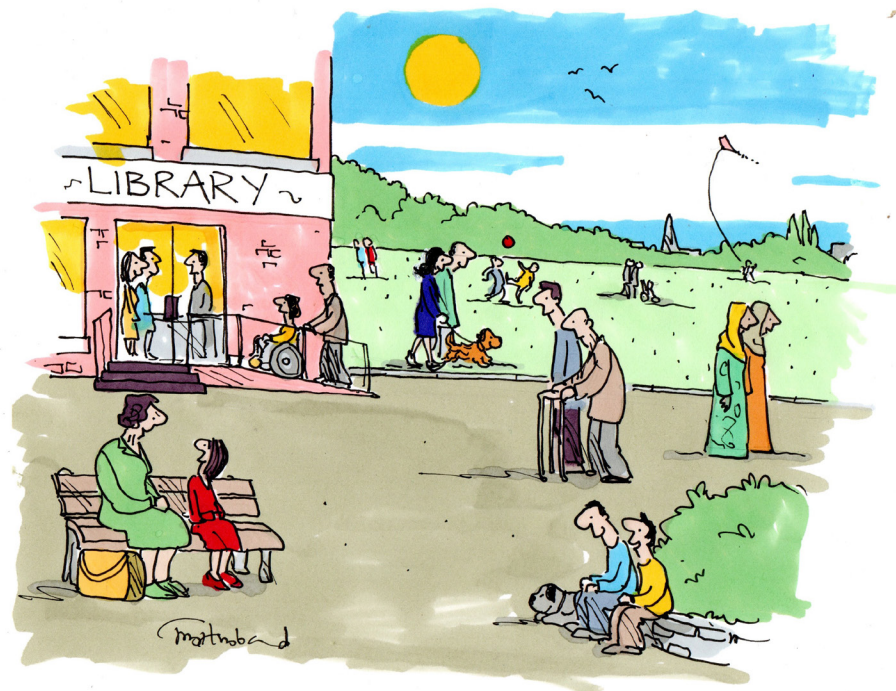
What matters most to people living with dementia is an agreed set of core outcome items for use when evaluating health and social care interventions for people with dementia living at home. The 13 outcomes items are detailed on pg. 19.

A systematic review was conducted for the third and final phase of the study to identify how to measure the outcomes agreed in Phase 2. The research team were not able to identify suitable measures for all of the 13 outcomes (Harding, Morbey, Ahmed, Opdebeeck, Elvish, Leroi, et al., 2020).

Professor Reilly gave examples of some of these outcomes using quotes from people with dementia and cartoon illustrations by Tony Husband (see example below). The findings of the study are published in the journal *Age and Ageing* (Reilly et al., 2020) and Professor Reilly commented that the systematic review, undertaken to identify how to measure the outcomes agreed in phase 2, did not uncover many useful measures. She pointed out that many of the final set of 13 outcome items overlapped with impact measures used in the evaluation of the HSE's Dementia Post-diagnostic Support Grant Scheme (Pierce et al., 2019), although a very different approach (using a wellbeing framework informed by a capabilities approach) has been taken to arrive at the impact measures in that study.

What matters most to people living with dementia

- Continuing good relationships with people who are important to you
- Being able to communicate with others
- Feeling safe and secure at home
- Feeling valued and respected to others
- Feeling able to have a laugh with other people
- Being able to do things that you enjoy and want to keep doing
- Keeping interested in things you like
- Being aware of your surroundings indoors and outdoors
- Being able to find your way around a familiar place
- Being as clean and comfortable as you would like
- Not falling at home or when out and about
- Being able to see, hear and understand
- Feeling able to keep your identity



What matters most to people living with dementia



The final part of Professor Reilly's presentation discussed the relevance and implications for assessing the effectiveness of post-diagnostic supports. A person-centred approach and continuous quality assurance should underpin post-diagnostic support, and it is important to have ongoing evaluation in the form of service user feedback, which could be along the lines of checking against the 13 items in the core outcome set. An example was given of the use of the outcome measures in a RCT of a post-diagnostic support intervention called Journeying Through Dementia, a 12 week intervention developed by Professor Gail

Mountain to support self-management and participation in life after dementia diagnosis.³ Professor Reilly highlighted the importance of measuring outcomes consistently, robustly and rigorously. She concluded by recommending participants to consider adopting a similar process to identify and find ways to measure outcomes of greatest importance to people living with dementia in Ireland when evaluating post-diagnostic services.

3 <https://www.bradford.ac.uk/dementia/research/journeying-through-dementia/>

3.4

Dr Fiona Keogh, Senior Research Fellow, Centre for Economic & Social Research on Dementia, NUI Galway

What should a post-diagnostic support pathway look like?

Dr Fiona Keogh made a presentation on the Post-diagnostic Support Pathway, one of the three elements making up the Dementia Model of Care referred to earlier by Dr Emer Begley in her presentation. The NDO has established a Project Team to develop this pathway and is working in collaboration with a multi-disciplinary Advisory Group. The members of the project team are Mary Manning, Dr. Emer Begley, Dr. Suzanne Timmons, Grace Kelly, Matthew Gibb and Dr. Fiona Keogh.

