

Proceedings of the Virtual International Dementia Conference: Transforming Care and Communities

2-3 November 2020

Monday 2nd November - Plenary Opening Session - 9.00 to 10.45

<https://youtu.be/QgOJHeDqGbl>

The opening session of the Engaging Dementia conference was chaired by **Sinead Grennan**.

Professor Des O'Neill, Consultant Geriatrician, Tallaght University Hospital

Covid: The Great Revealer of Gaps in Our Approach

In his presentation, **Professor Des O'Neill** asked the question 'what does Covid-19 reveal about us and our way of viewing dementia?' Thinking about Covid-19 as the 'Great Revealer', we need to think about not only what it reveals about things outside the service, but ask ourselves - as a group of people involved in advocacy, in a professional capacity, from a research perspective or as care partners - what does it reveal about us and our way of viewing the world and life with dementia?

At conferences, presenters are often asked to state any conflict of interest, but there are often *confluences* of interest. Being deeply interested and aware of 'our own skin in the game', Professor O'Neill stressed the importance of being mindful about where each of us fits in with respect to dementia, especially as we have one in ten chance of developing dementia at some stage in our life, and many of us have experience of family members living with dementia. Professor O'Neill recounted his childhood experience of dementia as a positive one in which he viewed all four of his grandparents with dementia as complete, whole people with barriers of memory. His experience of the last three years of his mother's life in which she lived with dementia, and the last few months of his father's life during which he developed peri-operative cognitive impairment, were also positive. A useful phrase from disability studies is 'being presently able-bodied', and those of us who are *presently* without significant barriers of cognition and language need to bear in mind our own futures.

Professor O'Neill highlighted some positive developments with respect to dementia. In 1983, when the Oxford Textbook of Medicine was first issued,¹ it contained only one paragraph on Alzheimer disease out of 2,700 pages, despite it being one of the most significant and important acquired disabilities in the population. As Medical Director of the Alzheimer Society of Ireland (ASI) in 1987, he was one of only a tiny group of people involved in the area of dementia. A lot has happened in the interim for which we need to be grateful, as exemplified by the Engaging Dementia's fantastic conference programme. Ireland has a National Dementia Strategy,² which while not perfect, is certainly a step forward, and a National Dementia Office. There has been a lot of strong positive developments. However, in

¹ Weatherall, D.J., Ledingham, J.G.G. and Warrell, D.A. (Eds.) (1983) *Oxford Textbook of Medicine*, First Edition, Oxford: Oxford University Press.

² Department of Health (2014) *Irish National Dementia Strategy*, Dublin: Department of Health.

terms of our preparedness and engagement with the public, there is still a long way to go. For example, in any major teaching hospital in Dublin, a large cancer information centre operating Monday to Friday, 9.00 a.m. to 5.00 p.m. can be found. While dementia is equal to, if not greater in significance to cancer, Tallaght University Hospital is the only hospital in Dublin that has a 'Memory Hut' open one afternoon a week.

With regard to placing stress on health and social care systems, Covid-19 can be summed up by a quote from Warren Buffet, 'Only when the tide goes out do you discover who has been swimming naked'. With respect to people living with dementia, we have seen marked changes, almost certainly due to the reduction in services including day care centres, fears and concerns about Covid-19, and insensitive use of notions such as 'cocooning'. We have seen a worsening of memory, increased caregiver stress, and these are being studied more closely to understand which responses are most beneficial. Nursing homes have been a neglected area, and we need to ask ourselves: to what extent have we engaged with a vibrant policy for high quality of life, empowering and supporting people with dementia in nursing homes? Nursing homes are clearly a setting where dementia presents in its most complex form and is a setting which perhaps needs the most skilled and sophisticated support. An Irish study using a census-based approach shows a figure of 60% cognitive impairment in nursing homes, and a figure that rises to 90% in a more finely tuned study.³

What we saw in nursing homes during the Covid-19 pandemic was quite tragic, a perfect storm underpinned by many determinants, whereby there was a generalised neglect of focus on older people in nursing homes, predominantly older people but also younger people living with dementia. A first issue, likely to be the absolute foundation of the problem, is the privatisation without debate of nursing homes by the Department of Health and without linkage to the health system. Unlike commissioning bodies in the UK which seems to take an interest in quality of care and work with quality improvement initiatives, the National Treatment Purchase Fund in Ireland appears to be 'a fire and forget' commissioning body without clear evidence of gerontological or dementia care expertise. The Health Information and Quality Authority (HIQA) has inadequate regulations and regulatory framework, with respect to complexity of care, and these have not been sufficiently updated. But what about us as health and social care professionals? What degree of leadership and focus relative to the need and complexity of care did we receive from the medical community, the nursing community and other health and social care professionals? A question for advocacy groups as well as other health and social care professionals is: Are we somewhat in the position that oncologists were in many years ago when they regarded referral to palliative care as some form of a failure? Do we see progression of a person with dementia to a nursing home as a systematic failure or do we not see it, if judiciously used, as an integral and really important part of the health and social care system that needs focus, attention, vision and inspiration?

Not only have we had a terrible death toll among people living in nursing homes during Covid-19, there has also been high levels of depression and anxiety. The crisis has shown us the devaluation of nursing home staff, their supports, their inputs, their expertise, as

³ Cahill, S., Diaz-Ponce, A., Coen, R. and Walsh, C. (2010) The under-detection of cognitive impairment in nursing homes in the Dublin area: The need for on-going cognitive assessment, *Age and Ageing*, 39(1): 128 - 130.

highlighted by an international group.⁴ While people may say, 'But it is terrible in nursing homes elsewhere', it shouldn't be terrible elsewhere. What the crisis has borne out, something that we have known for some time, is that if we underfund and fail to place a focus on care expertise, independence and empowerment, we are going to see abusive care.⁵ Indeed, the most recent study from primary care GPs in Ireland showed that one-third had seen sub-standard or inappropriate care in nursing homes, of which a quarter has not reported it or taken any action. Clearly, we need to do something.

A particular issue is around nursing home visiting, which became a political football early on in the Covid-19 crisis. In the very first weeks and month or two, after seeing what happened in Italy, radical, drastic measures were needed. However, it became increasingly clear that it is not visitors by and large who bring Covid-19 into nursing homes, but is largely related to staff. But, were people living with dementia in nursing homes and their care partners seen as people with whom to negotiate the issue of risk and independence? Was the idea of balancing public health protections with the right to a full and good life considered? A broader context to this, which is quite worrying, is the blasé and dismissive attitudes of some health professionals towards nursing home residents, as exemplified by Twitter posts, and that low expectations of nursing home residents are inured in research scholarship.

Let's think about 'our skin in the game'. While we work towards maximising supports to maximise care in one's own home/community, how do I view the high likelihood of spending some of my later life in a congregated care setting? Do we/I have a positive vision and realistic expectation for how life in nursing homes could and should be? Currently, the signs are not positive, but Covid-19 presents us with an opportunity to generate this type of debate. In National Dementia Strategies in Ireland and many other countries, there is a strong emphasis on prevention, on treatment, on supports, but a great gap in what care in congregated settings should be like. There is also an extraordinary emphasis on palliation. Nursing homes should be for living. Yes, people will die in later life and people living with dementia have a higher likelihood of dying in a nursing home, but the emphasis on palliation ahead of living is troubling. We have a big question to ask ourselves about how we have developed perceptions of worth, status and rewards of working in nursing homes. The accessible, empowering and supportive language and elements in the National Standards for Children's Residential Care⁶ are useful for thinking about how we could do things better for people living in nursing homes including around care planning, review meetings, everyday living and key workers for support.

It is not all doom and gloom. We have the wherewithal and the opportunities, should we turn our focus and start accepting that life in a congregated setting is a positive alternative to

⁴ McGilton, K.S., Escrig-Pinol, A., Gordon, A., Chu, C.H., Zúñiga, F., Sanchez, M.G., Boscart, V., Meyer, J., Corazzini, K.N., Ferrari Jacinto, A., Spilsbury, K., Backman, A., Scales, K., Fagertun, A., Wu, B., Edvardsson, D., Lepore, M.J., Leung, A.Y.M., Siegel, E.O., Noguchi-Watanabe, M., Wang, J. and Bowers, B. (2020) Uncovering the Devaluation of Nursing Home Staff During COVID-19: Are We Fuelling the Next Health Care Crisis? *Journal of the American Medical Directors Association*, 21: 962-965.

⁵ E.g., Cooper, C., Marston, L., Barber, J., Livingston, D., Rapaport, P., Higgs, P., et al. (2018) Do care homes deliver person-centred care? A cross-sectional survey of staff-reported abusive and positive behaviours towards residents from the MARQUE (Managing Agitation and Raising Quality of Life) English national care home survey, *PLoS ONE* 13(3): e0193399. <https://doi.org/10.1371/journal.pone.0193399>.

⁶ HIQA (2018) *National Standards for Children's Residential Centres*, Dublin: HIQA. <https://www.hiqa.ie/sites/default/files/2018-11/national-standards-for-childrens-residential-centres.pdf>

home care, especially since there comes a point when having a constant cavalcade of people through your home actually diminishes what home was in many ways. In the literature, there is evidence of a fight back against the idea predominant in the early days of the Covid-19 pandemic of nursing homes as ‘besieged castles’⁷ to one of partnering with people with dementia and their care partners around sharing risk and understanding the broader picture.⁸ It is pleasing to see that the latest version of the HSE’s guidance on visiting in nursing home is that visiting is really about compassion and appropriate mental health. Nursing home design is not a magic bullet for infection prevention and control, but we need to start talking about design and nursing homes. A good place to start is to build small units in the community with a domestic, empowering and individualised setting, rather than 200-bed nursing homes, akin to institutional hotels, on the periphery of cities, as is currently allowed.

In conclusion, Covid-19 must forge a sharper focus **by us** on congregated settings for **those of us** living with dementia. The National Dementia Strategy⁹ (Department of Health, 2014) and its review¹⁰ (Department of Health, 2018) lacked any sense of a vision for nursing homes as empowering, supportive, which are in effect an inevitable part of the dementia care pathway. It is saddening, yet commonplace in the public domain, for people to say, ‘I’d hate to end up in a nursing home’ and we have to start working in our discourse and dialogue to a point where we can say ‘I feel secure that my wishes, comfort and independence will be maximised and supported when I transition to nursing home support’. Indeed, Covid-19 has been the ‘Great Revealer’ not just for the system, but actually for ourselves as well.

Deirdre Lang, Director of Nursing and National Lead for Older Persons Services and Integrated Care

Get Up, Get Dressed, Get Moving: My Future Self

Deirdre Lang began her presentation by saying that she, like Professor O’Neill, too wanted to talk about her future, older self in the context of life in Ireland at the moment. There is a need to rejoice in the fact that we are living longer. For a man, life expectancy in 2046 will be about 85 years compared to our fathers, grandfathers and great-grandfathers who lived for 57.4 years in 1926. For a female, you would have lived for 57.9 years in 1926 but now will be living to 85 years of age. That is a success. However, there are a lot more people living longer, which means that by 2026 there will be 860,700 people aged 65 years and over and 1.4 million by 2046. These figures may resonate more with people in light of their own age currently. Compared to 2011 when there was 128,000 people aged 80 years and over, there will be 484,000 people in that age group in 2046.

⁷ E.g., Trabucchi, M. and De Leo, D. (2020) Nursing homes or besieged castles: COVID-19 in northern Italy, *Lancet Psychiatry*, 7(5): 387-388, DOI: 10.1016/S2215-0366(20)30149-8

⁸ E.g., Stall, N.M., Johnstone, J., McGeer, A.J., Dhuper, M., Dunning, J. and Sinha, S.K. (2020) Finding the right balance: An evidence-informed guidance document to support the re-opening of Canadian nursing homes to family caregivers and visitors during the Coronavirus disease 2019 pandemic, *Journal of the American Medical Directors Association*, 21(10): 1365-1370. <https://doi.org/10.1016/j.jamda.2020.07.038>.

⁹ Department of Health (2014) *Irish National Dementia Strategy*, Dublin: Department of Health.

¹⁰ Department of Health (2018) *Mid-Term Review of the Implementation of the National Dementia Strategy*, Dublin: Department of Health.

There is a lot to celebrate about ageing. It is important to consider the difference between chronological and biological ageing. To represent chronological ageing, a picture was shown of Ernestine Shepherd who, at 84 years of age and the oldest female bodybuilder in the world, may be regarded as a 'super-ager'. Biological ageing was represented by a picture of another woman also in her 80s using a walking aid. Chronological age cannot be equated with biological age. Ageing is not the issue. The most challenging expression of ageing is frailty. This raises the question for all of us regarding how we are going to age in the future.

Frailty is a complex intermingling of biological, social and cognitive factors that negatively impact on an individual's ability to independently complete their activities of daily living. Drawing on a model adapted from Clegg et al. (2013),¹¹ frailty involves genetics, which we can't do much about, and environmental factors such as poverty, education, lifestyle, and the environment, e.g., pollution. Together, genetics and environmental factors bring about cumulative cellular damage. When poor nutrition, decreased reserve and decreased physical activity are added to that, there is an increased vulnerability to frailty. Stress or a stressor event can also increase vulnerability to frailty. Covid-19 is one such stressor event. Frailty can present as instability, falls, incontinence, and changes in cognition, all of which can lead to increased care needs and eventually admission to hospital.

Frailty as the most problematic experience of population ageing can be illustrated by comparing the vulnerability of frail older people to a sudden change in health status, such as a urinary tract infection, to that of a fit older person. After a minor stressor event such as a minor infection, a fit older person will have a small deterioration in function before returning to homeostasis, whereas a frail older person experiencing the same stressor event, will have a greater deterioration, which may manifest as functional dependency, and the person may or may not return to baseline status. Recognising and understanding frailty demands that we plan for frailty and how we are going to support and care for those living with frailty in our community and in our hospitals. We need to future proof the delivery of our health care services for the people who will be using it.

Frailty is a long-term condition sharing the typical features of long-term conditions. It is common; up to 50% of people aged 80 years and over affected by frailty. It is costly at an individual and societal level. It is typically but not always progressive. It is potentially modifiable. It presents as episodic crisis. People move from fit to mild, moderate and then severe frailty. Considering frailty as a long-term condition allows for the application of internationally established models and implementation of evidenced-based care.

