

Pre-Budget Submission 2021
Dementia: The Forgotten Crisis



THE ALZHEIMER
SOCIETY *of* IRELAND



Executive Summary

Total €19.667m

- 1. Invest €10m in Urgent Infrastructure Support**
- 2. Invest €6m in Dementia Home Care Supports**
- 3. Invest €589k in Dementia Adviser Service**
- 4. Invest €2.31m in Dementia Key Workers**
- 5. Invest €768k in Dementia Inclusive Community Coordinators**

The ASI calls on the Government to invest €19.667m in urgent infrastructure and community supports for people affected by dementia. This request is both critical and essential in view of the profoundly detrimental impact of COVID-19 on people living with dementia and their family caregivers. The continued absence of vital services and the growing gap between service need and delivery has led to a forgotten crisis in dementia care. The above investment will curtail and mitigate the widening service gap, and will support people to stay at home, which is stated Government policy and the preferred choice of people with dementia¹.

The theme of ASI's 2021 Pre-Budget Submission, 'Dementia: The Forgotten Crisis' highlights the need for immediate and critical re-opening of day care services and the expansion of community supports. This Submission calls on Government to address the growing service gap between need and the actual availability and delivery of services. Since the cessation of services due to COVID-19, people affected by dementia have been struggling to cope. The need for services is growing, not only among existing ASI clients but also among those who had not previously been in contact with The ASI services. Furthermore, the increase in prevalence rates of dementia in Ireland from 54,000 to 64,000² points to a deepening gap between service and need. It tells us that people affected by dementia are being left behind and rendered invisible and forgotten, and that the growing crisis in dementia care needs to be swiftly addressed.

Addressing this plight and implementing a system of care that involves appropriate services for all people with dementia and their family caregivers requires addressing infrastructural and capital challenges. At present, there are more limited services available than pre-COVID-19. Therefore, investing in re-opening day care services, alongside increasing the numbers of Dementia Home Care Supports, Dementia Advisers, Dementia Key Workers and Dementia Inclusive Communities must be prioritised.

Living with dementia at any time brings everyday challenges for the person and those around them. The challenges from the impact of COVID-19 have made daily life considerably more difficult and are exacerbating the vulnerability of this group. A recent ASI research³ report uncovered the extent of the plight and

¹ Donnelly, S. O'Brien, M. Begley, E. and Brenna, J. (2016) Meeting Older People's Preference for Care: Policy but what about practice. University College Dublin/Age Action/Alzheimer Society of Ireland/Irish Association of Social Workers.

² Health Atlas Ireland, 2020.

³ The Alzheimer Society of Ireland, (2020) Caring and Coping with Dementia during COVID-19.

predicament facing people living with dementia and those who support them, as they struggle to cope with increased care workloads and decreased supports. Stress, exhaustion, loneliness and anxiety have intensified as many COVID-19 restrictions imposed on dementia services continue with no end in sight. Many fear they have been forgotten and abandoned.

The current 2020 Programme for Government states a commitment to implementing the National Dementia Strategy (NDS), developed to *“improve dementia care so that people with dementia can live well for as long as possible, can ultimately die with comfort and dignity, and can have services and supports delivered in the best way possible”* (The National Dementia Strategy, 2014⁴). The NDS provides guidance on how to facilitate and support people to live at home for as long as possible, in their communities.

Overview of Asks

The impact of COVID-19 restrictions and increasing dementia prevalence figures have resulted in greater demand for dementia services at a time when less services are available. This Submission calls on the Government to address the increasing service gap between need and the delivery of services.

1. **Invest €10m in Urgent Infrastructure Support:** The ASI is calling for this critical Government investment in capital infrastructure to enable our day care services to reopen by ensuring they are fit for purpose and of a necessary standard in relation to COVID-19 guidelines. Refurbishment needs to be carried out on existing day centres at an estimated cost of €6 million in 2021, in order to maintain day services at two-thirds capacity of the pre-COVID-19 rate.

Based on an assessment of existing facilities, new purpose built facilities are also required in order to reinstate full pre-COVID-19 service levels, at a cost of €14 million over three years with an initial investment of €4m in 2021 and a further €5m in 2022 and again in 2023. This costing assumes the provision of state land for construction. This investment would enable the creation of a new model to meet community demand as need and numbers increase and would provide a wider service to people affected by dementia.

2. **Invest €6m in Dementia Home Care Supports:** There is an acute need for home care support services to be sufficiently funded to allow for an individual needs-led approach. Long-term residential care is not only expensive, it is often inappropriate for people with dementia. This investment in dementia-specific home care will meet the often complex and individualised care and support needs of people with dementia.
3. **Invest €589k in Dementia Adviser (DA) Service:** DAs play a pivotal role in efficient dementia care in the community by sign-posting families to relevant services and supports available. Their role is to work with individuals and their families, giving information and support in a timely manner, directing people to appropriate agencies and supporting them throughout their journey.
4. **Invest €2.31m in Dementia Key Workers (DKWs):** The DKW role is of paramount importance to coordinating the care of each person with dementia and promoting a collaborative management plan for individual dementia care.
5. **Invest €768k in Dementia Inclusive Communities (DIC) Coordinators:** Communities are key to ensuring that living at home is a feasible option for the person with dementia. The DIC initiative works to ensure that people are aware of and understand dementia, and that people with dementia feel included, having choice and control over their day-to-day lives. This investment would ensure that DIC initiatives can be rolled out nationwide.