The Dementia Model of Care is still a work in progress. However, five supporting principles have been identified. These are:

Citizenship – people with dementia are given the same access to treatment and degree of care and support as other citizens and they are involved in decision-making relating to their care;

Person-centred approach – the person is viewed, treated and valued as an individual with dignity and respect; where personhood is at the centre of care provision and people with dementia have to be involved in treatment and support decisions;

Integration – dementia care is delivered in a coordinated, integrated way that focuses on the needs of the individual;

Outcome-focused – care and support centres on identifying and delivering the desired outcomes for the person; and

Timeliness – assessment, diagnosis and interventions are delivered in a timely way, supporting the person's autonomy and continuity of their care.

The Post-diagnostic Support Pathway element of the model is designed around five strands: (1) Understanding and planning; (2) Staying connected; (3) Staying healthy; (4) Supporting cognition; and (5) Supporting emotional wellbeing. Examples of the types of supports provided within each of these were provided. Supports for understanding and planning include information provision, peer support groups, signposting, personalised profile, carer training, and advance care planning & healthcare directives. Dementia Cafés, community-based activities, assistive technologies (AT) and life story work are among the services and supports aimed at enabling people with dementia and their family carers to stay connected. There are many different ways in which people with dementia can be supported to stay healthy, such as through health promotion, meaningful activities, self-management interventions, exercise interventions and telecare. Cognitive therapies and AT can be offered as a means of supporting cognition. Different approaches, therapies and interventions such as sensory approaches, creative arts therapies, counselling and behaviour support interventions can be used

to support wellbeing. These supports can come into play at each stage of dementia, from when early symptoms of dementia are first recognised, through to moderate and advanced stages and at the end of life. All people with dementia can be supported, including people with younger onset dementia and people with intellectual disability and dementia.

Dr Keogh outlined four dimensions for consideration when any type of post-diagnostic support is being prescribed. These are: (1) Target Recipients; (2) Modality; (3) Setting; and (4) Level/intensity. Post-diagnostic supports may be designed for one target beneficiary, but are often designed for more than one target beneficiary. Therefore, it is important to ask 'Who is the target beneficiary or beneficiaries?' Is it the person with dementia only; the carer only; the dyad; or the wider family network? Modality refers to the mode of delivery i.e. how is the support going to be provided? Will it be a group intervention or a one-to-one intervention? Will it be delivered online as a virtual intervention and/or in-person? It is important to be clear about where the supports will be provided and there are many different settings including a person's or family carer's home, at a day centre or similar or in a MTRR or 'dementia hub'. Supports can also be provided in a residential setting, healthcare setting, or outside of these in a non-health or social setting. Clarity on each of these helps to tailor the support to the person.

The concept of 'stepped care' with three tiers is useful for thinking about intensity or level of support. Tier 1 refers to the lowest level of intensity and includes, for example, self-management, support from family, friends and peers, and support from community and voluntary organisations. Tier 2 involves more formal and structured support from community and voluntary organisations and interventions from health and social care professionals. Tier 3 refers to more specialised interventions from health and social care professionals.

Finally, Dr Keogh presented a diagram to illustrate that post-diagnostic supports do not stand alone, but fit into an overall dementia care pathway, which follow on after assessment and diagnosis, disclosure, and support and treatment planning. Since there are a wide array of post-diagnostic supports that can be offered to people diagnosed with dementia and their family carers, one option might be to make a core offering to each person and their family carer in a timely way after the diagnosis has been made and disclosed. This might include information, a named point of contact, and onward referral. Other post-diagnostic supports would then be offered based on needs and circumstances.

During the next part of the Forum, participants heard from a range of practitioners about their experience of translating evidence on post-diagnostic supports into practice. Three presentations were given.

3.5

Colm Doody, Assistant Psychologist, Psychiatry of Later Life Team, St Brendan's CNU, Ballinasloe

From face-to-face to phone: The adaptation of Maintenance Cognitive Stimulation Therapy groups to individualised phone calls during Ireland's COVID-19 Crisis

Colm Doody gave the first presentation on the adaptation of Maintenance Cognitive Stimulation Therapy (MCST) groups in East Galway to phone-based MCST in response to the Covid-19 crisis and the pausing of face-to-face interventions. The origins of this intervention lie in funding by the NDO under the Post-diagnostic Support Grant Scheme in 2018 for the delivery of a 7-week group Cognitive Stimulation Therapy (CST) programme to people with dementia living in East Galway. CST programme delivery was led by Dr Diane O'Mahony, Senior Clinical Psychologist, Psychiatry of Later Life (POLL) team, St Brendan's Community Nursing Unit, Ballinasloe. CST is an evidence-based intervention, which is designed for people with mild to moderate dementia and is usually delivered over seven weeks in group sessions (Spector, Thorgrimsen, Woods, Royan, Davies, Butterworth et al., 2003). CST is recommended for use with people with mild to moderate dementia by NICE (2018) and it has been adapted to be used as an individualised intervention. In East Galway, two assistant psychologists were engaged to deliver CST groups, and between January 2019 and February 2020, multiple CST groups were delivered across the East Galway area in both community and hospital settings.