The Irish Longitudinal Study on Ageing shows that there are geographical differences in the prevalence of frailty in community-dwelling older people in Ireland, with County Donegal showing the lowest level of frailty in the country.¹² Among people aged 65 years and older using public health nursing services, 57% are frail. People aged 65 years and over make up

¹¹ Clegg, A., Young, J., Iliffe, S., Rikkert, M.O. and Rockwood, K. (2013) Frailty in elderly people, *The Lancet*, 381(9869): 752-762.

¹² Roe, L., O'Halloran, A., Normand, C. and Murphy, C. (2016) *The Impact of Frailty on Public Health Nurse Service Utilisation: Findings from The Irish Longitudinal Study on Ageing (TILDA)*, Dublin: TILDA.

22% of those attending emergency departments, 40% of acute medical admissions and 50% or more of hospital bed days.

In addition, 5% to 6% of older people require residential care, consistent with international trends.¹³ However, bed capacity within the nursing home sector is no longer keeping pace with increasing demand for long-term residential care. ESRI projections for 2030 show that there will be increased demand for hospital in-patient beds and hospital day cases, GP visits, home care packages and home help hours.¹⁴

Unfortunately, attitudes and perceptions of frailty tend to be negative and phrases with negative connotations such as 'can't do anything', 'shrivelled' are frequently used. The 1998 report on the Commission on Nursing indicated that older person's services were seen as the least preferred place to work and as 'settling', i.e., unrelated to science.¹⁵ Terms with negative connotations such as 'bed blocker', 'delayed discharge', 'acopia', 'poor historian', 'pleasantly confused', 'elderly', 'the vulnerable', and more recently 'cocooners' are also frequently used.

Negative attitudes and perceptions contribute to increased functional decline among people aged 75 years and older who are admitted to hospital. A study of 615 people requiring human assistance with a range of activities of daily living (ADLs) including bathing, dressing, mobility, transfers, toileting and eating at baseline, admission to hospital and discharge from hospital, showed a major functional decline across all ADLs. One study highlighted that 65% of older people are deconditioned after just 48 hours of being in hospital and of those 67% failed to improve before discharge and 10% deteriorated further. Older people in hospital have a 23% risk of being unable to return home and require admission to a nursing home because they have lost the ability in some basic ADL during even a short stay in hospital. Evidence suggests that up to 50% of older people become incontinent within 24 hours of hospital admission.

We know that one in four adults are physically inactive, spending up to 12 hours a day sitting¹⁶ and when in hospital can spend up to 20 hours (73% of their day) in bed.¹⁷ To change this, the narrative has to change. We need to empower people by letting them know that getting up, getting dressed, getting moving can help to maintain their muscle strength, and asking them to spend some time exercising for their future older self. While the muscle mass of a sedentary 74-year-old male compared poorly with that of a 40-year-old triathlete, that of a 70-year-old triathlete compares well. It is possible for a person to have two comorbidities and still function well if the person keeps socially connected, but also possible to function poorly if social connections are not maintained, according to TILDA.¹⁸

¹³ BDO (2015) *Annual Private Nursing Home Survey 2014/2015*, Dublin: Nursing Homes Ireland.

¹⁴ Wren, M-A., Keegan, C., Walsh, B., Bergin, A., Eighan, J., Brick, A., Connolly, S., Watson, D., Banks, J (2017) *Projections of Demand for Healthcare in Ireland, 2015-2030 First Report from the Hippocrates Model*, Dublin ESRI.

¹⁵ Government of Ireland (1998) *Report of the Commission on Nursing: A Blueprint for the Future*, Dublin: Stationary Office.

¹⁶ WHO (2018) *Global Action Plan on Physical Activity 2018-2030: More Active People for a Healthier World*, Geneva: World Health Organization.

¹⁷ Brown, C.J., Redden, D.T., Flood, K.L. and Allman, R.M. (2009) The underrecognized epidemic of low mobility during hospitalization of older adults, *Journal of the American Geriatrics Society*, 57: 1660–1665

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With respect to Covid-19, quarantine and self-isolation and social distancing means that people's physical activity has reduced, levels of stress have increased. It has impacted on dietary intake; most people's weight has increased and Vitamin D is reduced. Our bodies are changing because we are losing muscle mass, which can lead to sarcopenia, which can lead to falls leading to long-term health risks. There will be increased frailty and increased levels of cardiovascular disease, diabetes, osteoporosis, anxiety, depression post-Covid-19 and decreased quality of life.

Malnutrition is linked to frailty. Improved diet can help slow progression but one in seven do not comply with the recommendations in the food pyramid, three in five do not get their five-a-day in fruit and vegetables, and two in three consume one or more servings of foods high in fat, salt and sugar. One in eight are vitamin D deficient, increasing to one in four during the winter months. All of this is more common among those who live in north and west of the country, those who are overweight, physical inactive, smoke or living alone.

The response has been a Call to Action, a call to Ireland to Get Up, Get Dressed, Get Moving. The purpose is to create a scalable, sustainable model of Get Up, Get Dressed, Get Moving that can be adopted and implemented at home, in the community and across all health and social care settings. The programme has around 200 members representing a wide spectrum of sectors including health and social care, universities, sports, community and voluntary, nursing homes and organisation in the ageing sector. Ms Lang encouraged participants to join the network.

Professor Eamon O'Shea, Director, Centre for Economic and Social Research in Dementia

The Continuum of Care for People with Dementia in Ireland

Professor Eamon O'Shea pointed out that compared to the 1980s, things have certainly improved significantly with regard to dementia, both with respect to research on dementia and how people think about dementia. This is reflected, for example, in the Irish National Dementia Strategy¹⁹ and the recent increase in resources, but much still needs to be done.

A key question is where older people are positioned in society. It is important to carefully consider how we engage with older people and people with dementia. The voice of people with dementia have not been as strong, particularly during the Covid-19 crisis. Although not done deliberately, direct engagement with people with dementia in decision-making has not happened, whether it be in relation to nursing homes, or 'cocooning' or other issues. The voices of people with dementia are an important backdrop, and although diminished, are still there impacting on day-to-day activities as well as on policy-making and on thinking about the possibilities of age and the possibilities of ageing.

This is an important point to make at the outset, but also in the context of what is coming in the future. We know that the number of older people is set to increase and will have implications for resource allocation. By 2031, people aged 65 years and older will generate

¹⁹ Department of Health (2014) *Irish National Dementia Strategy*, Dublin: Department of Health.

half of health care activity. Projections are that there will be a 46% increase in demand for primary care, 39% increase in demands for residential care beds, 70% increase in demand for home care, and 24% increase in demand for non-elective in-patient episodes in public hospitals. The increased demand for health services is sometimes problematised with negative terms such as 'burden' used or alarmist language such as 'look what's going to happen'. This problematisation of population ageing is part of the negative portrayal of older people in society, and older people are us. There is a lot of living to be done, whether it is living in the community, living in households, living in residential care in terms of the next 20 or 30 years for people in their 60s and in their 70s. It is important that we don't get wrapped up in negative thinking about ageing, particularly when thinking about the economic implications of population ageing. Rather, we need to think about investing in older age, and there are many good reasons for doing so, but we need to think about it as proper investment in older age and the implications of funding, which will be returned to later.

There are many strategic issues at play. Amongst these is the spending bias towards nursing home care; figures show that in Ireland we spend twice as much on nursing home care as on home care. That data needs to be digested and interrogated and questions asked. Should we be spending more on both? Should we be looking more carefully at what happens in nursing homes? Do we need new models of nursing homes? However, it doesn't mean that we should be detracting expenditure from nursing home provision. Quite frankly, there is a lot we can do, some of which we can do without much additional funding, and some will need much more resourcing.

Despite the great work that has been done over the last number of years, Ireland still has a relatively weak social model with respect to ageing and family responsibility remains very high. There is a normative discussion to be had around how we think about families, the role of families in care to older people, and the autonomy of older people and people with dementia within families. There is also a need to categorise and interrogate the care work that families do. Without families, much of the care that goes on in communities couldn't take place. That is not to say that the State needs to take over, but there is a requirement for this to be articulated in a different way and to address issues that family carers have in the context of the provision of care.

The new home care legislation is pending and it is hoped that it will not be pending for too long, because the legislation and funding around it needs to be put in place. We may need to think differently about funding, but an increase in funding is definitely needed.

Sláintecare and its implementation is another important issue, as is integration, a very strong theme in Sláintecare.²⁰ Integration between nursing home care and home care is particularly important. Nursing home care and home care are seen as direct opposites, but the dichotomy between the two in practice and in policy has not served us well. It is more important to think carefully about the continuum of care, what that actually means, and how to address the continuum in an integrated way. That is not to say that there has not been any focus or good work undertaken in this area. A lot of good work is ongoing to bring about integration of care services.

²⁰ Oireachtas Committee on the Future of Healthcare (2017) *Sláintecare Report*, Dublin: Houses of the Oireachtas.

Of course, there is Covid-19, its legacy and responses. However, even without Covid-19, many of these issues such as lack of integration and an almost forgetting about older people in nursing homes, of which we are all guilty, would still be there. What Covid-19 has highlighted is that these issues need to be addressed explicitly and questions raised and discussed and debated such as how do we want care to be organised and to be provided. Discussions is needed as to what is person-centred care, what is the right design for nursing homes, what relationship should there be between a nursing home and the community. The dichotomy between nursing homes and home care creates an 'othering' of people in nursing homes, which feeds into public fears about nursing homes and fears about ageing and fears about the future. These discussions need to happen in the public domain.

These strategic issues are related to the issue of future funding models. Intergenerational relationships and solidarity continue to be strong, and the contractual relationship between younger and older people should inform future decisions about funding. There is an opportunity now to work on a funding model that taps into intergenerational solidarity and allows us to properly fund both nursing home care and home care.

Among recent interesting publications is the report from the Oireachtas Special Committee on Covid-19,²¹ which contains some very interesting aspects. If these were followed through, positive change could happen quite quickly, allowing us to take advantage of this terrible crisis and turn around the way we think about care at home and in nursing homes. Work on integration is really important, and presents opportunities with respect to an integrated system of long-term support.

Shifting care from congregated settings does not mean that nursing homes will no longer be necessary, but we need to encourage in and through public policy and within the nursing home sector, a new model of nursing home care that is underpinned by highly autonomous living within nursing homes with a high degree of connectivity within nursing homes and to surrounding communities. We have seen the impact in nursing homes of the absence of visitors. We have seen impact on staff. These can be used to accelerate policy change, if the will is there. This goes back to an earlier point about how we view ageing, how we view older people, how we view the solidarity relationship, how we view our own futures. Our experiences of Covid-19 over the last six months presents an opportunity for us to do something really special. The integration of private nursing homes into the wider framework of public health and social care is critical. Nursing homes should not be outside the health and social care system. They should be part of the system, part of the continuum, and it should be appropriate care at the appropriate time for the appropriate person. Not everybody can be cared for at home, and we need to have care pathways. We tend to see life in a nursing home as passive, as being outside and not relevant to the day-to-day life of a community. That has to change and we need to start using terms such as 'exciting' and 'innovative' with respect to residential care opportunities and different forms of living and of

²¹ Houses of the Oireachtas (2020) *Special Committee on Covid-19 Response: Final Report*, Dublin: House of the Oireachtas.

https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/special_committee_on_covid_19_response/reports/2020/2020-10-09_final-report-of-the-special-committee-on-covid-19-response-sccr004_en.pdf

lifestyle. There are many good examples of how to do this, but it needs to be envisioned wholly, not just by individuals or managers who want this to happen, or by the nursing home sector, it needs to be taken on board as a social view of what the future should look like. For that to happen, there needs to be a coming together of funding, although this is not easy.

Principles for change are also important. These include choice, flexibility, inclusion, engagement, connectedness, privacy and citizenship. These principles are often taken for granted in our everyday life, and it is only when they are taken away that we start to pay attention to how significant they are. We have experienced restrictions during Covid-19, which, although necessary for the benefit of society, still made people feel uneasy and empty. Imagine then a situation where just because you are getting older chronologically, that these principles no longer apply. How does it feel for older people whose choices are taken away, who are not included, who are not engaged in the normal everyday activities that we all take for granted, that add real goodness to our lives and are part of the continuous search for the good life in some way and living a life that makes it meaningful for us and those around us? How does it feel for older people whose privacy is taken away? All of these are wrapped up in citizenship. Imagine what life would be like if all of these were taken away? All matter, but they only matter when we have a process of making them happen, and they have been increasingly made to happen for people with dementia due to the Irish National Dementia Strategy, which has brought about accelerated change, and they are principles that we must continuously focus on.

Professor O'Shea set out the current predominant frame for dementia and its six elements - biological, residential care, risk, deficits, exclusion and disconnection. He suggested that a counter frame and its six elements - social, home, capabilities, assets, inclusion and connection – is needed to enhance dementia care. These frames are not mutually exclusive. For example, social does not preclude the need for good clinical care of a person with dementia, but does mean that in any care setting including residential care or hospital care, the social dimension of care needs to be taken into account. Capabilities, including physical and emotional capabilities of the person, are very important. Assets, while drawing on economic language, conjures up the importance of investing in people. It is hard to imagine a society without older people because of contribution that older people make to society.

Before Covid-19, O'Shea et al. (2020) set out the broad continuum of care and the range of possibilities, all of which have advantages and disadvantages.²² Fundamental to this continuum is our own housing, and its design, modification and adaptation. Others include home sharing, split housing, boarding out, retirement villages, communal living, and supported housing. Housing with social care and technological supports should be an important focus when thinking about supporting people as part of the continuum of care. Finally, there is a need to think differently about residential care in terms of size and scale, Professor O'Shea urged the nursing home sector to begin that thinking supported by public policy and new investment. With respect to home, it is essential to think about

²² O'Shea, E., Keogh, F. and Cooney, A. (2019) *The Continuum of Care for People with Dementia in Ireland*, Tullamore: National Dementia Office.

<http://dementiapathways.ie/permacache/fdd/cf3/861/4dfe34f03a7ddadc0e08378d6e2ebcd3.pdf>

intergenerational housing and independence through adaptation and bring about the best version of home possible.

Relocation is easier for some, not for others, which makes it important to think about home differently, both with respect to being 'at home' in our own homes and 'at home' in other places. When autonomy is compromised, the result can be vulnerability and people being out of place. In addition to autonomy, proactive and controllability of the physical environment, adaptability and the person-environment fit cannot be ignored at home and in other places.

