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**Harrowing accounts of life in lockdown reveal crisis for family carers and sharp deterioration of health for people with dementia as vital services remain closed**

New research carried out by The Alzheimer Society of Ireland has found a rise in the cases of immense ***stress***, ***burnout*** and ***anxiety*** with one respondent describing their loved one as: *“Depressed, agitated, angry, anxious and unhappy”* as the result of the impact of the COVID-19 health crisis on their lives due to the withdrawal of vital dementia-specific supports and services.

The second research report produced by The ASI on the issue, ***‘Caring and Coping with Dementia During Covid-19’*** further highlights the ***crisis aftermath*** ***of life in lockdown*** which has taken an enormous toll on people’s lives resulting in carers facing crisis with extra workloads, constant anxiety and exhaustion. As carers are witnessing an ***alarming deterioration*** in the health and wellbeing of people with dementia, they are also coping with grief, loss and powerlessness.

The toll on people’s lives has only intensified as the COVID-19 restrictions imposed on dementia-specific services continue with ***no end in sight*** despite other lockdown restrictions lifting in recent weeks. In the first report, people wondered would people with dementia be ***forgotten***; it turns out they were right.

The report highlights that ***86%*** of carers are concerned about a decline in their loved one while ***58%*** of people with dementia report feeling “lonely”, “isolated”, “trapped” and “confined”.

Family carers who are dealing with grief, loss and a tremendous workload, are often facing this crisis alone as they feel unable to reach out to family members at this time with ***77%*** agreeing that their caring workload has increased since COVID-19. This situation is being made all the more unbearable as there is currently ***no information or guidelines on a roadmap for reopening vital services*** such as day care, Alzheimer Cafes and support groups for their loved ones.

The report reveals worrying long-term implications of the lockdown including significant concerns about the future with ***75%*** of respondents with dementia concerned about a decline in their mental health and ***61%*** of family carers also being concerned for their own mental health.

Full-time carer Denise Monahan (56) from Tallaght in Dublin believes that it is crucial that the Government now issue a roadmap for the reopening of dementia-specific services such as day care. Denise’s father, Seamus Cunningham (82), was diagnosed with Alzheimer’s eight years ago and has attended The ASI’s Rose Cottage day care centre in Dublin since his diagnosis.

***Full-time carer Denise Monahan said:***

*“The lockdown has proved very challenging for my dad and for us as a family. He had no concept of the word virus and so could not understand why he could not go out. Dad is a sociable man and it caused him great confusion, not seeing friends, neighbours and family. I am worried about the impact it will have on him – he is so used to cocooning now, he just wants to stay in the house. Perhaps the most heart breaking aspect of the lockdown is that my brothers could not visit and now Dad struggles to identify them. He has not seen some of them since March and Zoom and technology like that only confuses him. The closure of the day centre was a huge loss and now does not really remember Rose Cottage. The worry for me now, the longer this goes on, is that he might not want to go back at all. He used to be the first person on the bus with his suit on ready to go. I fear this time has been lost and we can’t get it back. It is frustrating that I can get my hair, nails and eyes done and yet this vital service is not available for Dad's social and emotional wellbeing. He went three mornings a week and that gave my Mam a much needed break; she has chronic obstructive pulmonary disease (COPD) and is not long home from a five-week stay in hospital herself. We need the day care centre open as soon as possible – the sooner, the better.”*

The lack of certainty around re-opening of services is a source of ***ongoing frustration and angst*** as it means there is no end in sight to carers’ stress and workload, thereby leading to feelings of desperation and hopelessness. 41% of carers and 50% of respondents with dementia are worried about when normal dementia services will resume. Respondents with dementia miss socialising with friends.

In the report, callers to ***The ASI’s National Helpline*** also echo concerns about progression in the person’s symptoms which has been a significant issue since the temporary closure of services. Callers express confusion, upset and surprise by the rapid and sudden progression of their loved ones’ symptoms over recent weeks and months.