⁴ The Irish National Dementia Strategy (2014) The Department of Health, Dublin

1. Invest €10m in Urgent Infrastructure Support

The ASI is calling for emergency investment of €10m in our capital infrastructure to enable delivery of services in centres that are fit for purpose and of a necessary standard in relation to COVID-19 guidelines. The ASI will only be able to provide day care services for just one third of its pre-COVID-19 client base as things currently stand. Investment in both refurbishment and rebuilding is urgently required to enable the ASI, the single largest dementia specific service provider in the country, to bring its day service client base back to pre-COVID-19 levels.

Of the €10m required, €6m will provide the critical refurbishment investment that is needed to reopen some of our existing day centres. The remaining €4m will provide the first phase of investment for building the future of dementia specific day care in Ireland over three years, with a further investment of €5m in Budget 2022 and €5m in Budget 2023.

Prior to COVID-19, The ASI had highlighted that no county in Ireland has a minimum standard of services to meet the needs of both family caregivers and those with dementia. The 2017 mapping exercise⁵ pointed to serious geographical inequity and black spots where there are inadequate or non-existent services. Much of the 2017 mapping exercise is now no longer current as many of these services remain closed and some may never reopen. It will take time to assess the true extent of the growth in dementia service gaps as a result of the challenges presented by COVID-19.

The ASI is seeking investment of €6m in capital infrastructure so that our existing day care services can safely and appropriately operate to meet existing and growing need and demand across communities. Dementia services are now in a more precarious state and even more lacking than prior to COVID-19, compounding the urgency of this investment. People with dementia and their family caregivers are in dire need of immediate services and support, which have largely ceased since the outbreak of COVID-19. However, in their present state many of The ASI day care centres simply cannot reopen, and prompt investment is fundamental to this. For example, investment is needed to ensure that an isolation room, adequate hygiene facilities and space for social distancing can all be provided in our existing centres.

As some buildings where day services operate will simply not be suitable for adaptation and will not reopen, we must reimagine how we deliver dementia specific day care and investment will be needed to make this a reality. Delivering dementia care in a way that upholds personhood and citizenship can potentially be enabled through the creation of Dementia Community Hubs. A phased investment of €14m over three years will enable the development of Dementia Community Hubs which would be a community based space that provides, among other services and supports, dementia specific day care for people living with dementia and their family caregivers. People using the Community Hub will be able to access different health and social care professionals and community and voluntary organisations under one roof. It is envisaged that this Community Hub would give people affected by dementia a pathway and an outlet to a range of relevant services to support them through their journey of dementia, all based in a community setting where needs are identified as being greatest.

This proposed infrastructural investment should be addressed in the context of the renewed HSE capital plan which is planned in 2021 and in future frameworks setting out infrastructural development in Ireland. It is regrettable that there is currently no strategic plan for capital investment for dementia-specific services in Ireland. This should be considered in the longer term vision of the HSE capital plan and in national public capital investment requirements.

⁵ Dementia Specific Services in the Community: Mapping Public and Voluntary Services (2018) The Alzheimer Society of Ireland and the National Dementia Office in the Health Service Executive.

Infrastructural Costings

As we prepare to resume face to face services it is envisaged that only a limited number ASI day care centres will re-open. We estimate that in the immediate term we can provide day care services to only approximately one third of the total number of clients' pre-Covid. Urgent investment of €6m in existing ASI infrastructure refurbishment is needed to meet this immediate need. A further investment of €20m will be needed on a phased basis over the next three years in order to both provide the same level of day care to people with dementia that was being provided pre-Covid, and to be ready for increasing need and demand.

The above figure represents a plausible estimate, and it is possible that some criteria or factors may change or fluctuate, particularly given the uncertain nature of this current environment. The ASI plans to develop an updated scoping and mapping exercise of need and services across the country in 2021, thus replacing the existing but now largely redundant mapping exercise. This updated mapping exercise will support and inform proposed infrastructure investment and development.

Case for Infrastructural Support

- **Role of Day Care**

In February 2020 prior to the COVID-19 pandemic, The ASI completed an independent evaluation of its day care services, examining dementia-specific day care from the perspectives of those directly involved in the service - people with dementia, their family caregivers and staff working in the day care centres.

This study found that dementia-specific day care is a highly valued service by all the stakeholders surveyed. People with dementia attending day care were very positive, welcoming the opportunities for social interaction and participation in enjoyable activities. They reported day care to be a positive experience, spoke appreciatively about staff, and valued having their voices heard and having an input into everyday decision-making in day care.

Family caregivers and other informal caregivers of people with dementia also highly valued the service, including those who currently use dementia-specific day care and those who have used it in the past. These findings are consistent with the results from studies in other countries exploring day care from the perspective of people with dementia (Aggarwal et al., 2003; Brataas et al., 2010; Rokstad et al., 2017) and family caregivers (Gústafsdóttir, 2014; Tretteteig, 2017a; 2017b).