With respect to nursing home care, there are a range of broad issues that matter including scale, coverage, staffing, design, ethos, integration, governance and the funding model. The issues highlighted by the Expert Committee are really important,²³ but there are broader issues that we can't lose sight of. Knowing what we know now and through fostering of intergenerational solidarity so evident during Covid-19, it will be possible to bring about longer-term change in the relationship between age, need, location of care, integration of care and the primacy of the person in the caring relationship, as well as the primacy of the family carer and the wider family network. There are residential care models from which to draw including person-centred and relationship-centred models, small home-like setting such as the Teaghlach model.

Courage is needed to actually bring about the investment to support the nursing home and community care sectors and redirect over the next five years the way in which we think about ageing, care, autonomy and community. The one thing that the crisis has taught us is that when we become disconnected, we lose so much. Connectivity needs to become central and much more to the fore in the ongoing reform of care, rather than thinking about particular sectors. A stronger resolution to bring about change is needed.

In conclusion, autonomy and choice really matter. There are times when autonomy and choice are compromised, but they should not be given up easily by anyone including older people and people living in nursing homes. Place in the environment is central to the way we live our lives, and when taken away our lives are diminished. Belonging means having much more than nursing homes beds available or home care hours availability. Belonging means creating a sense of worth, of being, of living, of loving and so on. There is potential for a very different residential experience and while many people are trying to deliver that right now, there is an onus on government to deliver more in this area. More generally, it means creating a society where age and ageing are central to the wellbeing of that society.

Susan Cliffe, Deputy Chief Inspector of Social Services, HIQA

Susan Cliffe in her presentation provided the regulatory perspective on caring for people with dementia. HIQA is the independent statutory authority established to promote safety and quality in the provision of health and social care services for the benefit of the health and welfare of the public. The Chief Inspector in HIQA is responsible for registering and

²³ Government of Ireland (2020) COVID-19 Nursing Homes Expert Panel: Final Report
file:///C:/Users/New/Downloads/84889_b636c7a7-a553-47c0-88a5-235750b7625e.pdf

inspecting nursing homes where many people with dementia are living. The purpose of regulating nursing homes is to ensure that residents living there receive an appropriate standard of care and support and are enabled to live their best possible lives.

Staff in HIQA act within a regulatory framework, a legal framework that underpins the regulation of nursing homes. Within that legal framework is the Health Act 2007 (as amended), the primary legislation, and an associated suite of regulations, focused on the care and welfare of residents in nursing homes and the registration of designated centres regulations. Also associated is a suite of standards, the National Standards for Residential Care Settings for Older People²⁴ and the National Standards for Infection Prevention and Control in Community Services.²⁵ The Act and the Regulations set the minimum standard of care that must be provided for people living in nursing homes in order for registered providers to remain registered and continue to operate. Inspections of social services within HIQA are appointed to assist the Chief Inspector in registering and inspecting designated residential centres. The team of inspectors who carry out this work comprise professionals with expertise in regulation and experience in either care of the elderly, general nursing, fire safety, infection prevention and control, occupational therapy, physiotherapy and social care. Over the last number of years, the team have focused on ensuring a social model of care in nursing homes.

As of December 2019, there were 585 registered nursing homes in Ireland, home to 31,969 people. Undoubtedly, Covid-19 has had an impact on the number of nursing homes and the number of places, with some designated centres electing to de-register to provide an alternative model of care and others reducing the number of people living in the centre.

Nursing homes continue to increase in size, as evidenced by the average number of beds per centre and also by the size of new nursing homes registered or the extension of existing nursing homes. Currently, the largest nursing home in Ireland has 184 beds. A nursing home due to be registered in the near future will have a total of 220 beds. A total of ten new nursing homes have been registered by the Chief Inspector, which is a positive development, as new centres are generally purpose-built, where the majority of bedrooms are en-suite and single person occupancy, and there is space for circulation and communal areas for socialising among residents, staff and visitors. This stands in contrast to the older stock of nursing homes that have large multi-occupancy rooms and which are challenged by poor toilet and bathroom facilities and small communal and dining spaces. The majority of nursing homes accommodate residents with dementia. The difficulty that HIQA has is that there is only one model of what a nursing home should be in Ireland. The model that predominates is a hotel type of accommodation in a large congregated setting. Since May 2016, there has only been one nursing home registered that falls outside this model.

It is generally acknowledged that most people would prefer to be cared for in their own home or in their own community for as long as possible. Home care, day care and supported living arrangements are care models that present people with dementia with viable alternatives to

²⁴ HIQA (2016) *National Standards for Residential Care Settings for Older People in Ireland*, Dublin: HIQA. <https://www.hiqa.ie/sites/default/files/2017-01/National-Standards-for-Older-People.pdf>

²⁵ HIQA (2018) *National Standards for Infection Control and Prevention in Community Services*, Dublin: HIQA. <https://www.hiqa.ie/sites/default/files/2018-09/National-Standards-for-IPC-in-Community-services.pdf>

long-term residential care and support a continuum of care approach. However, none of these care models are compatible with the current regulatory model that is grounded in the definition of a designated centre. Ms Cliffe agreed with Professor O'Neill's earlier assessment of the regulatory framework as inadequate, a problem that HIQA has recognised for some time. HIQA submitted a paper on the issue in 2017 to the then Minister of Health and to the Department of Health.²⁶ Ms Cliffe also agreed with Professor O'Shea's view that Covid-19 present an opportunity and a new impetus to drive the reform agenda including the reform of regulation.

Of all of the care services that people with dementia might access, long-term residential care is the only service that is currently regulated. With the exception of acute care, all other services including home care, day care, respite care, sheltered/assisted housing, hospice and palliative care fall outside the remit of regulation. If it is accepted that the purpose of regulation is to protect users of health and social care services, then users of unregulated services are not afforded this protection.

With respect to the regulation of health and social care services, a distinction is typically made between an Establishment Model of regulation or a Service Model of regulation. Ireland's model of regulation is based on an Establishment model. In this model, each physical location at which a care activity takes place must be registered. The building rather than the care is regulated. In a Service model of regulation, a service provider registers with the regulator and informs them of the different types of care that they are providing and in which locations.

The current Establishment Model of Regulation that exists in Ireland is not supportive of effective continuity of care. For example, a company may provide several types of care services, but has to register only services that meet the definition of a designated centre. HIQA inspectors have no power to inspect or monitor care in non-designated centres, despite the fact that they may be on the same site such as a congregated setting with residential and day care services.

The Service Model of Regulation may offer an alternative model of regulation for Ireland. In Northern Ireland, the Regulatory and Inspection Quality Authority regulates day services, home care agencies, nursing agencies, adult placement, residential care homes and nursing homes. Different regulations are in place to govern the different service models. The Care Quality Commission in England also follow a Service Model of Regulation. It does not have a discrete set of regulations for each service, but uses fundamental standards that apply to all services. Elements of the fundamental standards that are appropriate to a particular setting are selected. Covid-19 pandemic has clearly highlight regulatory shortcomings, but has also provided an opportunity for reform and other forms of regulation need to be considered to ensure the safety of the service.

The advantages of the service model approach to regulation are that it achieves the principal objective of regulation which is the protection and promotion of vulnerable and dependent

²⁶ HIQA (2017) *Exploring the Regulation of Health and Social Care Services - Older People's Services*. Dublin: HIQA. Available from: <https://www.hiqa.ie/sites/default/files/2017-05/exploring-the-regulation-of-health-and-social-care-services-op.pdf>

service users. There would be separate regulations tailored to the service model that providers are providing. It would allow providers to be more flexible and innovative and bring forward models of residential care other than large congregated settings or nursing homes. HIQA would like to see the future of regulation framed in the context of a service model of regulation. There are many government initiatives currently at play that make this an opportune time to critically review the current model of regulation such as the work that is underway to allow for the future licensing of hospitals and the regulation of home care, high on the policy agenda before Covid-19. As a result of the Covid-19 pandemic, the up-to-date review of the functioning of nursing homes and care of residents in nursing homes provides a template for the future.

HIQA would like to see the future of regulation framed in the context of a service model of regulation. HIQA has issued a paper calling for the reform of the regulatory framework and setting out the need for fundamental change on how Ireland regulates health and social care services. More recently, the Covid-19 Expert Panel on nursing homes recommended a review of these regulations in the short-term.²⁷ However, in the Expert Panel report, regulatory reform is very much linked to infection prevention and control and that does need to happen, but equally important is the report's call for wider long-term reform as a key feature in the commissioning of care. There are many stakeholders in this reform agenda. HIQA is but one. Key players include providers, staff, the Department of Health, interested parties, the public, commissioners, professional bodies, and families, but all of these must be peripheral to the people with dementia. Providers know their service best, are familiar with the regulatory framework, and it is their responsibility to meet the requirements of the Act, Regulations and Standards. Therefore, they are key to any regulatory reform. HIQA is needed to administer and enforce the regulations through good regulatory practices and is very much playing its role. HIQA has amended its 2017 paper, which is currently being finalised and will be reissued to the Department of Health in the coming weeks. It will be the work of the Department of Health, national policymakers and key influencers to drive the agenda forward so that we can all be part of the reform of this sector and we can all look forward to changes in the sector that will make it a much more inclusive model of care for people with dementia, which will transition from care in the home to care in a nursing homes, because, as Professor O'Shea said, nursing home care will always be needed. However, the continuum of care needs to be safe, regulated and well defined, recognised and funded. People with dementia must be at the centre of decision-making on how they receive care – that is true person-centre care. There must be a range of care options available on a statutory basis that would support all people in a range of circumstances. Care should be supported by regulations, standards and safeguarding regulations. Most importantly, regulations need to move away from the concept of regulating buildings and centres to a model that focuses on services.

Panel discussion

The first question that the panel members were asked was: **Would a human rights approach would be a useful approach to take in the care for older people?**

²⁷ Government of Ireland (2020) COVID-19 Nursing Homes Expert Panel: Final Report
file:///C:/Users/New/Downloads/84889_b636c7a7-a553-47c0-88a5-235750b7625e.pdf

Professor O'Neill argued that of course there should be human rights approach, but that it is not sufficient. A real challenge is the lack of professional and other advocacy from within nursing homes. A bibliographical review of research in nursing homes in Ireland recently undertaken by Professor O'Neill and his colleagues showed that there was very little research from within nursing homes and a key issue is that people working in nursing homes are able to be to understand, interpret and exercise human rights.

Professor Irving suggested that, in addition to focusing on human rights in relationships, a human rights approach might be useful for examining structural issues related to care for older people and the challenges that this presents for human rights. For example, with respect to planning for nursing homes, many are built on greenfield sites, out of towns, which is a real challenge for realising the principle of connectedness, but also says something fundamental about how older people are viewed and positioned in Irish society.

The European Commission of Human Rights has questioned whether the human rights of older people in nursing homes who have died during the pandemic have been undermined by lack of provision of adequate care and the Oireachtas Committee on ... has said that there must be an external review of the adequacy of care of older people in nursing homes. The human rights dimension is absolutely critical.

Deirdre Lang argued that the building of nursing homes on greenfield sites is an indication of ageism that exists in Irish society. It is important to address ageism and be a disruptor of ageism, which is not always easy to do.

Ms Cliffe believes that Covid-19 provides an opportune time for reform, which should start with reforming the funding model that underpins care, as the current model of funding is driving the trend towards large nursing home buildings catering for large numbers of people. The average size of a nursing home is between 50 and 85 beds. However, the trend for bigger nursing homes rests on the assumption that economics of scale exists within the cost structure of nursing homes, and larger nursing homes will lower costs. As larger nursing homes are being built, smaller 20-bed to 30-bed family run nursing homes are closing. This is because the current funding model is not supporting this type of nursing home with the costs associated with meeting fire safety regulations or changes to meet regulatory requirements. We need to stop and ask: 'Is this what we want?' What do we as people ageing want for our future care? Some larger nursing homes are using household models to try to meet the care needs of residents, but it is much more difficult for larger nursing homes to provide person-centred care by virtue of their size.

Professor O'Shea pointed out that public policy can be used to bring about change. Public policy is an agent of change. Once an informed consensus is reached about what reform we want, incentives can be used to bring about change. Incentives brings about changes in behaviour and can be used to influence the location, scale and design of nursing homes, for example. This is a practical shift that needs to happen, to use public policy in a very proactive way to achieve what seems to be a consensus about the primacy of a rights-based or person-centred approach to achieve care in which human relationships matter, connectivity matters, where people in nursing homes can have autonomy and live and enjoy a good life at all times. Innovative ways need to be found for using incentives and other funding arrangements to enable this to happen.

Susan Cliffe pointed out that the responsibility for public policy reform does not lie solely with the Department of Health. It is a cross-departmental issue. In the UK, it is the governmental planning department that restricts the size of nursing homes, completely separately to the Department of Health and their social care services. Cross departmental policy change is required.

Nisha Joy from CareBright commented that having the right environment is key to quality of life alongside the need for government at a broader level to promote a household model of care.

Another attendee, who suggested that there is an overemphasis on nursing homes care and a need to focus more on community care, asked how more attention could be brought to bear on the community.

Professor O'Shea replied by acknowledging the work that has been done in recent years to promote community care and also to bring attention to social/psychological elements of care at home, in the community and in nursing homes. There has been a definite shift in terms of home care and legislation reform that is promised will bring about fundamental change in home care, as long as it is support with resource allocation. There is good evidence that investment in home care will enable more people to live at home. Homes need to be designed to be better places to live and communities need to enable older people be able to live better and navigate. As well as having more home care, the way in which home care is organised is important. All of this links back to how we think about ageing and older people, their engagement and visibility in society. The recognition that older people are central to the wellbeing of society is paramount to public policymaking on ageing and older people.

Professor O'Neill explained that changing the narrative around older people is an iterative process and that the Understand Together Campaign was an important step in the right direction. Its focus has been on people at the milder stages of dementia and those living in the community, and needs to be expanded. There needs to be an understanding that care is 100% focused on personhood irrespective of a person's stage of dementia.

Deirdre Lang believes that there is a sense of fatalism surrounding ageism, particularly in relation to a diagnosis of dementia, which highlights the necessity of keeping older people and people with dementia in view, both those who are ageing successfully and those ageing with long-term health conditions. It is important not to hide people away, as hidden away people become the 'other'. We need to think about our future older self, and how that might be. We need to be educating ourselves about how to stay well for longer. Negative perceptions of the elderly need to be challenged and changed.

The second question that the panel was asked was: **Has the notion of cocooning had an impact on public attitudes towards ageing?**

TILDA had done a lot of work on older people and volunteering and has shown that from 75 years of age, older people seem to stop volunteering, which may be linked to older people's self-perception of being too old to volunteer or adult children telling older they are too old to volunteer and a sense of risk aversion. 'Cocooning' has made older people feel afraid.