Nearly ***40%*** of Helpline callers are not linked with any ASI service currently, which highlights how much of a lifeline this vital service is for people. The ASI’s Helpline also reports increased challenges for callers including anxiety, insomnia, paranoia, aggression and hallucinations

In addition, ***Dementia Advisers*** are deeply alarmed about the quickened deterioration in symptoms, as reported to them by family carers. Inherent in carers’ experiences is a sense of grief and powerlessness, “watching the change on a daily basis” as they watch their loved one's symptoms deteriorate. This comes in addition to a reported tremendously increased workload and carers often being alone as they are unable to reach out to family members during this time.

***The ASI calls for these key recommendations in the report:***

* *Need for guidelines for reopening of services and supports for people with dementia and family carers as a matter of urgency*
* *Dementia should be included specifically in data collection relating to COVID-19 mortality or public messaging*
* *Need to support family carers who have shouldered a disproportionate burden during this global pandemic*
* *Enhanced in-home support that caters specifically for people with dementia should be implemented immediately*

The ASI has submitted proposals to expand home care support and the safe reopening of day services to the HSE which are under active consideration.

The ASI has ***continued to support*** people with dementia and their families as our ***Home Care,*** ***Dementia Advisers***, ***National Helpline*** and ***Online Family Carer Training*** have remained open. The ASI has also implemented new ways of providing ASI supports remotely to our clients:

* *Expansion of* ***National Helpline*** *which offers a 1:1 call with a Dementia Nurse*
* ***Alternative Activity Therapy*** *for people living with dementia and their family carers who availed of day care prior to COVID-19*
* ***Social Calls*** *and* ***Activity Engagement Calls*** *(with Activity packs) on a weekly or biweekly basis*
* ***Online Support Group for Family Carers*** *to provide support and information to family carers*

***The Alzheimer Society of Ireland CEO Pat McLoughlin said:***

*“This research paints a very dark and disturbing picture of the plight and crisis that people with dementia and family carers now face in life after lockdown. While many family carers were struggling to cope prior to COVID-19, this crisis has amplified their difficulties and turned everyday caring into a daily struggle. It is also clear that the health of people with dementia has deteriorated during lockdown. In our initial COVID-19 Survey in early April, some carers expressed the fear that they would be forgotten in the midst of the crisis. It is so obvious from reading this report that this fear has been realised as they and those they care for have been rendered invisible throughout this pandemic. Our research findings show that living in lockdown has taken an enormous toll on the wellbeing and mental health of family carers, a toll that has intensified as COVID-19 restrictions on dementia-specific services have continued despite other lockdown restrictions lifting. It is clear from this report that face-to-face services, such as day care, must reopen as soon as possible. We are waiting for Government guidelines and information on this. But it is obvious from this report that given the very dark picture of people’s reality that it presents, this wait cannot go on any longer. We are eager to get this process started as soon as possible.”*

***The Alzheimer Society of Ireland North Dublin Dementia Adviser Ana Dalton said:***

*"Since COVID-19 lockdown began, I have received an increasing number of calls from family carers relaying levels of burn-out previously not experienced within their caring role. Many of the calls hold a much greater emotional weight as carers try to process how they can sustain the level of care they are providing to their family member. COVID-19 further exacerbated the feelings of physical and mental exhaustion and social isolation for many family carers who need and should have access to a solid structure of support services to enable them to sustain their demanding care roles. But the closure of vital services such as day care and respite care and the ongoing limitations within home care means carers just can’t get a break now. The urgent need for the safe reintroduction of practical support services and emotional support are all high priorities in meeting family carers’ needs in this report. For many family carers the informal routes of accessing this type of support, through the channels of family and friends, became depleted during the lockdown due to the necessary restrictions. This further compounded the sense of hopelessness for many. Many carers are still feeling the impact of the lockdown. They are stressed and overwhelmed and many fear a second wave. Their lockdown is never-ending.”*