Given the significant role of day care, the current absence of this service needs to be addressed promptly and urgently. Indeed, The ASI's recent research report during COVID-19 shows that those affected by service closures, in particular day care, are adversely impacted by the absence of these important services. Respondents with dementia expressed sadness and regret about the loss of social interaction and engagement with friends, and many family caregivers feel that the absence of routine, cognitive stimulation and activities is leading to a decline in their loved one and leading to an increase in responsive behavior such as agitation, anger, sleep difficulties and overall stress levels among those with dementia and their families.

- **Infrastructural Challenges**

The above day care evaluation also noted infrastructural challenges, even prior to Covid-19, and recognised that infrastructural constraints in many day care centres present important challenges for achieving personalisation and meeting individual needs. Unsuitable buildings also pose a range of challenges for day care staff, and many of the same issues were previously raised by a study of dementia-specific day care conducted over 15 years ago (Cahill et al., 2003).

Day care centres that share their premises with other groups face particular challenges, including lack of flexibility to set up the facilities in an optimal manner for the client group concerned and having to set up *de nouveau* each morning. Having only one room for activities and no quiet space are also noted as important challenges.

Separately and in combination the above infrastructural challenges have made it difficult to provide a range of activity options simultaneous to providing individualised attention to the desired extent. This can be an issue in finding optimal solutions when one or more attendees present with responsive behaviours.

Given the above infrastructural difficulties and the challenges and limitations now imposed by COVID-19, it is not possible to deliver even basic dementia services in many of our day care centres, while individualised and person-centred care would be an impossible task. Prior to COVID-19 many of these facilities were not appropriate and in the current context of COVID-19 and HSE guidelines, attempting to deliver dementia services within the existing infrastructural landscape would be unfeasible and impractical. This situation can only be mitigated by an immediate injection of infrastructural investment leading to a reimagined approach to the delivery of day care services.

- **Growing Service Gap**

There is a growing need for dementia services and the gap between need and actual delivery of services is widening. The 2017 mapping exercise highlighted that no county in Ireland has even a minimum standard of dementia services, and showed a lack of services to meet the overall need. Since the outbreak of COVID-19 and the cessation of services, people affected by dementia have been experiencing dire need and are struggling to cope in deeply challenging circumstances with very limited support at best.

Our recent research report shows that service need is growing not only among ASI clients but also among those who had not previously been in contact with ASI services. The pandemic has had a profound impact and people who had previously been coping well are now struggling and in crisis.

In addition, new prevalence rates indicate that the incidence of dementia in Ireland has risen from 54,000 to 64,000, and approximately 30 people are now diagnosed with dementia every day in Ireland. The combination of these factors suggests that the gap between service delivery and need is widening at a fast pace and dementia care is at a precarious juncture. Emergency infrastructural support must be put in place promptly to address immediate need.

It is also noteworthy that the ASI's pre-COVID-19 day care evaluation found that many of the people with dementia and family caregivers surveyed who had not yet used day care expressed an interest in attending either now or in the future. The study indicated that overall there is considerable unmet demand for day care places, reflected in waiting lists for a place in the first instance and/or requests for more days for people who already have a place. Clearly, this all points to significant growing demand, and The ASI is calling on Government to act swiftly in responding to this need.

As Sláintecare and overall Government plans focus on a shift to community based care and pathways of community care, particularly in light of Covid-19, capital investment is essential to allow us to provide safe, vital services for people living with dementia to support them to remain at home in their communities.

Total Cost of Urgent Infrastructure Supports: €10m

2. Invest €6m in Dementia Home Care Supports

State policy is that older and infirm people should be catered for in the comfort and security of their own homes. The majority of people with dementia want to live at home, in a familiar environment linked to their communities. The risks and challenges posed by COVID-19 strengthens the case for appropriate home care that can sustain people in the community and offer vital support for family caregivers, who provide the vast majority of home-based care for people with dementia.

During the COVID-19 pandemic, home was deemed the safest place for older people, and The ASI's recent research report indicates that people with dementia and family caregivers are in need of increased dementia specific home care as a result of the COVID-19 restrictions. The ASI is calling for investment of €6m in dementia specific home care supports. Home care that is dementia appropriate and offered by home care workers with adequate dementia training is crucially needed to meet growing demand.

As we learn to live with COVID-19 it is crucial that people with dementia can be prevented from entering the acute system and admission to long-term care is delayed through the availability of community care, which should be viewed as an integral part of the health system in itself. The protracted pace of investment and implementation of dementia specific home care is of serious concern.

As COVID-19 leads to an increased demand for home care and as the number of people with dementia increases, there is an urgent need for substantial investment in home care services to keep pace with demand. Implementing agreed NDS guidelines regarding home care and community support and enactment of the Statutory Home Care Scheme will significantly address this need. The Sláintecare Implementation Strategy sets out plans to introduce the statutory scheme for home care to support people to live in their own homes by 2021.