According to ALONE, there is a huge amount of fear among older people. They have been told that they are not safe, but what is not safe about going for a walk, doing exercise, enjoying your environment?

'Cocooning' demonstrates a troubling mindset of paternalism, of objectification, of simplification of older people. It is troubling that there are older people who are being pressurised by their adult children into not going out. An unfortunate paradigm has been created. There is much to be done to change that and needs to develop partnership with and respect for older people.

The balance of risk approach did not play out well at the start of the pandemic. The focus was on the risk of getting Covid-19, rather than on the balance of risk. While individual health professionals may be taking a balance of risk approach, this hasn't been the case with public health messaging, which may be linked to a reluctance to give nuanced messages to the public for fear there will be public misunderstanding of the message. There is a role for the media to play in giving more nuanced messages about risk and risk-taking.

Commenting on the proposed legislative reform for home care, Susan Cliffe stated that the pandemic has without doubted impacted on progress with development of the legislation. New legislation on home care will be built largely around the Health Act and will be based on regulations such as the regulations in place for adults with a disability in designated centres. Service providers and not people's homes will be regulated. There is a recognition of a requirement for home care legislation, there is a recognition of the urgency for it.

Professor O'Shea added that people are now interacting through technology, and technology and how technology is used to engage and interact with older people offers possibilities. This brings us back to innovation, and the idea that the future does not need to be the same as the present, and if we can manage to think differently about the future and be really creative, a lot can be achieved.

Another issue raised by Susan Cliffe that needs to be taken into account is the workforce that is needed to provide care in the future. Now is the time for key stakeholders – the colleges, the professional bodies to be positioning themselves and their members to be able to produce the workforce There is going to be one pool of care workers from which to draw to provide care in different care settings. Workforce planning, how to enlarge and future proof this workforce, and issues related to differential terms and conditions of private vis-à-vis public sector workers are important policy issues.

Professor Irving has been working with the NDO to develop a FETAC Level 5 training course in dementia for home care workers, which is close to accreditation by QQI and will be delivered by Irish Times training. There are about 20,000 home care workers who needed to be trained, about 1,000 of whom have been trained in dementia care. In the training of home care workers in person-centred dementia care, the quality of the training provided by the facilitators is key. Training people to provide person-centred care is challenging. Another challenge is the insufficient number of people with strong facilitation skills who are available to train the home care workers. Therefore, there needs to be greater capacity to do this backed up by adequate resources. Susan Cliffe pointed out that professional bodies registered with CORU are also an important route to training.

Monday 2nd November - Plenary Support People with Dementia at Home Session - 11.30 to 12.45 <https://youtu.be/7z65HUVsnKs>

Dr Emer Begley, Senior Project Manager, National Dementia Office

Chair

Dr Emer Begley acknowledged that the majority of people with dementia live in their own homes in the community. While Covid-19 pandemic has had a significant impact on everyone, it is impacted heavily on people with dementia and their families, largely due to the fact that many services have had to close and the increase in anxiety due to the public health restrictions in response to Covid-19. In addition, the loss of or reduced level of social interaction has been a major challenge for people with dementia and their family carers. She notes that the speakers in this session may refer to Covid-19, but will be speaking more generally about different community-based services, supports and programmes.

Fiona Foley, National Coordinator, Dementia: Understand Together and Community Campaign, HSE

Let's Talk about Dementia: Creating Inclusive Communities

Fiona Foley's presentation focused on the Dementia: Understand Together campaign. While the campaign is led by the HSE, its key feature is its collaborative approach. The Alzheimer Society of Ireland and Age Friendly Ireland are campaign partners and more than 40 national organisations, ranging from retail, transport, financial services to academia and community organisations, support the campaign. It began as a media (TV and radio) campaign, grounded in evidence from research on how dementia was impacting on people with dementia and their family carers. The findings from literature reviews and focus groups showed a lack of awareness about dementia, poor understanding of the condition and stigma associated with dementia, leading to isolation and loneliness among people with dementia. The objective of the Dementia: Understand Together campaign is to create an Ireland that embraces and includes people with dementia, and which displays solidarity with them and their loved ones. It set out to achieve this by building awareness and understanding through the media campaign and the Dementia: Understand Together website. It also seeks to inspire individuals, businesses and service providers to take action to support people with dementia and their families in communities.

In a bi-annual study, the impact of the first two years of the media campaign was measured and shows evidence of a positive shift in attitudes and understanding of dementia. Considerably more people now also believe that people with dementia do participate in a wide variety of activities.

People with dementia, their families and carers are at the heart of this work. With respect to the outcomes across communities that would result from the Dementia: Understand Together Campaign, they were asked what matters to them. They identified the following outcomes:

- That people are understood, respected and valued
- That they can stay socially connected and engage in community life if they so wish.
- That local businesses and amenities are responsive to a person's needs

- Built environment is accessible

To achieve sustainable outcomes in society, a cultural shift in the way we think about dementia and interact with a person with dementia and their families is needed.

Culture is defined as ‘the way we think, act and interact’. A Social Movement model is the underlying framework of Dementia: Understand Together in Communities. It means that every individual person and each organisation or business within the community has a role to play in changing culture around dementia and can do this as part of a growing social movement of people taking action. Today, over 40 National Partner Organisations and more than 340 Community Champions are involved in the Dementia: Understand Together Campaign and taking actions to make communities inclusive and inspiring others to get involved. People with dementia are often involved in the actions taken by these organisations and champions. The work ongoing in community through the national partners and community champions has been evaluated. Over 80% of National Partners (81.8%) and Community Champions (86%) felt that there was a better awareness and understanding of dementia in their organisation and wider networks and close to two-thirds of National Partners (63%) and Community Champions (65%) felt that there was a better awareness and understanding of dementia in the wider community. As one participant stated:

“It has made integration a lot easier. It is great to have a national programme that is trying to achieve what we are trying to achieve locally.”

As pointed out earlier by Dr Begley, the Covid-19 pandemic has impacted hugely on people with dementia and their family carers, as evidenced in a study by the Alzheimer Society of Ireland. It has had an impact on the work of the Dementia: Understand Together Campaign, which adapted to respond to the identified needs of people with dementia, whilst continuing to raise awareness and understanding of the needs of people with dementia and their families in the community. Dementia: Understand Together surveyed Community Champions to find out more about the impact of Covid-19 on their work and roles. Community Champions were asked ‘since the beginning of Covid-19, have you undertaken any actions in your role as a Community Champion to support the inclusion of people with dementia?’, to which 64% responded that they had. Actions included shifting from provided face-to-face to online support, outreaching to people with dementia by phone or letter, continuing to raise awareness about dementia. When asked ‘what resources would be of use to you as Community Champions at this time?’, resources identified included Virtual Champions Cafes / Learning and Networking Opportunities; best practice examples and highlighting champion activities through social media; and continuing to have printed and online campaign resources such as and “Dementia Inclusive Design” guide.

During Covid-19, the objectives of the Dementia: Understand Together Campaign stayed the same. However, content and method of delivery of the campaign were adapted for national partners, community champions and people with dementia. The first piece of work involved bringing together a range of resources into one place to ensure that people with dementia, their families and carers could access COVID-19 related information easily. This was undertaken in collaboration with the National Dementia Office, the Dementia Services Information and Development Centre (DSIDC) and the ASI. A weekly activity planner and a booklet of activities that could be done at home were also developed and the “At Home Activities” booklet by Emma O’Brien from the MTRR was published. Training has always

been a key aspect of Dementia: Understand Together, and awareness raising and inclusive design training were moved online. A benefit of online training and programmes is that a wider range of people are reached.

Story-telling is an important element of the Dementia: Understand Together Campaign, as it allows people to see what actions are being taken by others and be inspired to take action themselves. Examples of the types of actions undertaken by partners and champions that were publicised and shared through social media include Virtual Dementia Cafes, dementia training of staff in Boots, An Garda Síochána 'Be a Good Neighbour Campaign', and Singing for the Brain. Stories, with people with dementia at their heart, are the most powerful way to connect. Dementia: Understand Together ran a local newspaper campaign with an audience of approximately 1.7 million people, a radio campaign with a listenership of more than 1.2 million, and podcast interviews with people with dementia shared with over 700,000 Facebook followers.

For its next steps, the Dementia: Understand Together Campaign will continue to inspire people to get involved. It will strengthen and grow the partner and community champion network. The creation of a local link between organisations, especially their branch networks and champions to work together in communities is also important. Engagement with key collaborators including the ASI, Age Friendly Ireland and Healthy Ireland will continue. Campaign resources are available on the Dementia: Understand Together website (<https://www.understandtogether.ie/understand-together-campaign/>)

Eibhlís Cahalane, National Office for Services for Older People and Palliative Care, HSE

Evidence on the Impact of the Community Memory Technology Resource Rooms

Eibhlís Cahalane gave a presentation on Community Memory Technology Resources Rooms (MTRRs) and the evidence from a recent evaluation of MTRRs. Assistive technology (AT) is a primary focus of MTRRs and refers to equipment that enables a person to complete a task to maintain their independence, help manage risks at home and reduce caregiver stress. AT is wide-ranging, from low-tech AT such as white board reminders to high-tech AT such as GPS tracking systems. The impetus for the development of MTRRs came in 2016 when the HSE's National Office for Older People provided funding from the Dormant Accounts Fund to facilitate the expansion of AT for older people living in the community, including those with memory problems or dementia. The first MTRR was established in 2017 and more were established in 2018 and 2019.

A wide variety of AT is showcased at MTRRs, for example, calendar clocks and easy to use telephones. MTRRs allow 'hands-on' experience of AT equipment to facilitate learning and experience of the products with support and advice from a professional. In some cases, people are given an opportunity to trial AT equipment and test its suitability. MTRRs are staffed by Occupational Therapists working on a part-time basis. OT staff are skilled in the therapeutic benefits of AT and offer both practical information advice and emotional support to people visiting in a timely manner. The role and skills of OTs were highlighted as important aspects in the evaluation of MTRRs.

MTRRs are housed in a warm, welcoming and non-clinical environment, set up to emulate a person's home and to provide a means of enabling people to look at the AT and how it might work in a home setting and in different rooms (e.g., bathroom, kitchen, sitting room, bedroom). The MTRR environment has been identified by people using the service as an important feature. At the end of 2020, there were 27 MTRRs in Ireland and three more MTRRs are planned to open in 2021. There is good geographical spread throughout the country.

An evaluation of MTRR project was conducted in 2019 by Work Research Centre.²⁸ It provided a detailed profile of the MTRR programme; examined impacts and value for MTRR clients; and identified areas for enhancement and improvement. A mixed-methods approach was adopted, drawing on a variety of data sources. It included primary data collection and secondary analysis of existing MTRR data:

- Data on 2,261 referrals and 1,875 appointments in 2019 from a national routine dataset, which was examined to assess the volume and type of MTRRs activities.
- Feedback on the visitor experience in 2019 from 895 individuals.
- A survey of 20 MTRRs was conducted to obtain an understanding of the position of MTRRs in the local ecosystem, their operating procedures and service assessment.
- A new assessment form was developed to gather information on the nature of presenting needs and interventions provided. This was piloted in nine MTRRs in late 2019/early 2020 and provided information on interventions for 107 people.
- Information on the usefulness of the service and what actions had been taken on advice provided during the visit, was gathered by way of follow-up phone calls with 34 people in late 2019/early 2020.
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Most people referred to MTRRs are aged 65 years or over (92%), with people in the age group 75-85 years making up the majority (48% of all referrals). A small but sizeable proportion are under 65 years of age (8%). Of those referred, 58.9% are people with a diagnosis of dementia, 12.5% a cognitive impairment (not dementia), and 22.3% had memory problems but did not have a diagnosis of dementia or other cognitive impairment. Referrals come from a variety of sources, most frequently from community-based primary care, social care and mental health services (36.7%), followed by geriatricians (13%) and acute hospitals (12.4%). Relatively few referrals are from GPs (1.3%).

The evaluation provided a detailed profile of the services provided or activities at MTRRs. A distinction can be made between support directly related to AT and support not directly related to AT. In MTRRs, OTs are involved in a range of AT-related activities including showcasing AT equipment, providing information on AT equipment, giving 'hands-on' demonstrations of AT equipment, advising and making recommendations regarding the set-up and use of AT equipment in the home, assisting people to source AT equipment, troubleshooting when people encounter problems with AT equipment purchased, and loaning equipment. With respect to supports not directly related to AT, OTs at MTRRs are involved in providing practical information and advice on maintaining daily routines and activities,

²⁸ Cullen, K. (2020) *Evaluation of the Role, Contribution and Value of the Memory Technology Resource Room (MTRR) Programme*, Tullamore: National Dementia Office.
<http://dementiapathways.ie/permacache/fdd/cf3/1ee/781e0fe187b89305c27e75fb135ada86.pdf>

memory strategies and signposting on to a variety of health and social care services and supports. There are also involved in providing practical information and advice on basic and instrumental activities of daily living, on how to respond to challenging behaviours presented by people with dementia, prevention of falls and keeping safe. These supports and activities were provided to family carers as well as to people with memory problems.

Feedback from people visiting MTRRs is very positive. An analysis of the 895 feedback forms showed that the majority (89.8%) reported visits to the MTRR to be 'very useful'. This positive experience is also illustrated by visitor comments: 'There are a lot of good things to help with everyday living which I didn't know were available' and 'I felt happy in the environment'.

Analysis of feedback from a subgroup of 34 MTRRs obtained via follow-up phone calls found that 85.3% found the interaction at the MTRRs to be 'very useful'. Two-thirds indicated that they had gone on to purchase AT, mostly commonly AT equipment for orientation purposes such as clocks. Of those who had purchased AT equipment, 72% reported that this had been beneficial.

Feedback from MTRR staff highlighted the important role that MTRRs play in a number of respects. These included facilitating a holistic approach, promoting awareness and offering advice not only on AT equipment that is potentially useful, but also that which is potentially unhelpful, providing a community-based resource post-diagnosis. MTRRs are easily accessible in that people can self-refer. They are operated by dedicated professionals who take a strengths-based approach.

COVID-19 has had a huge impact, but has also highlighted the important role that MTRRs play in supporting people with dementia and their family carers. AT has been important during COVID-19 in relation to safety issues and for reassuring family carers. The MTRRs adapted to telehealth very quickly and found that it was possible to provide information and advice on AT by telephone or video calls.