MCST is a follow-on intervention to CST (Aguirre, Spector, Hoe, Streater, Woods, Russell et al., 2011) and the original seven-week group CST programme in East Galway was developed into MCST. MCST is based on the same principles as CST (e.g. participation is encouraged over achievement; opinions are sought over facts; everybody's contribution is valued) and has a similar curriculum, but is extended to 26 weeks. In East Galway, it was decided to run a MCST group for 'graduates'

of their 7-week CST programme; delivery of these groups commenced in September 2019. MCST groups were run on a weekly basis by two facilitators, with between 10 and 15 people with dementia participating each week. The groups were structured in terms of themes (for example, using money, childhood, current affairs) and activities, but were flexible and tailored to the preferences and needs of people with dementia participating.

However, in March 2020, in-person CST and MCST groups were suspended due to Covid-19. The team set about adapting the MCST groups to be delivered individually to people with dementia by phone on a weekly basis. The main aims of the phone contacts were to provide a continuity of service and maintain valuable social contact for people with dementia. The team delivered the adapted phone-based MCST and evaluated the adapted intervention.

The weekly phone calls followed a similar structure to the face-to-face MCST sessions (i.e. intro, current affairs, weekly “theme”), as people with dementia were familiar with this structure, and it was believed that this would help them engage as they would in a group session. Flexibility was incorporated to allow the facilitators to respond to the identified needs of people with dementia participants. Resources were printed and sent to participants in advance to help the transition to the phone-based intervention and help with focusing attention during phone calls. The MCST facilitators completed Psychological First Aid training to enable them to respond in an appropriate and consistent way if a client expressed anxiety or other discomfort during a call. Typically, 15 older adults with dementia participated weekly. Calls lasted between 10-20 minutes on average. A protocol was developed to ensure that a process was in place to escalate any significant issues to the POLL (Psychiatry of Later Life) team in the first instance. A standard operating procedure was developed to log the details of each client phone call. While the target beneficiary of the call was a person with dementia, the MCST facilitator also had a brief conversation with their support person, if available. There was no break in service delivery between group in-person MCST and the adapted intervention. Calls

continued for 26 weeks, ending in early September 2020.

To evaluate the adapted MCST intervention, direct feedback was sought from participants. A service evaluation was conducted, and feedback was also sought from the multi-disciplinary POLL team. Client feedback on the adapted phone-based MCST was universally positive. Participants reported feeling a sense of togetherness with other MCST participants, despite the cessation of in-person group sessions. Clients also reported that the adapted MCST motivated them to stay mentally and physically active despite the public health restrictions on movements and social interaction. Feedback from participants included:

“It keeps us in touch, reminds us of what we were doing as a group.”

“You still care about us even though we have no meetings.”

“It’s wonderful to have the one-to-one chats.”

The adapted MCST proved to be a valuable support and source of information for carers:

“It’s lovely that you keep in touch, it shows that you care.”

“The activities are definitely helpful for her.”

All of the people with dementia participating in the adapted MCST asked that the calls be continued. Phone calls were identified as preferable to online formats by most participants, largely due to lack of access and not knowing how to use technology.

The team identified five key factors that were critical to the success of the phone-based MCST intervention. First, the pre-existing relationship between the MCST facilitators and people with dementia was

considered critical, as it was possible to build on an established trusting relationship and positive rapport. Second, established relationships and regular contacts with carers were useful in supporting the ongoing delivery of the intervention, as well as supporting carers in their roles during a challenging period. Third, the familiarity that people with dementia had with the structure of the MCST sessions was considered essential given participants' cognitive difficulties and the limitations of phone contact. Fourth, the understanding that people with dementia had previously gained from MCST session participation of the value of mental and social stimulation was considered important. Fifth, the familiarity that people with dementia had with topic-based discussions was also considered important.

Delivering phone-based MCST is not without its challenges. It relies on a single sense (i.e. hearing) for an intervention that emphasises the importance of multi-sensory stimuli to maximise people with dementia's comprehension and engagement. A wide range of resources and activities are used in face-to-face MCST sessions, but these were limited to the use of resources and activities that could be used in the phone-based intervention. Interaction over the phone was difficult for people with dementia who had a hearing impairment, or whose cognitive impairment was more severe. There were limits to the depth of engagement using a phone-based intervention when compared with the face-to-face sessions. The individualised nature of the intervention meant that the benefits gained from group dynamic and social interactions were lost.

The multidisciplinary POLL team felt that an important aspect to the adapted intervention was that the calls maintained social contact at a time when opportunities for social interaction were severely limited by COVID-19 public health measures.

"An invaluable intervention for our clients. I have no doubt that it has really helped to keep people well especially over lockdown."

"It might have been the call they needed at a time of stress."

The multidisciplinary team (MDT) also attributed a perceived reduction in carer stress to the phone-based MCST intervention, an outcome regarded as particularly helpful given reports by carers of increased stress in the months following COVID-19 (ASI, 2020).