Economic Rationale

Government policy, as set out in the NDS, is to support people with dementia to stay at home. However, evidence suggests that Government spending on nursing home care has increased significantly while home help and home care support has not kept pace with demand. The following shows spending on nursing home allocation compared to spending on home care since the development of the NDS:

	Nursing Homes Allocation	Home Care Allocation
2014	€863.9m	€315m
2015	€873.9m	€320m
2016	€940.0m	€324m
2017	€940.0m	€376m
2018	€962.2m	€408m
2019	€999.0m	€446m

Spending on the Nursing Home Support Scheme to support 23,000 people in 2019 amounted to €999m compared to €446m allocated for home care to support 53,000 people. Home care should be viewed as an integral part of the health system in itself and not just a response to the hospital and delayed discharge crisis.

Intensive Home Care Packages (IHCPs)

The NDS included funding of €22.1m for the delivery of IHCPs for people with dementia. These packages have been linked to delayed discharge, and offer a flexible and person-centred approach to support people in their own homes and to remain at home for longer, reducing the need for admission into long-stay residential care. However, NDS funding for the delivery of IHCPs has now come to an end. An evaluation of this programme has shown that it is feasible to support people with a high level of complex needs at home, including people with dementia.

The delivery of IHCPs was effective at maintaining people with dementia at home. IHCP recipients with dementia were less likely to be admitted to long-term care and less likely to have died than similar recipients without dementia. The evaluation indicates that the quality of life of the person with dementia did not deteriorate significantly for the majority of the sample which is important considering the progressive nature of dementia.

The economic merit of investment in IHCPs should be noted: the average weekly cost of a nursing home bed is c.€1,149 and c. €5,992 for a bed in an acute hospital. In contrast, the average cost of an IHCP for a person with dementia is c. €925 per week with an average of 39 carer work hours⁶. Investing in IHCPs is more economically favourable and represents value for money, and this is borne out in international studies whereby home care is viewed as a potentially cost-effective way of addressing the growing demand for care⁷.

Indeed, the HSE's aim of introducing IHCPs for people with dementia was to facilitate timely discharge home from acute hospitals and to prevent unnecessary hospital admission. Dementia is common among older people admitted to acute hospitals; about 29% of older people admitted to public hospitals in Ireland have dementia⁸. People with dementia typically have longer length of stay in acute hospitals⁹. A comprehensive and well-resourced system of community support services, including home care, is necessary to support people with dementia to remain living at home for as long as possible. It also facilitates timely discharge home from acute hospital admission¹⁰.

Statutory Home Care Scheme

The ASI has called for increased investment in home care and community based supports for many years in its Pre Budget Submission. A Statutory Home Care Scheme should be enshrined in law to meet the highly individualised and complex needs of people with dementia, needs that have grown and become more acute during COVID-19.

The ASI has contributed to public consultations on the Statutory Home Care Scheme and has set out the range of issues important to the development of a home care system in Ireland for people with dementia. The ASI has

⁶Keogh, F., Pierce, M., Neylon, K., Fleming, P. (2018) Intensive home care packages for people with dementia: a realist evaluation protocol (2018) BMC Health Services Research.

⁷ Genet N, Boerma WGW, Kringos DS, Bouman A, Francke AL, Fagerström C, Melchiorre MG, Greco C, Devillé W. Home care in Europe: a systematic literature review. BMC Health Serv Res. 2011;11(1):207.

⁸ Timmons, S, Manning, E., Barrett., A, Brady, N., Browne., V., O'Shea, E., Molloy DW., (2015) Dementia in older people admitted to hospital: a regional multi-hospital observational study of prevalence, associations and case recognition. Age and Ageing. 2015;44(6):993–999.

⁹ Ibid

¹⁰ WHO (2012) Dementia: a public health priority. Geneva: World Health Organization and Alzheimer Disease International.

also contributed to home care discussions through its membership of the Home Care Coalition. We are deeply concerned about delays encountered in the development of this scheme, more recently as result of COVID-19.

The current Programme for Government states a commitment to introducing a Statutory Home Care Scheme. The Department of Health must prioritise this and every effort should be made to progress its development without delay. The Government must activate a home care pilot programme as soon as possible and establish a steering group for this scheme. COVID-19 and the resulting disruption in dementia services have had dire consequences for people with dementia and family caregivers. Implementing the Statutory Home Care Scheme is paramount to alleviating carer stress and supporting people with dementia to live safely in their own homes for longer.

Family Caregiver Health and Wellbeing

Caring in Ireland is associated with poor health outcomes for the family caregiver¹¹. Even before COVID-19 family caregivers of people with dementia were struggling with stress, burnout, health challenges and experiencing immense difficulties accessing appropriate dementia services. The prevalence of clinical depression for family caregivers of persons with dementia is noted to be three times the Irish national average.

The ASI's recent research report highlights the impact of life in lockdown for family caregivers, which has taken an enormous toll on people's lives resulting in increased workloads, constant anxiety and exhaustion,

- 86% of family caregivers are concerned about a decline in their loved one;
- 77% feel their caring workload has increased since COVID-19, and feel unable to reach out to family members at this time;
- 61% of family caregivers are concerned about a decline in their own mental health.

