

Stakeholder submission – Covid 19 Evaluation

Name of Organisation: The Alzheimer Society of Ireland

Name of person completing the form on behalf of organisation: Dr Diane O'Doherty

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Which sector(s) does the work of your organisation primarily represent?

- Health & Care (including mental health)
 - Education
 - Human Rights
 - Justice
 - Social
 - Economics (Business & Workers)
 - Civil Rights/Democracy
 - Nature and Environment
 - Other: Please specify
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Which societal group(s) does your organisation primarily represent?

- Carers or Patients
 - Older People
 - People with Disabilities
 - Rural/Regional/Local Communities
 - Gender
 - LGBTI+
 - Frontline workers
 - Youth
 - Other Vulnerable Groups
 - Faith
 - Ethnic Groups
 - Not Applicable
 - Other: Please specify
-

Which business sector(s) does your organisation represent?

- Retail
 - Industry
 - Agriculture
 - Construction
 - Tourism including accommodation, pubs and restaurants
 - Distribution and Transport
 - Arts and Entertainment
 - Not Applicable
 - Other: Please specify – Charity Sector
-

Which of the following were the most important areas of concern or focus for your organisation during the pandemic? Choose up to 3 options.

- Relationships, Social Connection and Community
 - Physical Health
 - Digital Engagement
 - Work and time use
 - Civil liberties, human rights and trust
 - Mental Health & Well being
 - Housing and local environment
 - Education and development
 - Financial / job security
 - Important life milestones (e.g. deaths, births)
 - Other: Please specify
-

Please provide a brief summary of your organisation's submission on the impacts of the management of the pandemic. (1250 characters / 250 words)

(It would also be helpful to highlight if your organisation was involved in direct stakeholder engagement as part of the Government's response or if your organisation assisted Government in the delivery of mitigating supports, outreach or initiatives.)

Following the confirmation of COVID-19 cases in Ireland in late February 2020, the subsequent months were periods of transformation in terms of supports and services. The Alzheimer Society of Ireland could provide nationally to people living with dementia and family carers. Social supports were closed, swiftly followed by ceasing of fundraising community activities and closure of day services and respite services. Following request from HSE to Section 39 Agencies in March 2020, ASI responded immediately, and provided a

list of staff to the HSE who could be potentially available for external redeployment. Many worked as part of the HSE support to nursing homes who were dealing with significant crises. Whilst many of our core services such as homecare continued to be delivered to ensure families affected by dementia were not abandoned, others pivoted to an online format. We also saw the development of new services such as our Day Care at Home service, online support groups and expansion of our national helpline. Internal research was undertaken to assess the impact of the pandemic on people living with dementia and family carers to understand the devastating reality of caring and coping during this time, which in turn served as an evidence base for the development of new services.

Today, society at large has become more aware of the most vulnerable and the plight of older people is receiving long overdue attention. Further detail on such is detailed in our full submission.

Full Submission: Please attach your full submission below.

Context

The COVID-19 pandemic impacted and affected every aspect of Irish society. It posed a significant risk for people living with dementia and their carers. For people living with dementia and their carers, the COVID-19 pandemic compounded what were already difficult and precarious circumstances and pushed many carers into further difficulty and crisis.

The ASI's response to the COVID-19 pandemic

Timeline

February/March 2020

- Closure of 28 social clubs, 7 Alzheimer Cafes, 23 Support Groups, 48 Day Care Centres and 2 respite services
- Cease of all fundraising events based in communities with immediate effect
- 48 ASI staff redeployed to the HSE in the first phase of the pandemic to support nursing homes
- Online support groups for family carers developed March-May 2020

April 2020

- 1st ASI research report published identifying challenges and experiences of those affected by dementia
- Dementia Nurse / Dementia Adviser call-back service launched
- Day Care at Home service piloted and rolled out

May 2020

- Alternative Supports Therapy: Social Calls and Activity Packs launched
- Piloting of Virtual Alzheimer Cafés

June 2020

- National rollout of Virtual Alzheimer Cafés
- Online support groups for family carers launched

July 2020

- 2nd ASI research report published identifying challenges and experiences of those affected by dementia

December 2020

- ASI Virtual and Telephone Service Evaluation published

March 2021

- ASI internal Day Care at Home Evaluation complete

June 2021

- 3rd and final ASI research report identifying challenges and experiences of those affected by dementia published

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Ireland had its first case of COVID-19 confirmed on the 29th of February 2020. As the virus took hold in March, The ASI had to firstly close our social support services including 28 social clubs, 7 Alzheimer Cafes and 23 Support Groups, followed rapidly by all 48 day centres and 2 respite services. The ASI also had to cease all community-based fundraising events with immediate effect. Following request from HSE to Section 39 Agencies in March 2020, ASI responded immediately, and provided a list of staff to the HSE who could be potentially available for external redeployment. In the first phase of the pandemic, 48 of our staff redeployed to the HSE, many of whom worked as part of the HSE support to nursing homes who were dealing with significant crisis.