Overall, the adaptation of MCST to a one-to-one phone-based intervention during the COVID-19 period was regarded as successful, with an overwhelmingly positive evaluation by the clients and MDT team. Many of the clients commented on the sense of togetherness they felt with their MCST group, and the motivation that the calls gave them to continue to engage in mentally and physically stimulating activities during the lockdown period and beyond. The positive review of the adapted intervention raises some interesting prospects for the standard delivery of CST and MCST such as the potential to offer "catchup" sessions over the phone, thereby allowing the client to remain motivated and included in CST and MCST groups despite short or more long-term absence.

3.6

Sinead Grennan, CEO Engaging Dementia and Irish Dementia Café Network Coordinator & Carly Duggan, Carer and attendee of a Dementia Café

The Irish Dementia Café Network

The next presentation on the Irish Dementia Café Network was co-delivered by Sinead Grennan and Carly Duggan. Sinead spoke about the recently established Irish Dementia Café Network. The project, which brings together 21 Dementia Cafés, was commissioned by the NDO as part of the Dementia Post-diagnostic Support Project and is funded by Dormant Accounts. The project was informed by research on Dementia Cafés carried out in 2018/2019 by the CESRD at NUIG (Teahan, Fitzgerald & O'Shea, 2020).

The objectives of the project were to: develop a flexible Alzheimer Café model; support the development of new Alzheimer Cafés; offer support and guidance to Alzheimer Cafés; build a network of Alzheimer Cafés; and raise awareness about this type of support. A Project Advisory Panel was established, which included a person with dementia and their family carer, and a Café coordinator was engaged. A principle-based framework has been developed to underpin all Dementia Cafés in the Network. The term Dementia Café has been adopted as the shared name for all dementia/Alzheimer/memory cafés and mentoring is in place for new Dementia Café start-ups. The Network was launched on 17 September 2020.

The Dementia Café framework comprises four pillars and principles:

Atmosphere – key elements are that the café is warm and welcoming and offers a safe place to talk.

Information – key elements of which are signposting by other participants (both peers and café team) and an informative talk. An information table is another information element.

Support – key elements of support are peer support and information/advice from health and social care professionals.

Community – key elements here are a sense of community and raising understanding and awareness of dementia.

In response to the suspension of face-to-face Dementia Café meetings due to Covid-19, a virtual Dementia Café was developed in April 2020, and ran weekly thereafter. The project provided mentoring to café groups to set up their own virtual Dementia Café meetings while face to face meetings were suspended due to COVID-19 restrictions. It was planned that Virtual Dementia Café meetings would continue even when face to face café meetings recommenced, as this increased accessibility of the service, particularly for those who live in remote or rural areas.

Carly Duggan spoke about her experience of attending a Dementia Café, from the perspective of a carer of a person with dementia. Having attended the Dementia Café on a monthly basis with her partner Owen, she spoke about the benefits of attendance for her and her partner and the importance of having a safe space for her partner with dementia. It was a place where they were able to engage with other people with dementia and make new friends. Attending the Dementia Café was especially important because it was one of the few places where they could go out together as a couple. Carly commented on the 'huge learning' from the talks that were given at the Dementia Café. She described it as 'safe' and a 'life saver'.

3.7

Samantha Taylor, Head of Enterprise Risk Management, Compliance & Dementia Advisory Services at The Alzheimer Society of Ireland

Alzheimer Society of Ireland's Dementia Advisor Service

Finally, **Samantha Taylor** gave a presentation on the development of a National Dementia Advisor Service. This service came about in response to the expressed need made repeatedly by people with dementia and their family carers for a dedicated point of contact to provide accurate, accessible and timely information and signposting. A Dementia Advisor Service was first piloted by the ASI in Dublin and Cork in 2013 to build on and enhance existing information services such as the ASI National Helpline. Two staff were appointed to provide the service. From this initial pilot, the Dementia Advisor Service grew and between 2015 and 2020 there were eight Dementia Advisers providing this service across 11 counties.

As well as providing information, advice and signposting, Dementia Advisers play a role in supporting people with dementia and their family carers to access services and supports. They also have a role to play in early intervention and crisis prevention. Through the provision of these supports, the service aims to: reduce social isolation and stigma; enable participation and engagement; and maintain wellbeing and independence. Facilitating peer-to-peer supports is another feature of the Dementia Advisor service.

The Dementia Advisor Service has been evaluated and the ASI has conducted a client impact survey. The NDO/HSE commissioned external evaluation of the service, published in 2018 (Coffey et al., 2018). It found that the key attributes of Dementia Advisers is as someone who a person with dementia and their family carer can trust and who is on their side; who provides space and time to listen; and is flexible and knowledgeable. The Dementia Advisor Service is valued by

people with dementia and their family carers because it provides access to relevant timely information; offers a single point of contact; offers accessible and practical advice; and emotional support:

"it's brilliant to have someone to talk to and ask relevant questions ... [Dementia Adviser] has meant everything as I know when things get too rough, I can call someone".

