**IMMEDIATE RELEASE – Wednesday, 1st April 2020**

**Lack of services due to COVID-19 leading to deterioration in the health of people with dementia likened to ‘falling off a cliff edge’ – new research**

Research carried out by The Alzheimer Society of Ireland to identify the current challenges brought about by ***COVID-19*** health crisis as experienced by people with dementia and family carers has found a rise in the cases of isolation, loneliness, boredom, anxiety and fear.

The ASI’s ***Dementia Advisers*** have reported an increase in responsive behaviour from people with dementia including confusion, paranoia, delusions, agitation, and other behavioural changes, with one Dementia Adviser likening deterioration of one person with dementia like “falling off a cliff edge”.

The research, which included the views of 160 people with dementia, family carers, Dementia Advisers and Dementia: Understand Together Community Champions, found that 73.3% of ***people with dementia*** feel they need some support at the moment with most requiring both practical (e.g. shopping) and emotional supports (e.g. regular telephone check-ins).

77.6% of ***family carers*** reported needing supports including practical supports (shopping, information etc), emotional supports (e.g. peer support) and in particular, carers are worried about getting sick and not being able to care for loved ones. In addition, almost 95% of Dementia: Understand Together ***Community Champions*** feel that with local services such as daycare, Alzheimer Cafes and community activities suspended people affected by dementia require alternative practical or emotional support or both (e.g. advice on local supports, dog walking and regular check-ins).

The ***Alzheimer National Helpline 1800 341 341*** is experiencing an increase in callers with ***1,496*** service users getting in touch from January to March. In March, ***410*** people contacted the service.

The Helpline has seen a jump in enquiries relating to the following: ***Responsive Behaviours*** such as people with dementia becoming increasingly more confused, paranoia, delusions, agitated, sleep disturbances; ***Main Carers*** are looking for support and reassurance on how best to support their loved ones who are self-isolating or cocooning. The carers are experiencing burnout and stress as they were supported by services, family members and neighbours but are now caring 24 hours a day; and about ***Practical Support*** with people living with dementia lacking insight into current situation – continuing to go out, not aware of the need for social isolation, refusing to wash hands on return to the house and how to manage this in the best way. This was also found in the research.

The ASI continues to support people with dementia and their families as our ***Home Care***, ***Dementia Advisers***, ***Alzheimer National Helpline*** and ***Online Family Carer Training*** are all still running. In addition we are implementing new ways of providing ASI supports remotely to our clients and their families such as regular telephone calls and activity packages for people to use in their own homes.

For example, in the past five days ASI staff have made ***1,689*** telephone calls to their clients or their main carer, ***715*** calls to family members where needed and ***144*** follow-up calls to Public Health Nurses. In addition The ASI is developing alternative support services to be delivered remotely.

Last week, The ASI launched an ***urgent appeal*** asking members of the public to make a special emergency donation to help provide essential care and support to those living with dementia whose lives are being torn apart by Covid-19 on [www.alzheimer.ie](http://www.alzheimer.ie)

Covid-19 has resulted in a ***perfect storm*** for The ASI withAlzheimer’s Tea Day is now postponed contributing to a severe drop in fundraising of €1 million; 48 day care centres are closed;vital supports such as Social Clubs, Alzheimer Cafes and Support Groups are all postponed until further notice.

Without its usual fundraising income and without the ***HSE making up the shortfall*** in the immediate term the organisation will struggle to deliver these alternative services as well as be able to revert immediately to providing all services when the crisis is over.

***The Alzheimer Society of Ireland CEO, Pat McLoughlin said:*** *“There was a crisis in dementia care in Ireland long before COVID-19 – but now it’s unthinkable what people with dementia and their carers are going through with now access to vital key supports and services. This research reveals the true impact of COVID-19 on already vulnerable people in our communities. There is a real sense of fear, anxiety and isolation out there and people are crying out for support and this desperate time. Everyone’s lives have been turned upside down during this health crisis – but people with dementia are particularly vulnerable here. We have heard that people with dementia are being sent home from hospital without adequate home and community support in place; concerns raised about an increase in responsive behaviour due to social isolation and changes in routine; and immense pressure on family carers who are now housebound and can’t leave the house, even for a walk. People being diagnosed with dementia does not stop due to COVID-19 - it is increasing all the time with 30 new cases per day. These people need support. Despite a number of our supports and services being closed, we're still supporting people online or on the phone. We are still available to those who are most vulnerable in our communities during this health crisis.”*

The ASI has developed some ***tip sheets*** to help support people with dementia and their families in a challenging and rapidly changing situation including the following:

* *Tips for vulnerable adults*
* *Tips for supporting vulnerable people in the community*
* *Tips for nursing home restrictions*
* *Prepare & Care: A simple, step by step guide to caring for a loved one living with dementia*

All of these resources are available on [www.alzheimer.ie](http://www.alzheimer.ie/)

For more information on our supports and services during this challenging time, please contact The Alzheimer Society of Ireland National 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/)

**Website:** [www.alzheimer.ie](http://www.alzheimer.ie/)

***Highlighted Greatest Challenge for People with Dementia***

* Loneliness and Isolation due to social distancing issues include missing daycare services and the socialisation associated with it; Being housebound is very isolating
* Boredom and lack of routine included - Boredom making it difficult to sleep
* Anxiety/Fear - Unable to purchase supplies independently; Worried about being on their own and unable to get necessities; Scared of going shopping and concerned they will forget to keep a social distance; Concern about accessing healthcare services and GP.

***Carers – Highlight Greatest Challenges***

* Fear of not being able to cope with changes in behaviours for much longer; A lack of routine makes it difficult to motivate
* Anxiety and fear of uncertainty and unknown, Feeling helpless and smothered by caring work load, Marked increase in carer burden and stress with little or no support,
* Worry about the times when PlwD is alone during the day as there is no service to attend, including library, Church, Concern about impact of loss of social interaction

***Quotes from the report***

***Person with Dementia***

*“\*Jane (who has dementia) really misses the company of her day care, female friends and daughter. Her son feels she has slipped back due to lack of company.”*

*“Stuck in the house, feeling abandoned and scared of contracting Covid-19”*

*\*not her real name*

***Carer***

*“Fear of not being able to cope with husband's challenging behaviour for much longer.”*

*“Anxiety that I will contract Covid-19 as I have underlying health issues and there will be nobody to care for my wife.”*

*“I feel frustrated as I care for two people but I am also needed at home by my children. We miss the routine and explaining to parents why we cannot get out is also frustrating.”*

*“I worry about the times when my mother is on her own during the day and has no place to go. She used to go to the Church, the Library etc., and these are now closed.”*

*“Fear of the unknown, trying to remain calm while my loved one constantly asks me what is this virus thing that they are talking about on the news, etc.”*

**ENDS**

**For more information contact The Alzheimer Society of Ireland Communications Manager Cormac Cahill** **cormac.cahill@alzheimer.ie** **086 044 1214**

***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)

***Dementia: Understand Together:***
This is a public support, awareness and information campaign. It aims to inspire people from all sections of society to stand together with the 500,000 Irish people whose families have been affected by dementia. The campaign is led by the HSE, working with the Alzheimer Society of Ireland and is supported by over 40 national partner organisations and local community champions. Find out more about how you can take action and the supports available at http://www.understandtogether.ie/get-involved/

**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.*