Our current health and social care system depends largely on family caregivers who provide the main bulk of care; its estimated value to the State is in the region of €807 million per annum. A major increase in the levels of support and adequate and appropriate home care is essential in supporting family caregivers.

Total Cost of Dementia Home Care Supports Investment: €6m

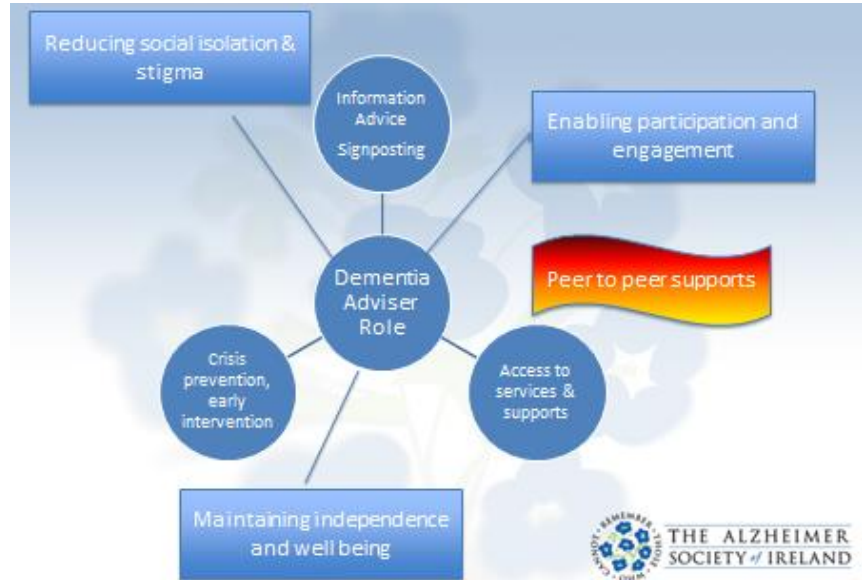
¹¹ Brennan, S., Lawlor, B., Pertl, M.M., O'Sullivan, M., Begley, E. and O'Connell, C., 2017. De-Stress: A study to assess health and well-being of spousal carers of people living with dementia in Ireland. Dublin, Ireland: Alzheimer Society of Ireland.

3. Invest €589k in Dementia Adviser Services in 2021:

The role of Dementia Advisers (DA) is to provide locally based, individualised information and signposting, and emotional support to people who are concerned about their cognitive health and/or have a diagnosis of dementia and for their families and friends, at all stages of their journey, from diagnosis through to end-of-life.

Their purpose is to:

- Provide information, advice and support to understand the condition, manage symptoms, support activity and maintain and encourage participation in their community,
- Signpost/connect people to appropriate services and supports to assist their independence and well-being and to maximise their quality of life, and
- Provide early intervention and prevent crises.



During COVID-19 DAs played a crucial role in supporting family caregivers and people with dementia as they cocooned and maintained social distancing. DAs who took part in the ASI's research report highlighted the challenges of their workload as they provided vital support mainly through telephone as their 1:1 service was restricted. For many family caregivers experiencing immense stress and crisis, DAs were their only source of support. The DAs also described, in detail, the harrowing circumstances of many family caregivers.

As the need for dementia services grows it is imperative that the DA service is expanded on a nationwide basis. In Budget 2020, an additional 10 DAs were announced at a cost of €722k. The ASI welcomes this development and is keen to fully support the implementation of this plan. In line with the phased approach, it is expected that in Budget 2021 a further 8 DAs will be funded at an extra cost of €589k. This will bring the total number of DAs, currently at 9 to 19 DAs by the end of 2020 and 27 DAs by the end of 2021.

The Department of Health has confirmed that funding for the current 9 DAs is secure and will continue and also that the additional 10 DAs will be delivered in 2020, and therefore we are seeking investment for a further eight DAs. This investment is vital to ensuring that the DA service will be available throughout the country, and it is expected that the roll-out of DA services will lead to an increase in demand for services as DAs refer and signpost people affected by dementia to various supports.

Meeting the information and advice needs of people with dementia and family caregivers is an identified priority area in both the NDS and the National Caregivers' Strategy¹². The NDS states that *"availability of relevant information and guidance can greatly assist those who have dementia and those who care for them"* and sets a clear objective in *Section 5 Timely Diagnosis and Intervention* that following diagnosis, people with dementia and their family caregivers know where to seek help or support, who to talk to about accessing services or entitlements and where to go for information. The National Caregivers' Strategy sets a national goal

¹² Department of Health (2012) The National Caregivers' Strategy, Dublin.

to promote the availability of user friendly and timely information and advice (National Goal 3: Objective 3.1). The development and expansion of the ASI's DA service will achieve priority objectives in both strategies. Importantly, the Government has made a commitment in the current Programme for Government to enhance dementia care, implement the NDS and increase the number of DAs.