Health and social care professionals also found the service to be valuable as a post-diagnostic support for people with dementia and their family carers:

"The Dementia Adviser has changed our service. We now refer direct from the memory clinic which is hugely beneficial."

The Dementia Advisor service provided a much-needed service responding to the enormous challenges that people with dementia and their families faced during Covid-19, as evidenced by the ASI's report

on *Caring and Coping with Dementia during COVID-19* (ASI, 2020).

In Budget 2020, funding was allocated to expand the National Dementia Advisor Service, resulting in 10 new Dementia Adviser posts and a National Coordinator being appointed. As Minister Butler mentioned in her opening address, a further 11 posts were announced in Budget 2021 to further expand the National Dementia Advisor Service. This will mean that there will be a full-time Dementia Adviser post in most counties and an enhanced service in areas with high population density. Part of the National Dementia Advisor Service is funded through the Sláintecare Enhanced Community Care Fund via the HSE & NDO.

4.0

Panel Discussion

The panel discussion was facilitated by Matthew Gibb, Director of the Dementia Services Information & Development Centre (DSiDC) at St. James's Hospital.

The panel members were:

Professor Sean Kennelly, Consultant Geriatrician & Clinical Director of the Memory & Assessment Service, Tallaght University Hospital

Susan Scally, Principal Officer, Social Care Division, Department of Health

Dr Emer Begley, Senior Project Manager, National Dementia Office

Sinead Grennan, CEO Engaging Dementia & Irish Dementia Café Network Coordinator

Colm Doody, Assistant Psychologist, St Brendan's Community Nursing Unit, Ballinasloe

Carly Duggan, Carer and attendee of a Dementia Café

Samantha Taylor, Head of Dementia Advisory Service, The Alzheimer Society of Ireland

The first question put to the panel was **what is an appropriate post-diagnostic care pathway and how has post-diagnostic care for people with dementia been affected by Covid-19?** In response, Professor Sean Kennelly welcomed the personal testimony of Carly Duggan, which highlighted the importance of post-diagnostic supports for family carers. Despite positive changes in the provision of such support, services are still failing people with dementia and their family carers, especially when they are left with a sense of no place to turn. This resonated because similar sentiments had often been expressed in his clinic in Tallaght Hospital. Professor Kennelly made four main points. First, he highlighted the links between diagnostic and post-diagnostic support and that disclosure is a very important part of the post-diagnostic care pathway. An appropriate, positive and hopeful disclosure is needed and reassurance that the diagnosis is accurate, as the way in which a disclosure is made is vitally important for setting people up for participation in post-diagnostic supports. Second, for many decades, there has been a biological/medical model on the one hand and a social model on the other hand, but in recent years, the importance of an ecosystem of support had been developing. For example, it is not enough for clinicians to make a diagnosis of dementia, clinicians also have a responsibility for starting that person on the post-diagnostic care pathway. The clinician must be part of the ecosystem of support, so that when an issue arises, the person can be linked back in to the clinician in a seamless way. Dementia Advisers sitting in the memory clinic offers an example of this connection. There is one diagnostic and post-diagnostic pathway, in which all health professionals and service providers are linked. Thirdly, where a person is diagnosed and how the diagnosis is made is changing, and diagnosis is being made much earlier. Therefore, the diagnostic process must be used as an opportunity for raising and promoting brain health with people with dementia and their family carers, and linking the dyad into programmes together, with a strengths-based focus. Fourthly, he stressed the importance of building capacity across the system. Despite investment, Ireland's health and social care system was still falling short for people with dementia and their family carers.

Covid-19, especially during the first wave of the pandemic, had a significant impact on people with dementia. Immediately, people with dementia on the memory service database were supported by telephone, and those identified as struggling got extra support from dementia nurse practitioners. Diminished access to day care and to respite has had the biggest impact on people living in the community. While some services had been resurrected, these services had not been. Covid-19 has also impacted heavily on family carers.

With respect to Covid-19, lack of access to nursing homes to visit relatives is leaving family carers feeling helpless and frustrated, a point made by Carly Duggan, and impacts significantly on the person residing in a nursing home.

A key element of the post-diagnostic support pathway, as highlighted by Dr Emer Begley, is crisis prevention, and a more practice care approach is needed. There is a seamless transition between diagnosis and post-diagnostic support, there is a single point of contact for the person with dementia and there is a holistic needs assessment, and services to wrap around the person. The needs assessment is updated over time as required. At the moment, people are hitting crisis before they can access any type of intervention, and the aim must be to avoid that. The aim of the National Dementia Strategy is to live well at home for as long as possible and that is something that needs to be realised.