Many staff continued their invaluable work in homecare, despite the restrictions to ensure that families affected by dementia were not abandoned and to ensure continuity of care. Our homecare teams delivered over 129,590 hours of care during 2020, maintaining this vital service without interruption. The reality of 'cocooning' often meant our teams were one of the very few people able to connect with service users at home. The challenges, fears and concerns were significant, and all demonstrated professionalism, resourcefulness and commitment to ensure ongoing safe service delivery.

During this time The ASI continued to support people with dementia and their families as through a hybrid approach of Homecare, Dementia Advisers, our National Helpline and Online Family Carer Training. Regular check-in calls also took place between Day Centre staff and clients nationwide, providing a lifeline to people living with dementia and their families.

In April 2020, following the immediate aftermath of cessation of in-person dementia services, The ASI carried out the first of three research studies to identify challenges and experiences, collate suggestions from people living with dementia, family carers and ASI

staff on how ASI could continue supporting in lieu of suspended services and to communicate the above in an accessible way. Challenges included a) loneliness and social isolation, b) lack of routine leading to deterioration of symptoms of dementia and responsive behaviours, c) fear and anxiety, and d) carer stress and fear of being unable to cope, feeling isolated and helpless. During this time, family carers cocooned and isolated themselves with their loved ones to protect them, which added to an ever-increasing workload without the normal support services and increased challenges in managing dementia symptoms. When asked if the services they normally received had been impacted by COVID-19; 47% of respondents noted cessation of day care services, 42% of support groups and activities for both the carer and person with dementia and 26% experienced closure of respite services. One spousal carer spoke about the impact on their partner and the cessation of services:

“Because day care is closed she gets very little stimulation and exercise. Has slowed down considerably”.

Findings from this initial research were instrumental in informing The ASI’s response to the temporary closure of in-person services and in re-designing a new suite of services to address need during COVID-19, detailed further below.

These new services were developed with the input of people living with dementia, family carers, ASI staff and other stakeholders.

- ***Expansion of National Helpline***

In 2020, The ASI national helpline celebrated its 20th anniversary. With the emergence of the COVID-19 pandemic, the helpline experienced increased calls from people living with dementia and family carers who felt increasingly isolated in their own communities. From January to March alone, 1,496 service users contacted the helpline.

Issues highlighted during these calls include difficulties adapting to new routines and to new challenges connected to sleep disruption, increased confusion, frustration and lack of motivation and concerns about personal care and continence management to name but a few.

The Helpline staff and volunteers moved the service to a fully remote operation, in line with public health advice. The Dementia Adviser team provided additional support to help respond to the call volumes. In light of decreased availability of community supports and key health and social care professionals such as public health nursing and dementia nurse specialists (due to redeployment), the Helpline expanded to offer a free 1:1 call back service with a Dementia Nurse or Dementia Adviser.

- ***Dementia Nurse / Dementia Adviser call-back service***

In April 2020, The ASI's National Helpline expanded which offered people with dementia and family carers from anywhere in Ireland the opportunity to book a 1:1 session with a Dementia Nurse or a Dementia Adviser. This new service was launched by then Minister for Health Simon Harris to deal with increased need during the pandemic.

This service offered 1:1 telephone or video conference call with a Dementia Nurse or a Dementia Adviser. This created a space for people with dementia and their families to raise issues that may be arising for them during the cocooning phase of the pandemic. This was particularly important as people were often unable to link with their normal health and social care professionals due to redeployment or leave. The issues raised with this service included progression of their dementia, changes in behaviour including anxiety, not sleeping, paranoia, aggression and hallucinations, how to keep active and engaged, and how to access services that may be available, like day care at home.

- ***Alternative Activity Therapy for people living with dementia and their family carers (Social Calls and Activity Engagement Calls with Activity Packs)***

This was a service for people living with dementia and their family carers who availed of day care prior to COVID-19 which was launched in May 2020. The ASI provided social calls and Activity Engagement Calls (with Activity packs) on a weekly or bi-weekly basis. This service sought to address needs and mitigate issues arising from the temporary closure of day care, recognising that a lack of activity opportunities can result in responsive behaviours (actions, words, or gestures that a person with dementia uses to communicate unmet needs or to react to their environment), boredom, loneliness, and the need for mental and social stimulation while reducing carer stress.

The aim of the service is to engage with the client and family carer either through a social engagement call and /or a variety of activities disseminated, which are stimulating and varied to maintain well-being. The activity packs contain a variety of recreational materials including crosswords, quizzes, colouring exercises and musical CDs that family carers can use with the person with dementia.