Impact of Dementia Advisers

The ASI's recent research report of the impact of COVID-19 highlights the vital role played by DAs during the restrictions, and many family carers reported that they trusted the advice of the DAs and described them as a "lifeline" during the restrictions. The ASI's DA service has been independently evaluated, commissioned by the NDO¹³. Interviews and focus groups with DAs in this evaluation highlighted a multi-faceted role that has grown organically from an information and advice service to include advocacy, incorporating a wide variety of person-centred tasks to meet the growing needs of clients. The evaluation, which included surveys with people living with dementia and family caregivers, provides evidence of overall satisfaction with the DAs:

- Respondents reported satisfaction particularly with the information, advice, support and signposting of services provided.
- The majority of people with dementia reported that the service helped them by providing support and understanding about dementia and confidence to ask questions.
- Results show positive influences of the DAs on people with dementia and their family caregivers, and that they valued the support and information provided.
- The most helpful aspects of the DAs as reported by family caregivers were assistance with signposting to formal health and social care services, help with understanding dementia, help with legal and care planning, and information about informal social supports available e.g. carer support groups and Alzheimer cafés.

In the survey of Health and Social Care Professionals (HSCP), the main reasons for contacting the DA service were: to help connect people with dementia, to learn about local supports and services, to provide information for families living with dementia especially post diagnosis, to support family caregivers. All stakeholders (people with dementia, family caregivers, HSCPs and DAs themselves) agreed that the advice and information support interventions of the service are most appropriate and achieve better outcomes for the people with dementia if accessed early in the dementia diagnosis. It is recommended that HSCPs and the public are encouraged to access the DA service as soon as possible following diagnosis in order to receive optimum benefit from the service and to have a local point of contact from the outset for further advice, signposting to other services and peer support as dementia progresses. The evaluation provides evidence of a need for an expansion of the DA service. All stakeholders recommended an increase in the number of DAs to meet the increasing demand, as a result of the increasing prevalence of dementia.

Total Cost of Dementia Adviser Investment for 2021: €589k

¹³ Coffey, A., Cornally, N., Hegarty, J., O'Caomh, R., O'Reilly, P., O'Loughlin, C., Drennan, J., Clarke, C., Hartigan, I (2018). Evaluation of The Alzheimer Society of Ireland Dementia Adviser Service. University College Cork.

4. Invest €2.31m in Dementia Key Workers:

The NDS outlines a priority action within primary care services of a key role in coordinating the care of each person with dementia and promoting their continuity of care. This role of a Dementia Key Worker (DKW) would help to coordinate individual care plans and assist people to navigate complex care pathways. It would be critical in supporting and facilitating an integrated approach to dementia care. The role of DKWs differs from that of DAs in that the former monitors and coordinates individual cases/caseload through the health and social care system, whereas the DA is concerned with signposting and advisory services.

While a need for the DKW role has been identified in the NDS, this role has yet to be implemented and funded. A DKW Working Group was convened in November 2017 to define the role of the DKW, identify where the key worker should sit within the existing system and determine the main duties and responsibilities of the role.

The implementation of the DKW within the health and social care system has resource implications which need to be considered at a systems level. The ASI is calling on the Government to immediately invest in funding this role. Government policy, as set out in *Sláintecare*, is concerned with reorienting the health service on a phased basis towards integrated primary and community care, and the role of the DKW should be an integral element of the dementia care landscape and support people to live well in their communities. Given the recent challenges posed by COVID-19, implementing this role has become particularly urgent.

Case Management and Need

In the ASI recent COVID-19 research report, DAs stressed that people with dementia and their family caregivers need a single contact person or key worker to help coordinate their care, provide ongoing support and help them access the services and supports they need. This is particularly pertinent in the current COVID-19 environment as family caregivers struggle to manage the care needs of their loved ones, as medical appointments have been postponed or rescheduled, and they observe a notable decline in the health and wellbeing of the person.

Dementia may impair the person's ability to seek assistance/care in the face of changes with respect to other chronic conditions and their condition overall. As dementia may impair an individual's ability to manage other chronic conditions, self-management and following treatment plans becomes very challenging. For example, the person with dementia and diabetes can have problems understanding their condition, managing medication and monitoring their blood glucose (Bunn et al., 2014).

The person with dementia who has other comorbid conditions will often have complex medication regimes that need to be managed. Managing comorbid chronic conditions in people with dementia is particularly challenging because of disease progression, since as the disease progresses, the ability to self-care reduces and the role of family caregivers increases. This is all the more reason why people living with dementia and their family caregivers need regular reviews and case management for managing comorbidity to optimise physical and mental health and wellbeing. The need for comorbidity to be managed in a holistic manner, accounting for the preferences of people with dementia and their family caregivers has also been highlighted (Prince et al., 2016).

Additionally, an expert policy paper commissioned by the ASI, 'An Economic Analysis of Home Care Services for People with Dementia' (2015) indicates that the dynamics of home care services can be commonly poorly coordinated. The variety of potential providers contributing to dementia care, compounded by continuously changing demands and variations in competencies of formal caregivers increases the likelihood of inefficient arrangements of care.

The above report identified *case coordination, management and collaborative care* as important factors to improve overall societal welfare. Good dementia care involves multi-disciplinary working and case management (Trépel, 2015¹⁴), requiring designated personnel at different levels in the health and social care system and effective inter-agency and interdisciplinary communication. Collaborative care monitors and co-ordinates the range of care providers involved in dementia care (e.g. family caregivers, public, private and voluntary care providers).