The next question posed to the panel was **how do we achieve the aims of the Irish National Dementia Strategy and what are the main elements of the post-diagnostic support pathway from the perspective of the Department of Health?** Susan Scally drew attention to Sláintecare and its vision to provide right care in the right place at the right time, which in practice means getting access to a timely diagnosis, getting access to post-diagnostic supports and services, and a continuum of care that provides the appropriate supports at the different stages of dementia right up to end of life. From the Department's perspective, it is about fully implementing the National Dementia Strategy, which sets out the policy direction and key principles needed to enable people to live well with dementia. The NDO has been excellent in piloting, testing concepts and getting NDS initiatives underway. However, a key issue has been a lack of resources to mainstream initiatives piloted with the support of once-off sources of funding such as Dormant Accounts funding. The substantial allocation of funding by the Government in Budget 2021 for the National Dementia Strategy is a major step forward and will enable significant progress on initiatives commenced by the NDO to be made in 2021 and in the future. Providing care and support which enable people living with dementia to live at home for as long as possible and practicable is a key element of the Strategy.

Covid-19 has shown that over reliance on residential care as a model of care for older people is not sustainable, and the focus needs to be on delivering services and making them accessible as close to home as possible, to prevent premature entry into long-term care. It is hoped that the funding allocated in Budget 2021 will support a range of services in 2021 and into 2022, such as the expansion of the Dementia Advisor service, greater access to memory assessment services and to address different aspects of post-diagnostic support. Optimising synergies between the National Dementia Strategy and the National Carers' Strategy is also important to ensure we support the needs of both the person with dementia and their family carer. In this context, it is important that where access to day care services is not possible for people living with dementia because of public health restrictions, there is access to in-home day care and other supports. The Department noted the contribution of the ASI in providing such supports during the pandemic and welcomed provision in Budget 2021 to resource in-home day care supports as we continue living with COVID-19.

Samantha Taylor identified integration as the most important element of a post-diagnostic pathway. Where Dementia Advisers have managed to do that, for example, through integration with the memory assessment service in Tallaght University Hospital (TUH), it has borne fruit for everybody, and came into its own during Covid-19. It enabled health and social care professionals from different backgrounds to come together to troubleshoot and navigate a new way of doing things, and respond to challenging cases. It really helped that the seeds of integration were there before the Covid-19 crisis.

Samantha also emphasised the importance of the link between diagnostic and post-diagnostic services and supports, but that Dementia Advisers are only one type of post-diagnostic support and a range of post-diagnostic supports has to be in place. With the expansion of the Dementia Advisor service, the NDO is providing support to replicate the experience of integrating the Dementia Advisers with the memory service in Tallaght University Hospital and what works around the country. But this is only one part of the jigsaw and other services need to be integrated as well. Covid-19 had forced service providers to innovate and there is

an opportunity to continue to harness this innovation. One example is the reconfiguration of day care away from centre-based provision to care workers visiting the homes of people with dementia for a two-hour block of activities and engagement, according to assessed need of the person with dementia, and to provide respite for and reduce isolation of family carers. Work is simultaneously ongoing with the HSE to develop a roadmap for the reopening of day care centres. A lesson from Covid-19 is that there is a need for a mix of supports and there should not be an over-reliance on one type of support.

The next question put to the panel was **what can we do to increase the implementation of post-diagnostic supports and encourage people with dementia and their family carers to take up post-diagnostic supports?** An issue highlighted by Dr Emer Begley was the time and resources it takes to raise awareness about the existence of services and supports, reach the right audience, explain what the services or supports are about and establish referral pathways. The resource intense nature of doing this is often underestimated. According to Professor Sean Kennelly, where information hubs are located is also important. Having a partnership with the ASI and having Dementia Advisers sit in memory clinics is very important for this reason. The ASI is a repository of information and it is important to be able to distil this information down to the local level. It is also important to acknowledge that people who receive a diagnosis of dementia and their care partners may or may not want to avail of post-diagnostic supports, and people will make their own decisions about if and when to take part. This is not something that can be manufactured; it is about creating a soft interface so that when a person has come to terms with the diagnosis and is ready to engage with post-diagnostic supports, there is an established pathway for linking them in to appropriate supports. This requires having as much linkages and partnering as possible between those delivering diagnostic and post-diagnostic services and supports at a local level.

Forum participants highlighted the role of transport to enable people with dementia access post-diagnostic supports. GPs and Public Health Nurses (PHNs) are well placed and play a vital role in linking people with dementia into post-diagnostic supports and increasing uptake. Matthew Gibb (DSiDC) highlighted the importance of getting information to the GP after a diagnosis is made, and also the importance of GPs acting on this information once it is received. The important role that PHNs play was echoed by Samantha Taylor. Raising awareness of the supports that are available through channels such as the ASI Mobile Information Service is important for increasing uptake of post-diagnostic supports. This involves bringing the information to where people are in their communities, for example, farmers' markets, the Ploughing Championships, and is a means of starting the conversation and embarking on a process of bringing people along. Understand Together in Communities and the Dementia Café are other examples mentioned by Sinead Grennan of bringing information to and mobilising communities, highlighting the multi-pronged approach that is needed, especially given the stigma that still exists around dementia, and the lack of awareness about services and supports that are available. The possibility of being able to reach people through online supports has been demonstrated during Covid-19.