As of December 2020, 2,313 Activity Packs were distributed, 16,407 calls made and 2,593 hours spent making phone calls. 86% of respondents to an evaluation of this service noted they would like to see activity packs continuing in the future. 90% of respondents wanted to see social calls continuing in the future.

- ***New Day Care at Home service***

Day Care at Home was set up to provide an interim alternative model of care and support to people who use ASI services and families to address the absence of the Day Care Centres. Its aim was to provide continuity of care and support to as many ASI clients and families as possible during the Covid-19 crisis. This service was initially piloted in April 2020 in Dundalk and Monaghan and subsequently rolled out to other areas.

In March 2021, The ASI undertook an evaluation of our Day Care at Home service which sought to assess and understand the impact of this service for people who use ASI services and staff. This evaluation highlighted that it makes family care in the community more sustainable by improving outcomes, including avoiding or delaying care home admission.

It is a unique service, offering much-needed relief and flexibility for family carers and provides opportunities for people with dementia to engage in positive social interactions and meaningful activities in their homes. Day Care at Home improves wellbeing and improves the everyday lived experience of people with dementia and their families. It also enhances the continuity of care for individuals who are unable or unwilling to attend day centres, ensuring they receive personalised, impactful support throughout their dementia journey.

ASI continues to advocate for funding of this service through our Pre-Budget Submission to Government to date (2026).

- ***Online Support Group for Family Carers to provide support and information to family carers***

In March to May 2020 to cater for the sense of helplessness and lack of in person contact, The ASI created online support groups that launched on June 1st 2020. These online support groups are a dedicated space for family carers to find information and resources, get support and guidance, and to talk and share openly with other family carers. There were approximately five online support groups with between 35 to 45 participants in each group. It was intended to mirror face-to-face support groups that were suspended. An evaluation of this service highlighted many positive factors of getting involved in this training including having an improved understanding towards the person living with dementia, more emotional awareness and insight into their loved one's experience and more patience and compassion. This service has made a tangible impact on how carers communicate, interact and provide care to their loved one. 95% of respondents said they would like to see this service continue in the future. Additionally, the number of online family carer training courses rose from 6 in 2019 to 17 in 2020.

- ***Virtual Alzheimer Cafes***

This service mirrored previous face-to-face Alzheimer Cafes and rolled out across the country in June 2020 following an initial pilot in mid-May. They were hosted weekly via Zoom. Each cafe included a talk from a speaker (e.g. lawyer, dementia adviser) and question and answer session. An evaluation of this service highlighted that it is a valuable service providing information and sense of community to carers. They also provided a welcoming, positive and supportive space for family carers to meet and learn from experts.

- ***Additional Research Undertaken***

In July 2020 and June 2021, two further subsequent reports detailing how those affected by dementia were impacted and highlighted the devastating reality of caring and coping with dementia during COVID-19 were published. This work was undertaken by The ASI's Research & Policy team, with input from departments across the organisation. Findings further reiterated the challenges and stresses felt by both family carers and persons living with dementia and built upon existing evidence base. Again, this included challenges such as lack of routine for people with dementia leading to responsive behaviours and boredom, increased anxiety, stress and fear for both the person with dementia and family carers. Stresses felt by family carers included being housebound, being unable to shop and lack of respite, loneliness and isolation. Our final research report completed in 2021 summarised the greatest challenges felt by carers and people living with dementia during this COVID-19 pandemic, which included:

- Top 3 Greatest Challenges by Carers; 1. Needing a break/respite, 2. Loneliness and social isolation, and 3. Anxiety and stress related to caring workload and attending to competing priorities.
- Top 5 Greatest Challenges by People Living with Dementia; 1. Lack of routine, 2. Struggling with activities of daily living such as taking medication, shopping, cooking etc., 3. Fear of contracting COVID-19, 4. Feeling down and sad, and 5. Loneliness: missing friends, family and the activities they attended before COVID-19.

During this time, family carers also spoke about how the COVID-19 guidelines and requirements such as wearing a mask and social distancing presented challenges, with one person commenting:

"The deterioration in the person I care for continues, his social skills are now non-existent due to Covid restrictions. He did not understand social distancing, mask wearing etc so I had to stop him going out. He was independently shopping etc March 2020 and now cannot leave home on his own."

Additional research completed by O'Leary (2024) highlighted that indeed social isolation was difficult for people living with Alzheimer's Disease and related dementias during the COVID-19 lockdowns.

Our evidence base continued to support the roll out and re-imaging of new and existing ASI supports and services. These reports were widely communicated, including on RTE news, highlighting the hidden challenges experienced by people living with dementia and their families.

