

IMMEDIATE RELEASE – Friday, June 11th 2021

Family Carers report enormous strain and plea for re-opening of dementia services

Family carers report significant decline in mental and physical health during COVID-19

Past year sees ‘Irreversible Deterioration’ for people living with dementia

The enormous challenges faced by the family carers of people living with dementia – and urgent need for access to support services – have been highlighted in stark report from The Alzheimer Society of Ireland (ASI).

The report found that the pandemic has led to a significant and irreversible deterioration in the condition of many people living with dementia – with their world becoming smaller and more frightening.

The research *Caring and Coping with dementia during COVID-19* was launched today and also found family carers to be at breaking point – with their mental and physical wellbeing seriously affected.

Findings include:

- 81% of respondents were concerned about decline in the person with dementia
- 54% of family carers reported a decline in their mental health, and 40% a decline in their physical health
- 54% of family carers were worried about how they will continue to cope, with 44% feeling less able to cope
- 28% of family carers reported considering a move to long term care for the person with dementia, with 65% saying that this has become a consideration sooner due to the pandemic.

The report comprised telephone and online surveys and focus groups including people living with dementia, family carers, Dementia Advisers and front-line service managers – and follows earlier surveys by The ASI in 2020.

The Alzheimer Society of Ireland CEO Pat McLoughlin said the lives of people with dementia and their family carers remain very seriously impacted by the pandemic period.



“This research shows the enormous sacrifices family carers have made in order to protect those they care for. Their struggles include heightened exhaustion, burnout, anxiety, grief, helplessness and despair.

“Other relationships and responsibilities (such as children or work) have also paid a price. The fact that there was no prioritisation of family carers in the vaccine roll out has left these people feeling abandoned. There were even cases of suicide risk reported among family carers.

“In parallel many people living with dementia have experienced irreversible deterioration over the past year. These families feel angry, betrayed and frustrated and we need the Government to take additional measures to address their needs.

“We now need to see urgent and safe re-opening of day care centres and social clubs. Our research found that family carers’ need for practical support almost tripled in the past year rising to 70%. They also need access to emotional support, including counselling services.”

Carers’ experiences

Describing her experience of being a full-time carer during COVID-19, Wicklow based Aisling Harmon said:

“My Mum has advanced Parkinson's Disease and dementia. Her needs could not be put on hold, but our day-care and community services were cut off overnight. There was no emergency or contingency plan to fall back on. The world went online, but homecare couldn't. My part-time caring went 24/7, without subsidy or alternative support. We are so vulnerable and have been left unprotected. Vaccines get rolled out, but carers were at the back of the queue. Everyone is focused on getting back to normal. My new norm is more of the same, only with less supports than before. It still feels like carers are invisible and have no voice.”

Cork based family carer Helen Higgins also described her difficulties:

“COVID-19 has been an extremely challenging time for me and my husband. His care needs have increased so much since the pandemic started. He found the restrictions during COVID-19 very hard and things like social distancing have been difficult for him to understand. I have been unwell during this time myself and my health impacted. It has been so isolating. I feel we have been the forgotten people during COVID-19.”

Recommendations

In response to the report The ASI set out the following recommendations:

- Provide the necessary capital and revenue resources now for day care re-opening arising from public health guidelines
- Better assistance for family carers through support groups and therapeutic services including counselling
- Continued funding of ASI's Day Care at Home service in order for additional support to be provided
- Provision of additional dementia appropriate home care hours to be provided urgently
- Pilot and develop the Statutory Home Care scheme without further delay
- Plan and coordinate dementia services post COVID-19 alongside other major chronic diseases
- Implement fully The National Dementia Strategy.

Download Caring and Coping with Dementia during COVID-19 at www.alzheimer.ie

More information

Ronan Cavanagh, Cavanagh Communications: (086) 317 9731 / ronan@cavanaghcommunications.ie

NOTES TO THE EDITOR

Research methodology

This report presents the findings of national research carried out during February and March 2021. It comprised telephone and online surveys with people living with Dementia and family carers. 17 people living with Dementia and 240 family carers took part. There was also a focus group with nine Dementia Advisers and six front-line service managers.

The Alzheimer Society of Ireland (ASI):

The Alzheimer Society of Ireland is the leading dementia specific service provider in Ireland. The Alzheimer Society of Ireland works across the country in the heart of local communities providing dementia specific services and supports and advocating for the rights and needs of all people living with dementia and their carers. Our vision is an Ireland where people on the journey of dementia are valued and supported. A national non-profit organisation, The Alzheimer Society of Ireland advocates, empowers and champions the rights of people living with dementia and their communities to quality support and services.

The Alzheimer Society of Ireland National Helpline is open Monday to Friday 10am–5pm and Saturday 10am–4pm at 1800 341 341. The public can also email helpline@alzheimer.ie, or use Live Chat at www.alzheimer.ie

ABOUT DEMENTIA

- There are 64,000 people with Dementia in Ireland and the number of people with the condition will more than double in the next 25 years to over 150,000 by 2045.*
- 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.**
- 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.
- 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 Pierce, T., O'Shea, E. and Carney P. (2018) Estimates of the prevalence, incidence and severity of dementia in Ireland.*