Diagnostic disclosure and post-diagnostic support for younger people with dementia were raised as issues by one participant of the forum. Professor Sean Kennelly responded by saying people with younger onset dementia need different approaches and often different supports,

but that the culture and philosophy that underpins such approaches and the delivery of supports should be the same for people under and over 65 years of age, such as supporting will and preferences. The Integrated Care Programme for Older People (ICPOP) that the Department of Health has invested in, is a phenomenal resource for people aged 65 years and over, and has allowed for domiciliary visits by geriatricians to the homes of people with dementia showing psychological distress, but those resources and supports are not available for people under 65 years of age. Ideally, people with dementia would be supported without an arbitrary age cut-off point, but supports for younger people with dementia have not been adequately resourced. Accessing supports for people with younger onset dementia is a challenge, including access to suitable long-stay residential care, access to information, support around occupational issues and around care issues.

Carol Rogan thanked the panel members and the Forum participants and brought the Forum to a close.

5.0

Further Information

Videos of the presentations can be found on the DRNI youtube channel:
<https://youtu.be/D3-CAnnCw10>

Copies of the presentations can be found on the DRNI website:
<http://dementianetwork.ie/policy-practice-forum-dementia-post-diagnostic-supports-0>

6.0

About the Organisers

Dementia Research Network Ireland

DRNI is an innovative, all-Ireland research initiative which supports and facilitates collaborative interdisciplinary research integrating the basic, clinical and social sciences. DRNI seeks to improve outcomes for people with dementia/neurodegenerative disease through improving our understanding of the causes and mechanisms of neuro-degeneration, the effectiveness of different models of care, and the policy changes required to improve individuals' quality of life.

The network comprises over 100 members. Membership includes leading Irish academics, clinicians, health & social care practitioners, early-career researchers, government representatives, community & voluntary sector members, people living with dementia and Parkinson's disease, and carers. DRNI is funded by the Health Research Board (Grant No. DNNI-2019-1).

Website: www.dementianetwork.ie

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Email: info@dementianetwork.ie

National Dementia Office

The National Dementia Office (NDO) was established in 2015 in accordance with the launch of the National Dementia Strategy (Department of Health, 2014). The NDO provides leadership at a system level for the implementation of the strategy. Its role and function is to oversee the implementation, monitoring, and ongoing evaluation of the National Dementia Strategy.

The NDO sits under Strategy and Planning within the Health Service Executive.

7.0

Speaker biographies

Dr. Emer Begley

Emer is a Senior Project Manager at the National Dementia Office. Prior to joining the HSE in January 2017, Emer worked for eight years in the Community and Voluntary Sector working with a number of advocacy organisations focusing on dementia and ageing. Most recently she was Policy and Research Manager with the Alzheimer Society of Ireland. Prior to this, she was with Age Action as their Senior Policy Officer.

Emer is currently part of the project team developing the Dementia Model of Care and between 2017 and 2019 she led the NDO's Dementia Post-diagnostic Project.

Minister Mary Butler TD

Minister Mary Butler has served as Minister of State for Mental Health and Older People since July 2020. She has been a Teachta Dála (TD) for the Waterford constituency since 2016. She previously served as Chair of the Committee on Jobs, Enterprise and Innovation from 2016 to 2020.

Minister Butler was the Fianna Fáil junior Spokesperson for Older People and Chair of the Oireachtas Cross Party group on Dementia. She had been a member of Waterford City and County Council from 2014 to 2016.

Colm Doody

Colm Doody is an Assistant Psychologist with the Psychiatry of Later Life team, St Brendan's CNU, Ballinasloe. Colm has experience of facilitating Cognitive Stimulation Therapy (CST) and Maintenance CST groups with Older Adults with Dementia. Colm is a final year PhD candidate in the School of Psychology, NUI Galway. His research is in collaboration with the Irish Defence Forces and is centred around the development of a pre-deployment resilience building programme.

Carly Duggan

Carer and attendee of a Dementia Café. Carly has been married to Owen Gallagher for 20 years, they met and married late in life. Owen had a heart attack 3 months after they were married, when he was a healthy 45-year-old. Owen continued to have a plethora of minor health issues until he was hospitalised for epilepsy in 2011 where he was diagnosed with cognitive impairment / early-onset dementia.

Carly says *"I didn't even know what it was then, I had to ask the doctor over the phone. He was only 56 years of age"*. Since Carly met Owen, they have been in 6 different hospitals dealing with a myriad of medical problems. Carly describes how *"Alzheimer's was the last straw and almost broke me"*.

Owen is now living in St Joseph's nursing home in Crinken Lane, Shankill, Dublin, for the last 4 years and was in the daycare unit there for a year before that. Because she was so traumatised at the time of the diagnosis, Carly religiously attended the Alzheimer Café in Donnybrook, Dublin, from the very beginning. She says *"it was a lifesaver"*.

Carly was Owen's carer from the very beginning, even though she didn't know she was a carer then. She had to take a lot of time off work over the years before Owen moved into his new home. Up until the COVID-19 pandemic, she spent most of her spare time with Owen in Crinken Lane. She describes how she *"was part of the furniture"* and *"it was more of a 'home' than the house I live in"*. Now she can't get in at all because of Covid-19 and she misses him desperately.