- ***Impacts / Insights from The ASI's perspective on the Covid-19 Pandemic***

Following on from the COVID-19 pandemic, society at large has become more aware of the most vulnerable and the plight of older people is receiving long overdue attention. It also offered opportunities to host more online and virtual support to those in remote or rural areas in ways that are creative and innovative. Our Day Care at Home service which was developed during this time as an interim alternative model of care and support continues to flourish, with over 89,212 hours of Day Care at Home provided to people living with dementia in 2024. We continue to advocate for investment in dementia specific day services; there are currently 2,000 families on referral lists for Day Care at Home.

A significant and deeply concerning issue that emerged during the COVID-19 pandemic was the isolation experienced by older people living in residential / nursing home settings. This impacted families across Ireland, including those with a loved one living with dementia. Members of The ASI's Irish Dementia Working Group (IDWG) are deeply committed to ensuring that the lived experiences and voices of those affected by dementia, particularly in nursing home settings, remained central to the discussion. In December 2022, The ASI published a briefing paper on adult safeguarding and people with dementia in nursing homes which was led by Prof Sarah Donnelly with input from IDWG members. Chair of the IDWG at the time, Mr Sean Mackell, wrote the opening foreword, highlighting the plight of those living in nursing homes in Ireland during this time.

The importance of upholding and protecting human rights of the most vulnerable people was explored, with a particular reference to those who passed away while living in nursing homes in the early stages of the pandemic. Those who did survive the pandemic were also seriously impacted as many were denied access to family and friends. This policy paper underscores the fundamental rights of people living with dementia to self-worth and self-esteem, agency, power and control, and affirms the urgent need to support them in leading full and meaningful lives. It also discusses in detail the criticality of adopting a human rights-based approach to care and for all those involved to have suitable training and awareness of such. A final important comment from Mr Mackell and members of the Irish Dementia Working Group:

"The report stresses that 'safeguarding' is everybody's business, I'm proud that that IDWG made it our business".

In reflecting on many of the organisational changes implemented during the COVID-19 pandemic, and the time shortly after, this has offered us the opportunity to learn about how best to structure our business moving forward. In doing so, this has helped us to understand the needs and challenges of people affected by dementia and has improved how we support them to present day.

As an organisation, we have also taken stock as to the impact of the COVID-19 pandemic on our staff. As mentioned, during this time a number of our staff were redeployed to the HSE with many others who continued to provide invaluable front line homecare services at a time of great change and insecurity. Staff also pivoted internally to support the changing needs of the organisation. Their resilience shown to adapt during this time and indeed during the phased re-opening of services, demonstrated great resilience and tenacity in the face of the ever-changing environment at this time. As the in-person services reopened, our staff often navigated the challenges of the Covid-19 health guidance, which were updated on a regular basis. They remained dedicated to their roles in ensuring that some of the most vulnerable people affected by dementia continued to be supported.

Further Reading

- ASI Research Report 1 – Covid19 Impact and Need for People with Dementia and Family Carers. Available: <https://alzheimer.ie/wp-content/uploads/2020/04/FINAL-Research-survey-results-on-need-1st-April-2020.pdf>
- ASI Research Report 2 – Caring and Coping with Dementia During Covid-19. Available: <https://alzheimer.ie/wp-content/uploads/2020/07/ASI-Follow-Up-Covid-Report-Final.pdf>
- ASI Research Report 3 – A Year of Caring and Coping with Dementia during Covid-19. Available: https://alzheimer.ie/wp-content/uploads/2021/06/ASI_Covid_Report.pdf
- ASI Virtual and Telephone Service Evaluation: Evaluating new services during Covid-19. Available: https://alzheimer.ie/wp-content/uploads/2025/06/ASI_Service_Evaluation_Report_.pdf
- ASI Annual Report 2021. Available: <https://alzheimer.ie/wp-content/uploads/2021/07/SIGNED-ASI-Year-End-31.12.2020-FINAL-Fin-Stats-v4-12.05.2021.pdf>
- Donnelly S. Adult Safeguarding & People with Dementia in Nursing Homes. Available: [Adult-Safeguarding-and-People-with-Dementia-in-Nursing-Homes-Final-Report-2.pdf](https://alzheimer.ie/wp-content/uploads/2022/05/ASI-Day-Care-at-Home-Evaluation-2021.pdf)
- Evaluation of Day Care at Home Report. Available: <https://alzheimer.ie/wp-content/uploads/2022/05/ASI-Day-Care-at-Home-Evaluation-2021.pdf>

- O' Leary, C.F. (2024), A Systematic Review on the Experiences of Social Isolation in People Living with Alzheimer's Disease and Related Dementias (ADRD) during the Covid-19 Lockdowns. [Master of Science Dissertation in Dementia Care, Trinity College Dublin]. TCD Dissertations and Theses.