A recommendation from the evaluation is to ensure that MTRRs are sustainable and expanded in the future. Others are that operations are standardised across MTRRs and that research should become embedded in the work of MTRRs.

The evaluation showed that MTRRs are a valuable asset in the community. They empower, educate and support people with memory problems including people with dementia, their family members, health care workers and members of the public. They offer a safe environment for people and their family members to discuss challenges they are facing in their day to day lives. They can contribute to improving quality of life of people with memory problems and reducing caregiver stress. They facilitate people to make informed choices and decisions regarding the purchase of AT. They act as a signposting service. Details about MTRRs can be found at www.understandtogether.ie

Fiona Keogh, Senior Research Fellow, Centre for Economic and Social Research in Dementia, National University of Ireland, Galway

Evaluation of the implementation and impact of the post-diagnostic support programme

Fiona Keogh's presentation focused on an evaluation of the Post-diagnostic Support Grant Scheme in Ireland, funded by the National Dementia Office (NDO), HSE. The evaluation was led by Dr Maria Pierce, Independent Researcher, and conducted with colleagues in the Centre for Economic and Social Research on Dementia (CESRD), National University of Ireland, Galway (NUIG).²⁹ Staff implementing the projects and people with dementia and their family carers participating in the projects all contributed to the project.

The National Dementia Strategy³⁰ recommended a number of actions under the heading of 'Timely Diagnosis and Intervention', and given the recognised gap in post-diagnostic supports in Ireland, the NDO formed a programme under the direction of a multi-disciplinary and cross-sectional support group. They undertook a range of tasks including a needs analysis of people with dementia, a scoping and a literature review of the international evidence on post-diagnostic supports conducted by Dr Fiona Keogh and colleagues in the CESRD, NUIG.³¹ These tasks were undertaken with a view to informing how the NDO might move forward with regard to post-diagnostic support provision.

Funding made available through the Dormant Accounts Scheme was used to develop a grant scheme to provide seed funding to increase availability of post-diagnostic supports across Ireland and increase staff capacity to deliver post-diagnostic support interventions. Eighteen projects were grant-funded to implement one or more of the following interventions: cognitive stimulation therapy (CST), cognitive rehabilitation (CR), and psychoeducational (PE) interventions. CST is designed to stimulate cognitive ability such as memory and thinking through a structured range of activities and is typically delivered as a group programme. The evidence-based Making a Difference developed at University College London (UCL) is one of the most well-known CST programmes. There are different types of CR. One is Home-based Memory Rehabilitation (HBMR), the most common CR programme implemented under the PDS grant scheme. It is an OT-led memory rehabilitation programme that focuses on structure and repetition to encourage the person with dementia to develop new habits and routines, and through the use of memory aids. As the name suggests, PE interventions have two components, an educational element such as symptoms, treatments and legal issues, and a therapeutic component to help people with dementia and their family carers to manage the circumstances of their dementia and deal with stress.

The evaluation was an overall evaluation of the grant scheme and was interested in both implementation and impact. The evaluation described the interventions, how they were delivered and context in which they were implemented. It assessed the overall impact of the

²⁹ Pierce, M., Keogh, F., Teahan, A. and O'Shea, E. (2019) *Evaluation of the HSE's Post-diagnostic Support Grant Scheme*, Tullamore: National Dementia Office.

³⁰ Department of Health (2014) *Irish National Dementia Strategy*, Dublin: Department of Health.

³¹ O'Shea, E., Keogh, F. and Heneghan, C. (2019) *Post-diagnostic Support for People with Dementia and their Carers*, Galway: Centre for Economic and Social Research on Dementia, National University of Ireland, Galway. <https://www.understandtogether.ie/news-and-events/news/Dementia-Post-diagnostic-Support-Literature-Review.pdf>

interventions for people with dementia and their family carers and if the overall PDS grant scheme had succeeded in addressing PDS gaps.

Methods used in conducting the evaluation included a review of the project documentation, meetings and interviews with project teams and the design of a data collection tool to collect project use data. To assess impact, a specific form was developed, informed by wellbeing domains. Public and patient involvement (PPI) with a group of people with dementia was used to inform the development of form, which was then tailored to each intervention type. These forms were completed by 174 people with dementia and 61 family carers.

Data was collected for six months from January to June 2019. During this time, 17 projects were delivered to a total of 232 people with dementia and 140 family carers. Of the 17 projects, seven delivered CST to 89 people with dementia, six delivered CR to 80 people with dementia and 64 family carers, and six delivered PT interventions to 63 people with dementia and 76 family carers. One project did not go ahead due to staff recruitment difficulties.

High-level findings for each of the intervention types were then presented. CST was delivered in a variety of contexts including day care and community hospital settings, and CST was also adapted for delivery to in-patients with dementia in an acute hospital setting. The UCL Making a Difference programme was most commonly delivered and there was good acceptability of this programme. CogsClub, adapted from the UCL CST programme was also delivered by one project. CST has a number of advantages; it is highly adaptable and the format in which it is delivered can be tailored to different contexts. While all projects made adaptations to the CST programme, fidelity to the original programme and adherence to its principles are important. Training on CST, either in person or online, for staff was very helpful in supporting the delivery of the programme. However, staff experience, their skillset, (e.g., group facilitation skills), staff readiness and flexibility were also important. The delivery of CST in the acute hospital setting worked very well and demonstrated that it is feasible to implement CST in an acute setting.

With respect to CR programmes, projects tended to opt for HBMR, and not surprisingly, OTs were highly involved in implementing this OT-led intervention. Whilst CR is typically delivered on an individual basis to people in their own homes, most of the projects implemented group-based CR and they were delivered in a variety of settings including MTRRs. Memory aids such as calendars, whiteboards and diaries were widely used, but access to these aids was variable. Some projects legitimately questioned the 'one size fits all' approach, whereby all participants receive all of the memory aids. Cognitive rehabilitation is designed for people with early-stage dementia and CR projects reached the intended target beneficiaries.

Unlike CST and CR, a wide variety of PE interventions were delivered by the projects. Most were dyadic (both person with dementia and their family carer) interventions, some of which were delivered to individual dyads and some to groups of dyads. Individual dyadic PE interventions were more successful than group dyadic PE interventions, which may be because people with dementia and family carers are less willing to share personal challenges in a group setting and such challenges may be easier to address in an individual programme. The number of people participating in group-based PE interventions was

relatively low for a number of reasons including delays in staff recruitment, stigma associated with dementia, and time invested in developing new PE interventions.

A number of other issues were highlighted by the evaluation. Recruiting new staff can delay the process of intervention delivery. While a wide variety of staff delivered the programmes, staff experience, motivation and skills were more important than disciplinary background. There is a demand for PDS, but recruitment of intervention participants can be challenging, and is related to the diagnostic process, highlighting the importance of links with diagnostic services such as memory clinics and post-diagnostic services such as MTRRs. Family carers play an important role in PDS, providing transport, supporting the person with dementia (e.g., implementing strategies learned at CR). Access issues are important, including getting to a venue, and access at (e.g., parking) and within the building (e.g., signposting).

The impact evaluation showed that the overwhelming majority of participants rated the interventions very positively. For CST, people with dementia really enjoyed the opportunity for social interaction and conversation, peer support and often wanted the group to continue. Participants in CR found the tips and strategies very helpful. They valued the peer support from group CR and connection with services at an early stage of dementia provided them with reassurance. There was positive feedback from people participating in dyadic individual PE interventions. They found the staff very knowledgeable, liked that the atmosphere was calm and relaxed and having an opportunity to be listened to and being heard. Staff found this work very enjoyable and rewarding, and linking people from diagnostic services and on to other services to be beneficial.

The international evidence shows that people with dementia can benefit from and value PDS and this was supported by the evaluation. How PDS are implemented and delivered is important. CST is worth scaling up, but attention needs to be paid to uniformity and consistency. Some consideration needs to be given to the approach and format that is taken to the delivery of CR in Ireland. Developing a new PE intervention is not a good use of resources because of the work involved and given that many PE interventions have already been developed. Individual, dyadic PE interventions appear to be more successful. To support wider implementation, additional funding will be needed. It is noteworthy that 14 of the 17 projects have continued, supported either through existing envelopes of funding or funding sources through the NDO. Overall, the PDS Grant Scheme was very successful and provided a lot of learning as to how to implement PDS interventions in the future.

Mary Bardin, Operations Manager, Easter Region, Alzheimer Society of Ireland

Mary Bardin's presentation focused on supporting people with dementia at home. The biggest challenge facing the Alzheimer Society of Ireland (ASI) currently is how to continue to deliver services to people with dementia living at home especially given the temporary closure of day care centres due to Covid-19. The ASI asked people with dementia what does living and being supported in their own home mean to them. People with dementia said:

- being able to live at home offers me a sense of comfort and independence
- being supported at home has helped me maintain and even increase confidence levels

- I love to go out into my garden
- I share my home with my beloved pet
- I know my neighbours and love to hear the local gossip!
- I know where my things are
- I have my favourite chair and I love my private space
- I get to see my family members in my home when it suits me
- I get to go to bed and get up when it suits me
- I have lived in my home for many years – Mary gave the example of one woman who had lived in her own home for 57 years
- Even during the coronavirus lockdown, I want to be supported to live in my own home
- Home is where my heart is

Knowing that people with dementia want to be supported in their own homes, the next question is how are people with dementia best supported at home? ASI have been delivering a person-centred home care services to people with dementia for many years. Trained staff ensure that the needs of people with dementia are met by providing support and practical information to people with dementia and their family carers. Feedback from people in receipt of ASI home care services is positive:

‘The difference in our lives have been enormous since Maeve (home care worker) came ... you can plan something on a Tuesday ... and Mam is in great form ... she is just so happy’ (Anonymous, Dublin)

ASI dementia-specific home care includes: one-to-one committed support to the person with dementia from the same home care worker; conversation and companionship; meal preparation, personal hygiene and dressing; assistance at mealtimes and exercise; and respite from caregiving from family carers.

A consequence of the Coronavirus pandemic has been the temporary closure of ASI dementia-specific day care centres nationwide. It meant that people with dementia could no longer attend day care, and the ASI were concerned about their wellbeing, lack of stimulation, potential to experience isolation and loneliness. ASI were also concerned about family carers now caring for people with dementia 24/7 without a much needed and well-deserved break.

To support people with dementia living at home during the pandemic, ASI developed a new Alternative Support Therapy. This project enabled the ASI to provide meaningful, therapeutic and age-appropriate activity or social engagement calls on the phone or via webcam to people living with dementia and their family carers, with the intention that both would benefit. The ASI first communicated with day care attendees and family carers by phone and webcam to identify their social and recreational requirements according to their preference. The ASI then engaged with the person with dementia either through a social engagement call or on a variety of stimulating and varied activities to promote wellbeing, fun and to reduce boredom.

ASI designed activity packs for the person with dementia and the family carers, and distributed these on a monthly basis. The activity pack consists of: Home Activities Booklet; Home Weekly Planner; and Home Activity Ideas Factsheet. The activity packs have been designed for people with dementia at different stages of dementia: early, mild and advanced. Feedback from people with dementia and their family carers about the activity packs has been very positive. For example:

“Good variety of material, ideas to plan and do daily, loves the crosswords, loves the colouring, family fun, words of songs, poems, puzzles.”

“I feel supported – not everyone understands what caring for someone with dementia in the house feels like.”

A decision was taken by the ASI to bring day care services into the home. A new model of care, Day Care at Home, was developed. It aims to provide an alternative model of care and support to people with dementia and their family carers in the home. It is a way of delivering a day care experience in the home. Its primary aim is to provide social and therapeutic activities – music sessions, reminiscence therapy, arts and crafts, gentle exercises, conversation, companionship and recreational activities - while promoting continuity of care and support to as many people with dementia and their family carers as possible during the pandemic crisis at home. The Day Care at Home service reflects what is normally provided in the day care centre. The service is delivered in blocks of 2 to 3 hours.

During the pandemic, the ASI National Helpline has been extremely busy. Through the Helpline, people can make an appointment to speak to the Dementia Nurse or gain access to a Dementia Adviser. Live Chat is available through the Helpline as well.

These services are part of a suite of services and supports that the ASI is providing to people with dementia and their family carers. In addition to Day Care at Home, Therapeutic Activity Packs, National Helpline, Dementia Nurse, and Dementia Adviser Service, other supports offered by the ASI are: Virtual Social Clubs, Virtual Sweet Memories Choir in collaboration with the HSE and Virtual Dementia Cafés.

Activity packs are usually distributed by local day care centre manager who either deliver, post or email packs. They can also be ordered through the ASI website (<https://alzheimer.ie/>). Any person with dementia, including current users of day care and new users, can avail of the ASI's Day Care at Home service, and access to the service will be made on

Panel discussion

Eibhlís Cahalane was asked: **Do MTRRs demonstrate robotics, and in particular Milo?** In the MTRRs, a wide range of AT are displayed and demonstrated, but currently this does not include robotic technology. Nevertheless, OTs in MTRRs are aware of the advantages of robotic technology, the ethical issues that arise and are keeping up to date with developments including related research. MTRRs are in contact with companies that produce this type of AT. Robotics is an emerging and dynamic technology and it may be that the MTRRs will stock robotics in the future, if it is deemed appropriate to do so. In the meantime, MTRRs can play a role in providing information to people interested in this

technology and signpost people to organisations that can tell them more about robotic technology.

The panel were asked: **How best can the wishes of people with dementia be balanced with the wishes and expectations of family members or carers?**

This issue has been discussed by MTRRs network members, and it is an issue that arises a lot in practice. Assessing the needs of the person with dementia is a key part of the work undertaken by OTs and other health professionals in the MTRRs, and the approach taken is an assessment of the persons needs which is undertaken in collaboration with the person with dementia. Ethical issues do arise when the person's expressed needs do not match those of the family carer, or family carers may look to introduce AT into the home without making the person with dementia aware of this. The MTRR staff have participated in Dementia Elevator training on Dementia and Everyday Ethics for health and social care professionals, which has provided staff with a framework for professional decision-making. Staff work through ethical dilemmas as they arise on a case-by-case basis, including highlighting the importance to family carers of involving people with dementia in the decision-making process.