Furthermore, case management also reduces inefficient use of other community services (Zabalegui et al, 2014)¹⁵. It provides for a collaborative management plan while systematically scheduling health and social care follow-ups and enhancing communication and supervision. Research by Reilly et al., (2015¹⁶) suggests that case management reduces likelihood of institutionalisation by 18% at 6-month follow-up. The research also interestingly finds evidence to suggest that case management may have a significant effect on improving symptoms of depression in family caregivers.

DKWs could play a significant role in facilitating the wish of many people with dementia, and stated Government policy, to stay in their own homes and communities for as long as possible. To enable appropriate reach the DKW role should cover each Community Health Organisation area at an annual cost of €2.31m. The ASI believes it is of paramount importance that the DKW role is implemented, as set out in the NDS and also in line with Government policy on community based care.

Total Cost of DKW Investment: €2.31m

One full-time DKW salary is **€70,000** per annum, including associated costs, and this investment should cover 33 posts, rolled out across all counties. There will be one DKW per county, aside from Dublin which will have five DKWs and Cork which will have four DKWs. This will help ensure that immediate and pressing needs of people with dementia and family caregivers are met. The cost of €70,000 per DKW includes the following:

- Salary and employer costs
- Mileage and expenses as service requires extensive travel throughout the county
- Laptop, mobile phone and associated office costs
- The above cost reflects the likelihood that DKWs would have a nursing background, work within the HSE system and collaborate closely with primary care teams.

¹⁴ Trépel, D. (2015) An Economic Analysis of Home Care Services for People with Dementia. Report independently prepared for Alzheimer Society of Ireland

¹⁵ Zabalegui et al (2014) Best Practice Interventions to Improve Quality Care of People with Dementia Living at Home. *Patient Education and Counselling* 95: 175-184.

¹⁶ Reilly, S. et al., 2015. Case management approaches to home support for people with dementia. *The Cochrane database of systematic reviews*, 1, p.CD008345. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/25560977> [Accessed February 27, 2015]

5. Invest €768k in Dementia Inclusive Community Coordinators:

The campaign *Dementia: Understand Together* aims to develop communities that are dementia inclusive and create awareness of dementia and associated risk factors. It is being led by the NDO and the ASI and has over 30 partner organisations, including retail, transport, banking, health and the voluntary and community sector. The campaign encourages individuals, businesses and organisations to sign up to support the campaign, and lead the way in creating communities that actively embrace and include those living with dementia and their families.

Its key messages have been promoted across media outlets, including TV and radio. A National Coordinator for *Dementia: Understand Together* in Communities is developing this project. However, funding for this post, secured from dormant accounts, is not guaranteed to continue, and it is important the progress that has been achieved is sustained and continued.

Dementia Inclusive Community (DIC) Coordinators are required to develop this work, as reflected in the EU's Joint Action on Dementia¹⁷: *"The development of Dementia Friendly Communities needs a group of committed people who will persist in speaking and meeting with organisations, businesses and community groups to raise people's awareness about dementia. ... if the impact ...is to be maximised and sustained, funding is needed to fund coordinator roles. These initiatives will tend to have clearer outcomes and demonstrate the most value for money"*.

Coordinators are required to develop DICs to ensure social understanding and supports enable people with dementia to live well and compliment any existing health and social service provision. Continuing to develop events with community champions and partners in this current environment is essential in order to improve care across communities and to continue to address the stigma and fear that often surrounds dementia. For the continued roll-out of this work, and to ensure its longevity and sustainability during COVID-19, investing in DIC Coordinators is critical.

To-date, investment in DICs through the Coordinator role has created over 340 community champions who are at the heart of this campaign. These community champions heighten awareness of dementia through information meetings and community talks, and have inspired other community members to get involved.

Currently, over 40 organisations are partnering with the campaign, taking a variety of actions to raise awareness, be inclusive and supporting people with dementia. During COVID-19 as vital services ceased, community champions played a key role in responding to the needs within their communities. Many have been willing to volunteer their time to raise awareness and understanding.

Even during COVID-19 they have created new initiatives to respond to the cessation of services and enhance existing activities and services to meet needs in their communities. As challenges continue, the DIC Coordinator role should be an integral part of the overall community response to COVID-19. Investment by Government is imperative so the *Dementia: Understand Together* in Communities campaign can be further developed and expanded on a nationwide basis.

Addressing Need

The DICs project has increased the capacity of communities across Ireland to support people with dementia, and as a result, many have remained involved and included in their communities for longer. Key stakeholders in

¹⁷ Evidence Review of Dementia Friendly Communities – European Union Joint Action on Dementia (2017), Imogen Blood and Associates in partnership with Innovations in Dementia.

the community are more dementia-aware and better able to respond to the needs of people with dementia and their families. There is considerable potential for DICs to be strategically incorporated within the health care system as part of an integrated and multi-disciplinary response by community services to support people with dementia and their family caregivers. This would be a cost effective way of delivering impactful care. DICs should be more closely allied with community care and play a role in supporting a 'whole community' approach which mobilises support and understanding for dementia care.

