***\*Photos being issued to photo desks by Karen Morgan Photography***

**IMMEDIATE RELEASE – WEDNESDAY, JULY 3rd 2019**

**PEOPLE LIVING WITH DEMENTIA TELL GOVERNMENT: STOP IGNORING THE HEALTH CRISIS OF OUR TIME AND START FUNDING VITAL COMMUNITY SUPPORTS AND HOME CARE IN BUDGET 2020**

The Government must start funding urgently needed community supports and home care for people living with dementia. This was the emotional appeal from Dr Helen Rochford Brennan, who was diagnosed with Alzheimer’s disease in 2012. Today, at the launch of The Alzheimer Society of Ireland (ASI) Pre-Budget Submission 2020 ***‘Dementia Supports Across Ireland – Still Asking, Still Waiting, Still Struggling’.*** The ASI are demanding that Government take notice of their plight. The ASI hasdetailed what the **€18.4m** national investment proposal could begin to do, to start supporting people with dementia and their struggling families across the country.

Helen, who is a member of the Irish Dementia Working Group and Chair of the European Working Group of People with Dementia, has witnessed numerous false dawns as successive Budget Days have come and gone without ring-fenced funding for dementia-specific supports and services. Helen, who is also now a carer for her husband who has a serious health condition, believes that the wait for extra funding must end.

***Person living with dementia Dr Helen Rochford Brennan said:***

*“I was diagnosed with Alzheimer’s disease in 2012 after a five year struggle to get a diagnosis. Since then I have campaigned relentlessly so that politicians will change policy and people with dementia are better supported from their diagnosis onwards. But I’m still asking, still waiting and still struggling. I do not believe that my own Government is actually listening. Dementia is the health crisis of our time and it has been completely ignored in the Budget. People with dementia and their families are sick and tired of waiting – we need extra community supports and home care now. My message to the Government is clear: stop focusing on spreadsheets and start looking at reality and deliver on extra funding for people with dementia in Budget 202, as I don’t know how much more time I have to keep asking.”*

**The ASI is calling on the Government to invest:**

* **€7.41m** to urgently fund the service gap by providing a minimum standard of community services in each county;
* **€1.68m** to Increase the number of Dementia Advisers so that people diagnosed with dementia have access to this crucial support;
* **€6m** to expand the number of Intensive Home Care Packages available to people with dementia;
* **€2.3m** to fund the role of Dementia Key Workers to provide a care pathway for each person with dementia;
* **€1m** to increase the number of Dementia Inclusive Community Coordinators to continue to support the development of a dementia inclusive Ireland.

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

*“We were left extremely frustrated last year when the Government decided not to make specific funding available for people with dementia and their struggling families in Budget 2019. There are thousands of families up and down the country who have been struggling to access services for loved ones and as a society we are failing to provide these people with the supports they need. No county in Ireland provides even a minimum standard of care for people with dementia and our funding call on the Government for Budget 2020 would triple the number of services and supports available, including an increase of 13 day centres and 118 Alzheimer Cafés. Currently there are only nine Dementia Advisers covering the whole country and our funding call today would mean that families in every county in Ireland would have access to this key service. This funding could represent a first step in dealing with the inadequate and glaring gaps in services and supports so recently identified across the country.”*

A special video has also been launched to mark the launch of The Alzheimer Society of Ireland’s Pre-Budget Submission 2020. Featuring **Dr Helen Rochford Brennan** it charts her story as an active campaigner for people with dementia since her dementia diagnosis and talks about her frustration of Still Asking, Still Waiting and Still Struggling. This video can be viewed ***[INSERT LINK]***

The ASI’s **Pre-Budget Submission 2020** event in Buswells Hotel in Dublin, which was attended by TDs and Senators from across the political divide, also included keynote addresses from carer, author and broadcaster **Teena Gates** and The ASI CEO **Pat McLoughlin**. The document outlines the urgency of the situation and makes the case for why the Government should start funding dementia-specific services and supports on Budget Day.