***The Alzheimer Society of Ireland Dementia Adviser for the Southern Region, Amy Murphy said:***

*“Supports and services are essential for the person with dementia to properly manage their condition. Because of the necessary COVID-19 lockdown these vital face-to-faces services were closed which has contributed to a rapid progression of the disease for many. People with dementia have had to deal with the closure of a number of services across social and medical sectors for a number of months. In my area, I have had people ring me in tears at the situation they’re currently in and I am extremely alarmed at witnessing such deterioration in people’s dementia during lockdown. From the daily calls that I am receiving, they are missing the human connection that face-to-face services provide. It’s very clear from this report that, due to the lack of multi-sensory stimulation, routine and interaction over a period of time, the impact of the lockdown on people with a dementia could be a lasting one. People’s conditions are progressing and the lack of access to face-to-face services could be a huge contribution to this. Life is extremely difficult for people with dementia to navigate without these vital services and clear guidelines need to be issued on how to reopen them as soon as possible. People with dementia cannot wait any longer.”*

***Responding to COVID-19 Public Health Emergency:***

The ASI has developed some ***tip sheets*** and a number of ***factsheets*** to help support people with dementia and their families in a challenging and rapidly changing situation including information on activities, changes in behavior as well as tip sheets for people with dementia and supporting people with dementia in the community.

***Website:*** www.alzheimer.ie/about-us/coronavirus-covid-19-update/

**ENDS**

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**NOTES TO THE EDITOR**

***About The Alzheimer Society of Ireland (ASI):***The ASI is the national leader in understanding and providing dementia-specific supports and services. With a national network of over 120 specialist services, 900 staff and 300 volunteers, each year they provide almost 900,000 hours of community-based, dementia-specific care throughout Ireland. For more information see [www.alzheimer.ie](http://www.alzheimer.ie)

***About this Research:***

This report presents the findings of national research undertaken by The Alzheimer Society of Ireland (ASI) between 8th and 26th June 2020, which explored how people with dementia and their carers are coping during COVID-19 and to understand their challenges and needs. This report follows on from a national survey carried out at the start of April 2020, when dementia services ceased operating and COVID-19 restrictions were imposed. This current research consists of online and telephone surveys completed by 126 carers and 15 people with dementia. The carers represent a broad range of experiences, including those caring for varying amounts of time, caring for different family members, different age profiles and those with multiple caring roles. The ASI National Helpline and Dementia Adviser service also contributed to this research.

***Alzheimer National Helpline:***

For more information on our supports and services during this challenging time, please contact The Alzheimer Society of Ireland National Helpline where you can now also book in a 1:1 session with a Dementia Nurse or Dementia Adviser. The Helpline is open six days a week Monday to Friday 10am–5pm and Saturday 10am–4pm on 1800 341 341. Email at helpline@alzheimer.ie or via Live Chat at [www.alzheimer.ie](http://www.alzheimer.ie)

**ABOUT DEMENTIA**  
• The number of people with dementia in Ireland is expected to more than double from 55,000 today to 141,200 in 2050.\*  
• Dementia is an umbrella term used to describe a range of conditions which cause changes and damage to the brain.  
• Dementia is progressive. There is currently no cure. Dementia is not simply a health issue but a social issue that requires a community response.  
• The majority of people with dementia (63%) live at home in the community. Over 180,000 people in Ireland are currently or have been carers for a family member or partner with dementia with many more providing support and care in other ways.  
• There are 11,000 new cases of dementia in Ireland each year. That’s at least 30 people every day and anyone can get dementia - even people in their 30s/40s/50s.\*\*  
• 1 in 10 people diagnosed with dementia in Ireland are under 65.  
• The overall cost of dementia care in Ireland is just over €1.69 billion per annum; 48% of this is attributable to family care; 43% is accounted for by residential care; formal health and social care services contribute only 9% to the total cost  
  
*Figures referenced to Cahill, S. & Pierce, M. (2013) The Prevalence of Dementia in Ireland*

*\*Figure referenced from Alzheimer Europe (2020)* *Dementia in Europe Yearbook 2019 ‘Estimating the prevalence of dementia in Europe’*

*\*\*Figure referenced from Pierse, T., O’Shea, E. and Carney P. (2018) Estimates of the prevalence, incidence and severity of dementia in Ireland.*