Carly and Owen have no children and Carly continues to work in the field of Adult Education. She is back working 4 days a week.

Sinead Grennan

Sinead Grennan is CEO of Engaging Dementia, a training and resource organisation focused on communication, engagement and connection for people with dementia and their families. Sinead is also an Assistant Psychologist, who has co-facilitated Cognitive Stimulation Therapy (CST) sessions in St Brendan's Community Nursing Unit, Ballinasloe. She is stepping down from her CEO role for the next year while she does a Masters in Psychology.

Matthew Gibb

Matthew Gibb is the Director of the Dementia Services Information & Development Centre, St James's Hospital, Dublin. Matthew has a professional background in Social Work practice and a Masters degree in Social Policy and Social Work Studies from the London School of Economics. Matthew has much experience working with people with dementia, older people, carers and people with sensory and physical disabilities.

Prof. Sean Kennelly

Professor Kennelly is a consultant physician in geriatric and stroke medicine in Tallaght University Hospital. He is the clinical lead and director of a specialist memory assessment service there. Sean is Clinical Associate Professor of Medical Gerontology in Trinity College, and a principal investigator in the Trinity College Institute of Neuroscience. A fellow of the Royal College of Physicians in London & Ireland, he has extensively published in his main research areas of Ageing, brain health and dementia. He has served as chief and principal investigator on several international clinical trials in early-stage Alzheimer's disease. He chairs the interdisciplinary Dementia Research Network Ireland (DRNI) and is a member of the clinical and research advisory panel for The

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Dr. Fiona Keogh

Fiona Keogh, PhD. is a Senior Research Fellow in the Centre for Economic and Social Research in Dementia (CESRD) in the National University of Ireland, Galway. Fiona's primary degree is in Psychology. She has over 20 years' experience in conducting health services research, evaluation and policy analysis in Ireland, in dementia, mental health, disability and other areas. Throughout her career she has worked directly with people using health services in research and policy development. Her special interests are public and patient involvement (PPI), policy development and the implementation of policy in complex systems. Fiona has written national policy in Ireland and has published numerous papers and reports.

Professor Siobhan Reilly

Siobhan Reilly, PhD. is Professor of Applied Dementia Care Research and Director of the Centre for Applied Dementia Studies, University of Bradford, UK. Siobhan has over 28 years of health and social care research experience. Her research is primarily concerned with improving the evidence base for the delivery of health and social care services for people with dementia, older people with long term conditions and people with severe mental illness. She has worked with a wide network of researchers and health / social care / third sector decision and policy makers. She has experience in leading mixed method social science research studies and evaluations using a range of methods.

Dr. Carol Rogan

Carol Rogan is Scientific Project Manager for Dementia Research Network Ireland (DRNI). Carol supports and facilitates collaborative interdisciplinary research integrating the basic, clinical and social sciences. Through outreach activities, policy & practitioner fora and tailored information & communication strategies, Carol supports the network to build on existing research and to positively influence dementia research and policy making. Prior to her role in DRNI, Carol worked in the disability sector and conducted clinical & social research in the area of Acquired Brain Injury.

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Susan is a Principal Officer in Social Care Integration Unit within Social Care Division at the Department of Health. Her Unit is responsible for oversight of the implementation of the National Dementia Strategy, the National Carers' Strategy and Palliative Care policies for children and adults. Her Unit is also responsible for oversight of the HSE's delivery of residential services for people with a disability and liaison with HIQA on its regulation of residential centres for people with a disability.

Samantha Taylor

Samantha is Head of Enterprise Risk Management, Compliance and Dementia Advisory Services at The Alzheimer Society of Ireland. Samantha leads ASI's information and advice services, including the National Helpline & Information service and Dementia Advisor Service, and represents ASI on the NDO's Dementia Post-diagnostic Project Advisory Group. Working with ASI since 2005, Samantha is a committed advocate for people with dementia and their families and for the role and impact the community and voluntary sector delivers. Samantha is leading the expansion of ASI's Dementia Advisor Service to develop a national service, working in partnership with the National Dementia Office and HSE. Samantha also leads ASI's compliance and risk function and holds a graduate Diploma in Corporate Governance.

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Acronyms

ASI	The Alzheimer Society of Ireland
AT	Assistive Technology
CESRD	Centre for Economic and Social Research in Dementia
CHO	Community Healthcare Organisation
CST	Cognitive Stimulation Therapy
DRNI	Dementia Research Network Ireland
DSiDC	Dementia Services Information and Development Centre
ESRC	Economic and Social Research Council
GP	General Practitioners
HSE	Health Service Executive
MCST	Maintenance Cognitive Stimulation Therapy
MDT	Multidisciplinary Team
MTRRs	Memory Technology Resources Rooms
NIHR	National Institute of Health Research
NUIG	National University of Ireland, Galway
NDO	National Dementia Office
NICE	National Institute for Health and Care Excellence
PHN	Public Health Nurse
POLL	Psychiatry of Later Life
TUH	Tallaght University Hospital
UK	United Kingdom



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