* ***Still Asking:*** People with dementia and their carers are still asking the Government why no county in Ireland has even a minimum standard of supports and services. The time to provide funding is now;
* ***Still Waiting***: People with dementia and their carers are still waiting for equitable and fair access to the supports and services that they desperately need. The time for action is now;
* ***Still Struggling***: People with dementia and their carers are still struggling on a daily basis, sometimes silently and painfully, due to the lack of services and supports. The time to end this struggle is now.

**Carer, author and broadcaster Teena Gates said:**

*My 94-year-old father, Terry, has an acquired brain injury and was diagnosed with dementia earlier this year. He was in hospital for two months and I was eventually successful in securing him a home care package. I felt very strongly that my dad did not deserve to be institutionalised. People with dementia who want to remain living in their own home and in their own community should be able to do so. I remember when my dad was in hospital and how frail he was. Once home, his transformation was startling – he went from being sad and lonely in a wheelchair in hospital one week to happily wearing a Louis Copeland suit at home the next. He loves being at home and doing simple things like pottering around the garden. Budget 2020 is the perfect opportunity for the Government to offer more community supports and home care to people, like my dad, across the country. The Government’s time to deliver has come.”*

**-Ends-**

**For more information, please contact The Alzheimer Society of Ireland Communications Manager, Cormac Cahill on 086 044 1214 or** [**cormac.cahill@alzheimer.ie**](mailto:cormac.cahill@alzheimer.ie)

**Notes to the Editor:**

**Pre-Budget Submission 2020**

* **€7.415 million to provide a minimum standard of community services in each county**

The HSE and The Alzheimer Society of Ireland mapped dementia specific community services across Ireland and found acute inequity of service between counties. This investment would triple the number of services and supports available, including an increase of 13 day centres and 118 Alzheimer cafes.

* **€1.68 million to increase the number of Dementia Advisers available**

Dementia Advisers support people and their families with information, advice and signposting throughout their dementia journey. There are only nine Dementia Advisers covering 11 counties yet demand is increasing fueled by a growth in awareness due to the HSE’s *Dementia:* Understand Together campaign. This investment would mean that families in every county in Ireland have access to a Dementia Adviser.

* **€6 million to develop and expand the number of Intensive Home Care Packages available**

Intensive Home Care Packages (IHCP) are responsive and flexible so they meet the often complex care needs of people with dementia. There is an acute need for more IHCPs to enable people with dementia to stay at home. This investment would double the number of packages available.

* **€2.31 million to fund the role of Dementia Key Workers**

Dementia Key Workers assist people to navigate complex care pathways by providing a coordinated care plan for individuals, as emphasised in the National Dementia Strategy. The investment in this new role would, at a minimum, support people and their families through a difficult health system.

* **€1 million to resource Dementia Inclusive Community Coordinators across Ireland**

Dementia Inclusive Community Coordinators build the capacity of communities to support people with dementia to remain involved and included for longer. Evidence has shown that the work of the HSE’s *Dementia*: Understand Together campaign is combatting the isolation and stigma of dementia. This investment is critical to ensure that this work can be enhanced and sustained.

**About The Alzheimer Society of Ireland:**

The ASI is the national leader in advocating for and providing dementia-specific supports and services and each year the organisation provides more than one million hours of community-based dementia-specific care throughout Ireland.

The ASI provides the following services:

* National Helpline
* Social Clubs
* Support Groups
* Day Care Services
* Home Care
* Dementia Advisor Service
* Mobile Information Bus

**Helpline:** 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.

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

**About Dementia:**

The number of people with dementia in Ireland is expected to more than double over the next 18 years, from 55,000 today to 113,000 in 2036.

* 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.
* Each year over 4,000 people develop dementia. That’s at least 11 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.
* 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.

Figures referenced to Cahill, S. & Pierce, M. (2013) *The Prevalence of Dementia in Ireland*