A 2019 report, 'Loneliness and Dementia'¹⁸, produced by The ASI, recommends that people living with dementia should be enabled to continue to engage in meaningful social activities they enjoyed doing before their dementia diagnosis, should they wish to do so. The report highlights engaging in meaningful activities and social connections as key to combating social isolation and loneliness.

For the roll-out of DICs, and to ensure its longevity and sustainability, resources are critical. Prior to COVID-19 The ASI was concerned about the low number of dementia inclusive activities, as identified in the 2018 mapping project. This mapping exercise highlighted the patchy and inequitable availability of DIC resources and the need for substantive investment to meet the needs of people with dementia in all counties. The harrowing impact of COVID-19 on those affected by dementia and the increase in dementia prevalence rates have together compounded the need for additional resources and supports that are appropriate and effective in meeting the growing needs of people at this time. ASI believes it is crucial that DIC activities, as a vital aspect of dementia care, are rolled out in 26 counties across Ireland, as is recommended in the NDS, and in a manner that is safe and consistent with HSE guidelines.

Total Cost of Investment in Dementia Inclusive Community Coordinators: €768k

The ASI is calling for an investment of €1 million to ensure the continued roll-out of the *Dementia: Understand Together* in Communities work on a nationwide basis, enabling equitable access for all people with dementia. This investment will fund and resource nine coordinators and the associated costs. One full-time coordinator cost is €70,000 per annum including costs, and four coordinators are required (**€280k each**). Additional costs include:

- DIC development and actions, including providing financial incentives and awards to local communities to establish and develop DIC initiatives in local areas (**€468k**)
- Travel expenses **€8k**
- Training for national and local businesses and community champions (**€12k**)

¹⁸ Hartigan, I., Park, G., Timmons, S., Foley, T., Jennings, A., Cornally, N., Muller, N., (2019) Loneliness and Dementia. Produced by The Alzheimer Society of Ireland.

Conclusion

Total €19.667m
1. Invest €10m in Infrastructure Development
2. Invest €6m in Home Care Supports
3. Invest €589k in Dementia Adviser Service
4. Invest €2.31m in Dementia Key Workers
5. Invest €768k in Dementia Inclusive Community Coordinators

Even before COVID-19 thousands of people living with dementia were experiencing immense difficulties accessing appropriate dementia services, while their family caregivers were struggling with stress, burnout and health challenges. Furthermore, the 2018 mapping report illustrated the acute gaps in service provision and the inequitable distribution of dementia services across the country. For people living with dementia and their family caregivers, the COVID-19 pandemic has compounded what were already difficult and precarious circumstances and pushed many families further into crisis.

Dementia and those impacted by the disease have been rendered invisible throughout the COVID-19 pandemic. Dementia has not been included specifically in data collection relating to COVID-19 mortality or public messaging. The lack of emphasis placed on the complex needs of those living with dementia, whether in the community or in residential settings, must now be addressed. Dementia as a disease should be considered not just by association or implication as it is a serious disease in its own right.

The ASI shares the vision of the National Dementia Office that *“people with dementia and their family carers receive the supports and services they need to fulfil their potential and maintain their identity, resilience and dignity as valued and active citizens in society.”* Investing in the recommended supports will enable people living with dementia to *“maintain their identity, resilience and dignity”*. Importantly, it will also serve to acknowledge that they and their caregivers have not been forgotten or rendered invisible but *“remain valued, independent citizens who, along with their caregivers, have the right to be fully included as active citizens in society”* (Alzheimer Society, UK, 2011)¹⁹.

The current Programme for Government has a stated commitment to implementing the National Dementia Strategy and enacting the Statutory Home Care Scheme, both need to be prioritised as a matter of urgency. The ASI is seeking an investment of €19.667m in capital infrastructure to support the appropriate re-opening of day care and other important services and national development of dementia services including DAs, DKWs and DICs, which must be given precedence.

For the time that COVID-19 strict lockdown restrictions were in place, society experienced what people with dementia and their family caregivers had already been experiencing on a daily basis; isolation, fear, anxiety, physical and social distancing for many including often from family and friends. The harrowing impact of the pandemic in nursing homes further highlights the vulnerability of this cohort, and also reminds us of the importance of supporting people living with dementia to remain in their own homes.

¹⁹ Alzheimer’s Society (2011) Support, Stay, Save Report. UK: Alzheimer’s Society.

The voice of a family caregiver in The ASI's recent research report demonstrates that it is incumbent upon Government to act promptly to address the urgent needs arising from the COVID-19 pandemic and the growing prevalence of dementia so that key services are restored and developed in a coherent and consistent way across the country for all people with dementia and their family caregivers.

"In the earlier days of lockdown, I was very depressed. It struck me very forcibly just how isolated my life had become...I suppose I never allowed myself to think about how small my world is. Of course I'm happy that Covid is coming to an end, but a small part of me resents the fact that the majority of people will go back to what they call 'normal' and we (carers) will stay as we are, in a never ending lockdown" (Family Caregiver, 2020).