Professor Kate Irving said that the idea of collaborative decision-making with people with dementia is not something that we as a society have fully engaged with. There is still a strongly held view that we are each autonomous decision-makers making independent decisions about what we want for the future, but few decisions are actually made independently of our families or other people who love us. There is a need to move away from pitching person with dementia's wishes and preferences against those of family members and thinking about how we can arrive at a decision that is shared by the person with dementia and their family. Ultimately, most families want what is best for the person with dementia and the person with dementia wants what best for themselves. The role of OTs and other health professionals is to create a space whereby the person with dementia and family carer can hear each other's views and wishes, and facilitate them to find common ground. Health professionals may need to use tactics of gentle persuasion.

Dr Fiona Keogh highlighted that the Decision Support Service, a new service in development under the Assisted Decision-making (Capacity) Act, 2015, will create a framework for an assisted decision-making process where somebody might need some external support in that decision-making process. She agreed with Professor Irving that it is best not to approach this as the person with dementia in conflict with their family carer in conflict but as a process by which to arrive at an outcome that is acceptable to both parties.

Mary Bardin explained that in the ASI, services managers and care workers are in constant contact with family carers, which has been a main issue during the pandemic. ASI are moving as many supports as possible online and the biggest issues is educating family carers and people with dementia to use technology that they have not used before.

Fiona Foley pointed out that a key part of addressing ethical dilemmas is to remember to see the person and not the dementia, that there is a person behind the diagnosis and it is important to take account of their needs and wishes and how they want to live. Where the focus is on the diagnosis of dementia rather than the person, certain suggestions might be

put forward that may not be a good fit for the person or what they want. Therefore, in agreement with other panel members, it is important to hear what the person with dementia wants, to keep lines of communication open between the person with dementia and their family carers, and to move from there to reach a shared decision with family carers. Facilitating communication between all of the key stakeholders is central to the work of the Understand Together Campaign.

Psychotropic Medication and Dementia: Maintaining Person-centred Care

Tuesday 3rd November - Plenary Psychotropic Medication and Dementia - 9.00 to

10.30 <https://youtu.be/Pu0U3n1zCnI>

Professor Clive Ballard, University of Exeter, UK

Improving Care for People with Dementia Living in Nursing Homes

Professor Ballard's presentation focused on psychotropic medication and people with dementia in residential care homes and nursing homes.

Of the estimated 40 million people with dementia globally, a large number live in residential care homes or nursing homes. In Europe and North America, around one-third of people with dementia reside in residential care homes or nursing homes. They are a vulnerable group of people who have mainly moderately severe or severe dementia and a lot of comorbidity. There are major challenges with residential care facilities and nursing homes, as quality of care is variable, inconsistent and often poor. Use of harmful antipsychotic and other psychotropic drugs is widespread. For example, in the UK, it has been estimated that out of the 750,000 people with dementia, 180,000 were taking psychotropic medications.³² Other studies of nursing homes conducted at around the same time by Professor Ballard and colleagues showed that almost 50% of nursing homes residents with dementia were taking psychotropic medications. In the UK, this proportion has since halved, indicating that some progress has been made, but the numbers are still high. Worryingly, since the start of the Covid-19 pandemic, monthly figures are suggesting that there is increased prescribing of antipsychotic medication to people with dementia.

Anti-psychotic medications include Risperidone, Aripiprazole, Olanzapine and Quetiapine. Meta-analysis summarising the results of studies on antipsychotics shows that these drugs are not very effective for the treatment of psychiatric symptoms in dementia.³³ For aggression, a meta-analysis across studies shows a statistically significant but small effect for 2mg Risperidone and probably not a clinically meaningful benefit. For psychosis, Risperidone 1mg produced a smaller effect, with most individual studies showing no effects. Similar results have been found for other antipsychotic medication such as Aripiprazole and Olanzapine, although the results from clinical trials are not in the public domain making interpretation difficult. An exception is the STAR trial of Quetiapine showing that it doesn't work,³⁴ although it is a widely prescribed antipsychotic for people with dementia.

Since neuropsychiatric symptoms of dementia can be extremely distressing, disabling and have a lot of negative consequences for people with dementia, antipsychotics with a small effect size can be useful. However, there are adverse effects of antipsychotic drugs for people with dementia, and these are likely to outweigh the benefits. Anti-psychotics cause

³² Banerjee, S. (2009) The Use of Antipsychotic Medication for People with Dementia: Time for Action, Department of Health.

<http://psychrights.org/research/digest/nlps/BanerjeeReportOnGeriatricNeurolepticUse.pdf>

³³ Ballard, C. and Howard, R. (2006) Neuroleptic drugs in dementia: benefits and harm, *Nature Reviews Neurosciences*, 7: 492–500.

³⁴ Zhong, K.X., Tariot, P.N., Mintzer, J., Minkwitz, M.C. and Devine, N.A. (2007) Quetiapine to treat agitation in dementia: A randomised, double-blind, placebo-controlled study, *Current Alzheimer Research*, 4(1), DOI: 10.2174/15672050779939805

Parkinsonism, sedation, gait disturbance leading to falls. Other adverse outcomes are increased respiratory infections, oedema, accelerated cognitive decline, three-fold risk of stroke, an 80% increased risk of thrombo-embolic events, and an almost doubling of mortality.

Most outcome studies on use of antipsychotic medication with people with dementia have been conducted over a twelve-week period. Longer-term studies also show no benefit. For example, the study by Ballard et al (2007) of Quetiapine showed no benefit with longer term use over six months and a significant impact on cognition.³⁵ Using the Severe Impairment Battery, this study showed that cognition was 14 points worse with Quetiapine than it was with a placebo, about a four-fold increase in the expected rate of decline.

The CATIE-AD (Clinical Antipsychotic Trials of Intervention Effectiveness–Alzheimer's Disease) study, another longer-term study, did not show any significant benefits on clinical judgements at 12 weeks. Over nine months the primary outcomes were whether antipsychotics were discontinued either for lack of efficacy or for adverse effects and the study found no difference between treatments. The study concluded that there were no benefits over nine months of antipsychotics compared to placebos.

DART AD is a UK study of people living in nursing homes already taking antipsychotics who were randomised either to continue to take or to stop taking the antipsychotics for a 12-month period and then followed up for five years.³⁶ The study found no significant benefits for people with respect to psychiatric symptoms of dementia from long-term continuation of antipsychotic medication, but showed the mortality risk was still evident over long-term treatment. For example, the study showed that 59% of people taking a placebo were still alive at 36 months compared to 30% of people taking an antipsychotic medication. The direct attributable mortality is much more evident with longer-term treatment with antipsychotics.

The following conclusions can be drawn from these studies. Over 12 weeks, most antipsychotics, excluding Quetiapine, produce some very modest benefits for aggression, but these benefits need to be weighed up against the risk of serious adverse events such as stroke and mortality and likely only worth using if neuropsychiatric symptoms are very severe. For longer term usage, there is no evidence of ongoing benefit and there is still evidence that mortality risk is very prominent.

The issue of improving outcomes for people with dementia living in care homes is linked to quality-of-life issues. A study investigating the impact of antipsychotic medication used to treat neuropsychiatric symptoms in people with dementia showed that the treatment had much more a detrimental effect on quality of life. However, few studies have investigated the impacts of antipsychotics on quality of life.

³⁵ Ballard, C. et al. (2005). Quetiapine and rivastigmine and cognitive decline in Alzheimer's disease: randomised double blind placebo controlled trial. *British Medical Journal*, 330: 874.

³⁶ Ballard, C., Hanney, M.L., Theodoulou, M., Douglas, S., McShane, R., Kossakowski K., et al. (2009) The dementia antipsychotic withdrawal trial (DART-AD): long-term follow-up of a randomised placebo-controlled trial. *Lancet Neurology*. 8: 151–157. 10.1016/S1474-4422(08)70295-3.

Nursing homes are challenging environments. A series of studies using dementia care mapping suggests that residents spend an average of two minutes in a six-hour waking period in social engagement (Ballard et al., 2001; 2006; 2018), indicative of an impoverished social environment, which is likely to be contributing to neuropsychiatric symptoms and which needs to be addressed.³⁷

Several programmes have been developed in nursing homes to address lack of social engagement. While many of these programmes claim to be evidence-based, in reality the vast majority are not underpinned by evidence, and the evidence base for these programmes is actually very thin. Fossey et al. (2014) identified more than 170 training programmes in the English language of which only three were evidence-based and two based on randomised controlled trials.³⁸ Two randomised controlled trials that have demonstrated benefit are a trial by Chenoweth et al. (2009) in Australia³⁹ and the FITS (Focused Intervention Training and Support) trial led by Jane Fossey in the UK.⁴⁰ Importantly, as well as initial training, both of these programmes included a period of working alongside staff in the care home to make sure that the programmes' person-centred principles were embedded in real life practice. The FITS programme demonstrated a 50% reduction in antipsychotic medications without any worsening of neuropsychiatric symptoms with the training programme. However, it did not succeed in improving quality of life.

The WHELD programme, funded by the National Institute for Health Research in the UK, sought to optimise the FITS programme. The main aim of WHELD was to find out the most effective combination of psychosocial treatments for residents to improve quality of life, reduce antipsychotic prescribing and reduce falls. Initially, a review was carried out to identify elements that may be able to enhance person-centred care. Elements identified included social interaction and pleasant activities, embedding antipsychotic review and enjoyable exercise. These were developed into three additional modules and added to the person-centred module.

The enhanced programme, the WHELD programme, was evaluated in a factorial study in 16 care homes involving 277 people with dementia.⁴¹ All care homes got the person-centred care modules and the other modules were implemented using a factorial system, whereby half of the care homes got the other individual modules in different combinations to allow for an evaluation of each individual element separately and the best combination of elements.

³⁷ Ballard, C., O'Brien, J., James, I., Mynt, P., Lana, M., Potkins, D., Reichelt, K., Lee, L., Swann, A. and Fossey, J. (2001) Quality of life for people with dementia living in residential and nursing home care: The impact of performance on activities of daily living, behavioural and psychological symptoms, language skills and psychotropic drugs, *International Psychogeriatrics*, 13(1): 93–106.

³⁸ Fossey, J., Masson, S., Stafford, J., Lawrence, V., Corbett, A. and Ballard, C. (2014) The disconnect between evidence and practice: a systematic review of person-centred interventions and training manuals for care home staff working with people with dementia, *International Journal of Geriatric Psychiatry*, 29(8): 797–807

³⁹ Chenoweth, L., King, M.T., Jeon, Y.H., et al. (2009) Caring for Aged Dementia Care Resident Study (CADRES) of person-centred dementia care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *Lancet Neurology*, 8(4): 317–325.

⁴⁰ Brooker, D.J., Latham, I., Evans, S.C., Jacobson, N., Perry, W., Bray, J., Ballard, C., Fossey, J. and Pickett, J. (2016) FITS into practice: Translating research into practice in reducing the use of anti-psychotic medication for people with dementia living in care homes, *Aging and Mental Health*, 20(7): 709–718.

⁴¹ Ballard, C., Orrell, M., Moniz-Cook, E., Woods, R., Whitaker, R., Corbett, A., et al. (2020) Improving mental health and reducing antipsychotic use in people with dementia in care homes: the WHELD research programme including two RCTs. *Programme Grants Appl Res*, 8(6).

The WHELD programme was evaluated over nine months. The Antipsychotic Review, which included educational training on the benefits and harms of anti-psychotic medication and the importance of psychosocial approaches, significantly reduced the use of anti-psychotic medication by 50% and mortality by around 29%. When combined with social interaction, the Antipsychotic Review reduced mortality by 36% and there was no worsening of neuropsychiatric symptoms. The exercise significantly improved depression and neuropsychiatric symptoms. The social interaction significantly improved quality of life, and in combination with the Antipsychotic review, also significantly improved apathy. Overall, there was a reduction in the use of antipsychotics, a reduction in mortality, no worsening of overall neuropsychiatric symptoms, an improvement in some neuropsychiatric symptoms with exercise, and some elements improved quality of life and reduced apathy. A manual of the WHELD programme was developed. A primary care training programme was also developed, accredited by the Royal College of General Practitioners, and delivered in parallel to the WHELD programme through a series of workshops and in general practices.

One of the aims of the National Dementia Strategy for England is to improve training of staff working in care homes and quality of life of people living in care homes.⁴² Kings College London has partnered with the Social Care Institute for Excellence to develop and evaluate an e-learning training intervention, based on the principles of the WHELD programme. The e-learning training intervention is referred to as tEACH (Improving staff attitudes and care for people with dementia). A pilot randomised controlled trial of tEACH involving 280 care staff and conducted over eight months demonstrated significant benefits in staff attitudes to person-centred care with a combination of e-learning intervention and facilitation support.⁴³ The qualitative element of the trial supported these findings and found that there was much better engagement from staff who were white and spoke English as a first language, which has implications for the development of materials such as making them more video based and more accessible to people with limited literacy skills or who do not speak English as a first language and making the materials more culturally diverse.

Funding has been granted by the MRC to develop and deliver a Covid-19 version of WHELD over the next 12 months. This will build on the model developed for the tEACH programme, and will involve reviewing and developing the digital materials and virtual coaching, using a Champions model. Covid-19 specific elements will be included, such as peer-support for care home staff for care home staff and managers, and best practice for enabling people with dementia to stay in touch with family members. A full RCT will launch in January 2021, with 1,280 care homes.

While the WHELD programme and tEACH interventions demonstrated positive results, the main challenge is achieving widespread implementation of evidence-based programme such as these in care homes in the real world.

Professor Suzanne Timmons, National Clinical Lead, National Dementia Office, HSE
Guidelines for the use of psychotropic medications with people with dementia

⁴² Department of Health (2011) Living Well with Dementia: A National Dementia Strategy, Department of Health and Social Care. <https://www.gov.uk/government/news/living-well-with-dementia-a-national-dementia-strategy>

⁴³ <https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/improving-staff-attitudes-and-care-for-people-with-dementia-elearning/>

Professor Suzanne Timmons presented on the National Clinical Guideline on Appropriate Prescribing of psychotropic medication for non-cognitive symptoms in people with dementia.

Within the Irish National Dementia Strategy, there is an action that the HSE would develop guidance on the appropriate management of medication for people with dementia, in particular psychotropic medication, and would make arrangements for the guidance material to be available in all relevant settings, including nursing homes.⁴⁴ Upon joining the NDO in 2017 as Clinical Lead, Professor Timmons was of the view that guidance would not change practice and that it would be better to develop a National Clinical Guideline, owned by the Department of Health, and based on a rigorous development process and on evidence, and against which it would be possible to audit. A decision was taken to develop a National Clinical Guideline.

Most people with dementia will experience distressing non-cognitive symptoms of dementia at some stage. These can include agitation, psychosis, hallucinations, mood changes, anxiety, and can be manifested externally through behaviours such as walking about, pacing or calling out. These behaviours are often referred to as Behavioural and Psychological Symptoms of Dementia (BPSD), but the term preferred by the NDO is non-cognitive symptoms of dementia, because it focuses on what the person has been experiencing and not on the behaviours that staff member might see.

Non-cognitive symptoms of dementia are associated with poor quality of life and poor outcomes such as admission to long-stay residential care because of the challenges of caring for the person in the community. Psychotropic medications have an important role to play in certain situations particularly where there may be an imminent risk of harm to the person and where the person is in severe distress. However, non-pharmacological interventions such as music therapy, pet therapy, environmental design and adaptations are always advocated as the first line of response.

For every 100 people with dementia who are treated with an antipsychotic for a correct indication, less than 20 people will derive benefit and the remaining 80 will derive no benefit, about one or two will have a stroke and one person is likely to die. Banerjee's (2009) findings have still hold true.⁴⁵ Antipsychotics have an adverse profile and are not very beneficial for a lot of people, but for some people it is a risk worth taking, but only after all other approaches have been ruled out.

Professor Timmons led out on the development of the National Clinical Guideline for "Appropriate Prescribing of psychotropic medication for non-cognitive symptoms in people with dementia". A Guideline Development Group was convened, co-chaired by Professor Steven Byrne, Head of Pharmacy, UCC and Professor Timmons. Other members of the group included Florence Hogan, people with dementia, family carers of people with dementia, pharmacists, nurses, doctors, health and social care professionals and from all

⁴⁴ Department of Health (2014) *Irish National Dementia Strategy*, Dublin: Department of Health.

⁴⁵ Banerjee, S. (2009) *The Use of Antipsychotic Medication for People with Dementia: Time for Action*, Department of Health.
<http://psychrights.org/research/digest/nlps/BanerjeeReportOnGeriatricNeurolepticUse.pdf>

care settings. International guidelines and evidence were reviewed by the expert group, and agreement was reached on the wording for recommendations.

The Guideline,⁴⁶ which is 180 pages long, focuses on psychotropic medications, which are drugs that affect how the brain works. Typical psychotropic medications are antipsychotics, benzodiazepines, Z-drugs which are hypnotics such as Zolpadem and Stilnoct, antidepressants and anticonvulsants (when used as mood stabilisers and not for seizures), and cognitive enhancing medications such as Memantine, Donepezil and Rivastigmine that are used to improve cognition in dementia but sometimes also used for non-cognitive symptoms of dementia. The Guideline is targeted at health professionals in any setting, including community, intellectual disability, residential care or acute hospital settings. The goal of the Guideline is appropriate prescribing. Rather than overly focusing on reduction in the number of people prescribed, the Guideline is concerned with the correct procedures and supporting the decision-making process.

The Guidelines contain 21 recommendations and 11 good practice points. Professor Timmons highlighted two recommendations that relate to psychotropic medications in general. The first recommendation is that prior to considering any psychotropic medication in a person with dementia, a comprehensive assessment should be performed by an appropriately trained healthcare professional who can assess a person with dementia even when the person is in a distressed state. The evidence base for this recommendation is low, but it is known intuitively and experts agreed that assessment was necessary and should be performed. The second recommendation is that non-pharmacological interventions should be used initially to treat non-cognitive symptoms of dementia unless there is severe distress or an identifiable risk of harm. The reason why it may be necessary to go directly to a pharmacological intervention is that a person who is severely distressed may not be able to participate in a non-pharmacological intervention and the risk of harm (e.g., the person is refusing to eat, drink or take any medications or is hallucinating and yielding a knife and in danger of injuring themselves or another person) is so great that the person is at risk of harm in the next few days if no action is taken. These types of non-cognitive symptoms of dementia are not commonplace, and most symptoms are not emergency situations.

Good practice points are where there is not a very strong evidence base but believed by the expert group to be very important. These include that an individualised person-centred approach should be followed at all times, the risks and benefits of using the medication should be discussed with the person with dementia and/or their relative or decision supporter. Whenever possible, the person with dementia should be included in the decision, but it is recognised that this is not always possible such as when a person is in a highly distressed stage, has advanced dementia or communication difficulties. The term decision supporter was agreed with the Decision-making Office to future proof the guideline for when the Assisted Decision-making (Capacity) Act, 2015, is fully commenced. Assessment must take place regularly after medication has commenced, including an assessment of whether the medication has worked, whether any adverse events have occurred, and whether or not medication should continue.

⁴⁶ Department of Health (2019) *Appropriate Prescribing of Psychotropic Medication for Non-cognitive Symptoms in People with Dementia, National Clinical Guidelines No. 21*, Dublin: Department of Health.
<https://www.gov.ie/en/collection/ac0046-appropriate-prescribing-of-psychotropic-medication-for-non-cognitive/>

With respect to antipsychotic medication, the Guideline has ten recommendations and four good practice points. In summary, when using antipsychotics, there has to be a correct indication, a risk/benefit discussion, and regular review. With respect to a correct indication, there are three main indications where antipsychotic medication has shown a modest benefit, i.e., severe agitation, psychosis and aggression where that either causes a risk of harm or severe distress. Medication is used to settle the immediate risk, following which pharmacological interventions are introduced and medication discontinued. Medication should only commence after a risk/benefit discussion which includes the person with dementia as far as practicable. The medication must not automatically be continued long-term even where it works. A decision about titrating down medications should be taken within three months. If the medication is not working, it must be stopped. Evidence suggests that antipsychotics do not work for walking about, hoarding, fidgeting, inappropriate voiding, verbal aggression, screaming, sexual disinhibition and repetitive action. If an antipsychotic is prescribed for any of these behaviours, the prescriber must be able to provide a strong justification for doing so.

Data for the second Irish National Audit of Dementia in acute hospitals was collected in 2019 and the report launched in September 2020.⁴⁷ The charts of 934 people with dementia in 33 hospitals in Ireland were audited. Most of these people with dementia were admitted to hospital from home, approximately 30% from long-stay residential care, and the remainder from other settings. The audit included a spotlight baseline audit of antipsychotic medication against the National Clinical Guideline, so that there would be a baseline available of practice before the guideline was launched. Overall, 38% of in-patients were taking antipsychotics on admission, and rose to 55% in people with dementia admitted from long-stay residential care. The audit revealed an increase in antipsychotic use for both people with dementia admitted from home and those admitted from long-stay residential care facilities, when compared with data from 2013. Overall, almost half (46%) of people with dementia were prescribed an antipsychotic during admission, excluding people with delirium or in receipt of end-of-life care or people prescribed with an antipsychotic for a medical indication. Antipsychotics were both newly prescribed and added to existing antipsychotic prescriptions. However, this seems to be related to increased prescribing for medical indications (e.g. end of life care and delirium). There were improvements in documenting of the reasons for prescribing antipsychotic medication, which improved from 50% to 81%. Somewhere between 11% and 17% of people with dementia in an acute hospital received a new or increased dose of an antipsychotic medication for non-cognitive symptoms of dementia, and while this is high, it has reduced from 2013. Of concern is that there was not sufficient review of effectiveness of the antipsychotic medication. Only 3% of cases had both effectiveness and side effects documented. Risk and benefits were documented in less than 10% of cases and discussion with the person with dementia and/or their family in less than 4% of cases. Where the antipsychotic medication was documented as effective, a planned review was documented in 10% of cases. This shows that before the National Clinical Guideline was introduced, hospitals were not performing well with regard to what is now known to be best practice for people with dementia and antipsychotic medications

⁴⁷ Bracken-Scally, M., Timmons, S., O'Shea, E., Gallagher P., Kennelly S.P., Hamilton, V. and O'Neill D. (2020) *Second Irish National Audit of Dementia Care in Acute Hospitals*, Tullamore: National Dementia Office.

There is a concern that if antipsychotic medications are demonised, health professionals may prescribe Benzodiazepines instead. The Guideline has a single recommendation on Benzodiazepines that due to the very limited for their use in the management of non-cognitive symptoms of dementia and their significant adverse effects, they should be avoided for the treatment of non-cognitive symptoms of dementia, and their use is strictly limited to the management of short-term, severe anxiety. This is a strong recommendation.

There is only moderate evidence for the effectiveness of Benzodiazepines in improving sleep and also moderate evidence for alternatives such as the use of personalised sleep management regimes. There has been a trend to use Melatonin for sleep disorders in people with dementia, but the evidence, which is only moderate, actually indicates that it is not effective and Melatonin should not be used. No evidence on the use of Z-drugs for treating sleep disorders in dementia could be found and while no recommendation could be made, it is advised that because of the side effects, Z-drugs should only be used for the shortest period possible.

Data from INAD 2019 showed that a lower proportion of people with dementia from any setting were taking Benzodiazepines on admission to hospital, but the proportion was higher among people with dementia from residential care settings, likely reflecting that more people with dementia in nursing homes will have advanced dementia and greater non-cognitive symptoms of dementia. During admission, most Benzodiazepines were prescribed for a medical issue such as seizures or end-of-life care - about 2% received an additional prescription and about 6% received a new prescription - and there tended to be good documentation of the indication. Others were prescribed Benzodiazepines for severe anxiety or non-cognitive symptoms of dementia - just under 5% received an additional prescription and 8% a new prescription. There was however, documentation of indication in only a quarter of these cases and there was discussion of risk/benefit with the person and their family in only one case. Therefore, although Benzodiazepines are not prescribed a lot for non-cognitive symptoms of dementia, the reasons for prescribing are poorly documented. Of the 22 people with dementia who were prescribed Benzodiazepines for severe anxiety, none recorded the maximum duration. Prior to the National Clinical Guideline being launched in 2019, the HSE had guidance for Benzodiazepines and Z-drugs, and these are useful for health professionals to read in conjunction with the National Clinical Guideline.

The National Clinical Guideline, with its clear evidence-based recommendations, is available, but a guideline alone is not sufficient to change practice. Factors influencing antipsychotic prescribing include organisational capacity, whatever the setting, and lack adequate resources and access to services, and poor skills and abilities among staff may be contributing to the relatively high level of antipsychotic prescribing in Ireland. Personal attitudes of individual staff members, organisational culture, and societal attitudes are also influencing factors. Attitudes towards people with dementia and how they are valued are important. How non-cognitive symptoms of dementia are viewed - as a problem that is an inconvenience for those (health professionals and family members) caring or from the person's perspective, their unmet needs and quality of life - also matters. Changes in all of these areas are needed to support the implementation of the Guideline. In the Budget 2021, funding was made available for a national implementation coordinator and national trainer and a national implementation team will be established. A key part of Guideline implementation is communication and engagement with key stakeholders. Resources to

support the Guideline have been developed. These include an algorithm to operationalise the Guidelines, which has been developed for use by health professionals. A leaflet developed for people with dementia and their family carers, which summarises the contents of the Guideline in lay terms has been co-developed with the Alzheimer Society of Ireland, people with dementia and their family carers and includes a decision support aid. To complement the Guideline, the National Dementia commissioned the Dementia Services and Information Development Centre to develop Guidance on non-pharmacological interventions for non-cognitive symptoms of dementia.⁴⁸ The evidence base for many of non-pharmacological interventions is not very strong, but these have little risks and may be enjoyable for their own sake. The Guidance covers and give practical examples of most non-pharmacological interventions including aromatherapy, animal therapy or robotic assistance. An audit tool and an audit manual has been developed for acute hospitals. An audit tool for long-stay residential care has also been developed and is currently being piloted. An e-learning module will be developed for health professionals and will be available on HSE LanD. An e-learning module will also be developed for GPs and will be available through the ICGP website. A national Train-the-Trainer education programme will also be developed, whereby volunteers from different care settings will be trained to be a trainer and will then train others on the appropriate use of psychotropic medication.

The National Clinical Guideline (full report and summary) is available from the Department of Health website. The Dementia Pathways website, a one-stop-shop for any healthcare professionals, includes a section on non-cognitive symptoms of dementia (<https://dementiapathways.ie/resources-for-practice/non-cognitive-symptoms-of-dementia>).. Information for people with dementia and their family carers is available on the Understand Together (www.understandtogether.ie) and the ASI websites (www.alzheimer.ie).

Florence Horseman Hogan, Quality and Patient Safety Manager, Leopardstown Hospital

Quality Improvement in the Use of Hypnotic and PRN Psychotropic Medication: A Residential Care Setting Experience

Ms Hogan presented on an interdisciplinary quality improvement project on psychotropic medication, which commenced in 2016 in Leopardstown Hospital. She started by highlighting the important role that Occupational Therapists (OT) play with regard to non-pharmacological interventions for the management of non-cognitive symptoms of dementia. In the project, OTs carried out cognitive assessment of residents and advised on activities and a Speech and Language Therapist carried out assessments of communication abilities and provided advice on communicating with residents with communication difficulties.

When first commenced, the project focused on hypnotic medication, with the aim of not only reducing the number of people prescribed with hypnotic medication, but also to demonstrate that, where hypnotic medication was prescribed, it was being appropriately prescribed and administered, in accordance with evidence-based guidelines. Staff knew that hypnotic

⁴⁸ McGowan, B., Gibb, M., Cullen, K. and Craig, C. (2019) *Non-Cognitive Symptoms of Dementia (NCSD): Guidance on Nonpharmacological Interventions for Healthcare and Social Care Practitioners*, Tullamore: National Dementia Office.

medications are not effective for some people (e.g., disrupted sleep continued), there are risks associated (e.g., falls) and may increase day time somnolence. Some residents were taking hypnotic medications on admission to Leopardstown Hospital. They knew of the importance of balancing benefits and risks, residents' rights to be involved in decision-making and a meaningful consent process. As some residents and/or their family members wanted hypnotic medication to continue, education and resident buy-in was key. Where a resident was unable to consent to discontinuation, a 'best interests' decision was taken.

A survey of nurses was carried out to obtain their views on the use of hypnotic medication and 42% of respondents reported that residents would not benefit from discontinuation of hypnotic medications. Following education, only 5% of nurses continued to have this view.

Evidence shows that the use of sedative medicines - anti-anxiety medication such as Benzodiazepines, and hypnotic medication or sleeping tablets - do not address the underlying causes of insomnia or responsive behaviours, but exacerbate symptoms of dementia and increase frailty.

Ms Horgan explained the importance of nurse education and management in this area. Doctors are the main prescribers of psychotropic medication, but many long-stay residential care settings do not have a resident Medical Officer and multiple GPs may be attending, which gives rise to inconsistent practices. Nurses are at the frontline of providing care to residents and are well placed to know and understand residents' care needs. Nurses have a duty to advocate on behalf of their patients and to protect residents' right to live full and meaningful lives to the best of their ability. They have a duty to promote person-centred care and to use evidence-based practice. Under the Assisted Decision-making (Capacity) Act, 2015, nurses have a duty to act in the residents' interests, taking their will and preferences into account. In both residential and acute care settings, doctors frequently report that it is nurses who most often request doctors or recommend to doctors to prescribe hypnotic and/or PRN ("as needed") psychotropic medication. Nurses are more likely to make such recommendations, if their understanding of insomnia and responsive behaviours is sub-optimal. Nurses must comply with legislation and regulation and consider ethical issues. Article 14 on Liberty and security of person in the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) is also relevant.⁴⁹ Informed consent should be obtained from residents using a meaningful consent process, although this is not straightforward for residents with dementia.

For the project, nurses acted as resident advocates and delivered specific non-pharmacological interventions to manage sleep and responsive behaviours that were appropriate and personalised to the needs of residents, and psychotropic medications were only administered as a last resort.

The project was underpinned by the ethical principles of autonomy, beneficence, mal-beneficence, justice and fairness. Residents' rights to autonomy and to live a full and meaningful life were promoted. Person-centred care was at the heart of the project. The

⁴⁹ United Nations (2006) *Convention on the Rights of Persons with Disabilities*
<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

project was underpinned by nurses' core values of care, compassion and commitment to residents and professional ethics.

The project was supported by the Medical Officer and Chief Pharmacist, which was deemed essential. For example, a challenge facing the project was the potential for residents to experience withdrawal symptoms if hypnotic medication is discontinued, and therefore required the involvement of the Medical Officer and Chief Pharmacist.

The project led to a decreased in the prescription of hypnotic medication and Benzodiazepines. In September 2016, approximately one third of residents were prescribed hypnotic medications (36.4%) and Benzodiazepines (34%). By March 2018, this had decreased to 11% and 10% respectively. This represents a decrease of approximately 70%. Feedback from staff was that residents' perceived quality of life had improved. The project has led to a culture change, whereby the non-pharmacological interventions are the first line of treatment for resident with insomnia or responsive behaviours.

Insomnia is a disturbance of normal sleep patterns commonly characterised by difficulty in initiating sleep (sleep onset insomnia) and/or difficulty in maintaining sleep (sleep maintenance). Patterns of sleep vary greatly between people. Before a hypnotic medication is prescribed, the underlying cause of insomnia should be established and where possible the underlying cause treated. The project found for residents admitted from both home and acute hospital and who were taking hypnotic medications, there was no documentation of reasons for prescribing hypnotic medications or whether it was prescribed for sleep onset insomnia or sleep maintenance insomnia.

Approximately one-third (36.6%) of people across all age groups report experiencing insomnia. However, insomnia is report to be clinically significant in about 10% of people. Older people are more likely to experience clinically significant insomnia for multiple reasons including changes in circadian rhythm, anxiety, pain, and reduced need to sleep. Z-drugs (zopiclone and zolpidem) are licensed for short-term treatment of insomnia (maximum four weeks including tapering off) that is severe, debilitating and causing extreme distress to the individual.

With respect to the management of insomnia, the project first set out to establish if the resident actually had insomnia that was of clinical significance or if insomnia was affecting the residents' ability to enjoy daily life to the best of his/her ability. The type insomnia (sleep onset or sleep maintenance) was determined. A care plan for non-pharmacological interventions including sleep hygiene was developed and implemented by nurses. Residents were involved in discussions about sleep issues and their care.

Sleep patterns were recorded on a 24-hour sleep monitoring chart for 3 to 5 days. As well as recording whether the resident was 'asleep' or 'awake', information was given about what residents were doing (e.g., chatting with other residents, watching TV, reading, etc.) during the 24 hours. Residents who were able to actively participate in social activities and interact, were deemed not to have insomnia of clinical significance and there was no indication therefore for hypnotic medications.

Before a Medical officer was asked to review a resident for prescription of hypnotic medication, nurses assessed the resident to establish sleep patterns and identify sleep issues and factors contributing to sleep problems. Hypnotic medications, when prescribed were prescribed for a maximum of four weeks.

Information about previous sleep history was gathered, including information on how much sleep the resident usually required, their ability to manage well during the day despite sleep disturbances, and occupational history, e.g., night shift workers such as nurses, soldiers, Gardaí.

Steps were taken to ensure that sleep hygiene measures were in place before any attempt was made to request hypnotic medications.

Responsive behaviour is a means of communication for those with difficulty expressing thoughts, feelings and needs. It is a reaction to stimuli that triggers a 'fight or flight' response in the person with dementia. These reactions can be associated with real or perceived stimuli or unmet need. The social, emotional or physical environment can cause frustration, fear or confusion.⁵⁰ Intermittent episodes of responsive behaviours can be seen as an attempt by the person to meet or express a physiological or psychological need. Identifying and meeting these needs is central to mitigating responsive behaviours.

To address responsive behaviours, the project found the following to be important: care plans, cognitive assessments, assessments to identify previous triggers known, and communication care plans to facilitate better communication between resident and care staff.

Prescribing psychotropic medication on a PRN basis to manage episodes of responsive behaviours is evidenced as sub-optimal practice as the initial trigger may still remain and the side effects of the medication may outweigh any short-term benefits. Side effects include drowsiness, dizziness, muscle weakness, lack of balance or coordination and can lead to increased falls risk, dehydration and apathy.

To identify triggers, the staff first spoke to the resident and family members. For intermittent responsive behaviours, the ABC (Antecedent, Behaviour and Consequence) monitoring was used. It gives: a description of the 'antecedent' i.e., what is happening before the behaviour occurs, including the environment and behaviours of other people; a description of the 'behaviour', i.e., what the resident did; and a description of the 'consequence' i.e., what happens after the behaviour occurs, including the environment and behaviours of other people. Care planning was also useful, as it provided a full history of the interventions that had previously been implemented and whether they have been successful or not. Input from all members of the interdisciplinary team was also helpful.

The project developed and implemented a process for the management of PRN psychotropic medications for nurses, as the nurse is the assessor, decision maker and evaluator in residents' care. The process included:

⁵⁰ Ministry of Health and Long-Term Care (2007) A Guide to the Long-Term Care Homes Act, 2007 and Regulation 79/10 https://health.gov.on.ca/en/public/programs/ltc/docs/litcha_guide_phase1.pdf

- ABC monitoring and trending to identify triggers enhanced using the PIECES framework.
- Implementation of a Responsive Behaviours Care Plan using identified triggers and including all possible factors.
- Nurses PRN Psychotropic Medication Administration Report
- At least four non-pharmacological interventions prior to consideration of administering psychotropic medication, documented in the PRN Administration Report. This was found to decrease administration of psychotropic medications by 25%
- The Medical Officer reviewed all PRN psychotropic medication where it has not been administered in an eight-week period and a decision was taken regarding discontinuation.
- Recognition that onset of pain or infection may be triggering responsive behaviours.
- Weekly review of each unit by CNM of the Nurses PRN Psychotropic Medication Administration Reports.
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To ensure that there was appropriate use and to demonstrate that psychotropic medications were prescribed only as a last resort, governance is important and the process must be overseen by a nominated person such as a Director of Nursing, Assistant Director of Nursing or Clinical Nurse Manager or Quality Patient Safety team.

QPS reports are submitted to HIQA, and to the Director of Nursing and Medication Safety Committee in Leopardstown Hospital.

The issuing of relevant guidance and guidelines has been critically important for the project's work. These are: *Guidance on Appropriate Prescribing of Benzodiazepines and Z-drugs (BZRA) in the Treatment of Anxiety and Insomnia*;⁵¹ *National Clinical Guideline on Appropriate Prescribing of Psychotropic Medications for Non-cognitive Symptoms of Dementia*,⁵² and *Non-Cognitive Symptoms of Dementia (NCSD) Guidance on Non-pharmacological Interventions for Healthcare and Social Care Practitioners*.⁵³ The latter document has been the most important for Leopardstown Hospital's project.

Panel discussion

The panel were asked: **What is the role of nurse prescribers with respect to psychotropic medication?** Florence Horseman Hogan asserted that there is a role of nurse prescribers, both in prescribing and reviewing psychotropic medication, but it would necessary for nurse prescribers to be first trained if they want to be involved in Quality Improvement projects such as the one at Leopardstown Hospital. Professor Timmons added

⁵¹ HSE (2018) *Guidance on appropriate prescribing of benzodiazepines and z-drugs (BZRA) in the treatment of anxiety and insomnia*, Medicines Management Programme, HSE.
<https://www.hse.ie/eng/about/who/cspd/ncps/medicines-management/bzra-for-anxiety-insomnia/bzraguidancemmpfeb18.pdf>

⁵² Bracken-Scally, M., Timmons, S., O'Shea, E., Gallagher P., Kennelly S.P., Hamilton, V. and O'Neill D. (2020) *Second Irish National Audit of Dementia Care in Acute Hospitals*, Tullamore: National Dementia Office.

⁵³ McGowan, B., Gibb, M., Cullen, K. and Craig, C. (2019) *Non-Cognitive Symptoms of Dementia (NCSD): Guidance on Nonpharmacological Interventions for Healthcare and Social Care Practitioners*, Tullamore: National Dementia Office.

that decisions about prescribing psychotropic medication are not taken unilaterally but by the team involved in the person's care. However, nurses and health care assistants often know the person best, and while a doctor may attend and prescribe a psychotropic medication, often it is the nurses and health care assistants' experience of the person's behaviour in the preceding days or week that is driving the request for a prescription. Nurses also have a key role in administering PRN psychotropic medication. Therefore, alongside educating GPs and other doctors about psychotropic medication, nurse education is highly important. Florence pointed out that a one-hour training session for nurses and health care assistants about hypnotic and antipsychotic medication was a key component of the Quality Improvement project at Leopardstown Hospital. Professor Clive Ballard agreed that education is clearly important for staff in care homes and practitioners in other settings to understand the potential harms of psychotropic medication and to empower them to see that there are positive actions that they can take in routine care, as well as more specific non-pharmacological approaches are highly important in that regard. A key lesson from WHELD is how hard it is to get simple things to happen reliably and consistently and while people know the principles, get them to problem solve and operationalise the principles in their day-to-day work is not easy. Education is an important element of that but it is important to go beyond that and enable people to implement what they have learned in their everyday routine activities at work providing care to people with dementia.

With onset of the pandemic, e-learning offers great potential as an education tool, but as the evidence on e-learning and lessons from the tEACH programme shows, e-learning is only effective if it is supported by virtual coaching and supervision, including helping people to problem solve and apply what they have learned into their daily work is a critical element. To that end, the tEach programme has been presented as virtual coaching with digital resources, rather than as e-learning alone, which is unlikely to be effective. Professor Timmons agreed that the National Clinical Guidelines alone will have limited impact in bringing about change in psychotropic prescribing, and in addition to training, coaching and mentoring and champions in each unit will be needed to promote and facilitate the implementation the Guidelines. It is expected that it will take six months to a year to embed this into practice and bring about a culture change. An application for HRB funding has been made and if successful will provide funding for a mentorship programme for six months in each site, after which people will be able to Experience from the WHELD project is that it can take four months to really engage people in the project, followed by a few months of implementation and it takes six to nine months before any benefits are observed.

Is there a role for champions? Professor Timmons responded positively to this question and highlighted the benefits of having a champions model. Champions can be from many different disciplinary backgrounds. They come from within the setting and are familiar with the day-to-day work and act as a peer support, motivating and encouraging colleagues to implement change. Ideally, champions have an enhanced level of education, and they are supported and mentored. Professor Ballard agreed that the Champion model is important but equally important is supporting champions, and this has to be at two levels; first, with respect to the principles underpinning the work, and second, practical support from line managers and colleagues in their team.

Funding was sought from Budget 2021 for aware raising and educational activities to support the implementation of the National Clinical Guideline. Separate to that, there has been an

injection of funding through Budget 2021 for additional Home Support which can be used to enable people with dementia to have meaningful activities within their own homes. In future budgets, it is expected that resources will be allocated to long-stay residential care. Evidence based programmes such as WHELD need to be implemented in Ireland, but these need to be costed and resourced.

In a comment to the panel, Professor Ian James highlighted the importance of recognising the existing skillset of staff in nursing homes who are managing non-cognitive symptoms of dementia on a daily basis and often have a huge repertoire of skills and there is potential to build on existing skills. Professor Ballard agreed that in his experience this is definitely true. Another way in which to use existing skillsets is to harness the interests and hobbies of staff, which promotes self-esteem and enables staff to contribute more effectively to activities with residents. In Leopardstown Hospital, health care assistants have introduced new activities as part of their daily work and have made fantastic contributions. There is a great skillset on the ground, but champions are needed to bring these skills to the fore and give staff the autonomy to use these skills.

How can it be ensured that non-pharmacological interventions are the first port of call before reaching for psychotropic medication? According to Professor Timmons, the first step is for people to realise why they shouldn't be reaching for psychotropic medication. On the face of it, prescribing psychotropic medication is the quickest and simplest thing to do, and medications costs are relatively low. To ensure that non-pharmacological interventions are used first, a highly trained workforce is needed and resources are in place to offer non-pharmacological interventions. Funding models need to be reconfigured to allow this. Florence Horseman Hogan explained that obligating staff to trial non-pharmacological interventions before administering psychotropic medication and then to provide a justification for using psychotropic medication when it was given were key measures. These measures alone led to a significant decrease in the use of psychotropic medications. Education and training are also important, as is involving residents in decision-making. Professor Ballard opined that even before offering the non-pharmacological interventions, it was important to get the environment right, as providing the right environment prevents the emergence of neuropsychiatric symptoms. The environment could be considered as the base level, with the second level being simple non-pharmacological approaches such as music or enjoyable social activities that can be delivered with relatively low level of skill. The third level is a higher echelon of non-pharmacological therapies such as ABC approach or a more skilled approach from a clinical psychologist or nurse specialist. Enabling health care assistants was a key focus of the WHELD programme, as they are the people delivering the hands-on care, including enabling them to contribute to care plans and how they can be implemented. Part of the problem to be addressed is the lack confidence of health care assistants and also the hierarchical barriers that marginalise health care assistants within nursing homes.