**IMMEDIATE RELEASE – Wednesday, June 3rd 2020**

**Ahead of ‘Hear Our Voice!’ launch, campaigner Kevin Quaid – ‘Having the chance to influence dementia policy gives me great hope after coming out of a very dark place’**

***\*Interviews available on request
\*Pictures attached***

Campaigner and advocate ***Kevin Quaid*** has said that having the opportunity to influence dementia policy has giving him so much hope following the ***very dark place*** he entered following his ***Lewy Body Dementia*** diagnosis in 2017 at the age of just 57.

Kevin was speaking ahead of a launch of best practice guidelines ‘Hear Our Voice!’ which has been developed by ***The Irish Dementia Working Group (IDWG),*** supported by ***The Alzheimer Society of Ireland***, and the ***Centre for Economic and Social Research on Dementia (CESRD)*** at NUIG.

This ***ground-breaking*** documentprovides practical guidance in a user-friendly format for individuals and organisations that wish to involve people with dementia in their work or gain their views in a formal way. This publication is unique – it was co-produced by people living with dementia and was ***written by*** people living with dementia, not ***for*** them.

Vice-Chair of the IDWG Kevin Quaid, originally from Broadford in Co Limerick but now living in Kanturk, Co Cork, believes that the publication of this document gives him a lot of hope to ensure people with dementia can, in an effective way, influence policy groups, conferences and research in the future.

***Vice-Chair of the Irish Dementia Working Group (IDWG)******Kevin Quaid said:*** *“I was in a dark place after my diagnosis in 2017, I felt useless and I struggled to motivate myself. I know this is a progressive illness without a cure, but I also know that I need hope to live. Being an advocate and working to influence policy gives me great hope and this ‘Hear Our Voice!’ document shows that people with dementia can have their voices heard in society. I think about people with dementia who struggle to be heard, especially in these past couple of devastating months during Covid-19, and I keep them in my thoughts as I try to change things for the better for all of us. People with dementia, like myself, are experts by experience and our voice is critical in the planning of dementia supports and services. It has been such a devastating time for people with dementia and their family carers with so much anxiety, anguish and confusion. But this document has reminded me that there is hope for the future. Our voices can be heard loud once more. We will prevail. I hope you enjoy reading it.”*

***The scope of the guidance includes the involvement of people with dementia in activities such as:***

* *Membership of policy groups, advisory groups and similar committees;*
* *Involvement of people with dementia in consultation processes, either individually or as members of a group;*
* *The involvement of people with dementia in meetings and conferences as presenters, panel members or other roles.*

The cover image of the document was designed by ***IDWG member Marguerite Keating***. Marguerite used the forget-me-not flower and worker bees; the bees symbolise the members of the IDWG.

The Virtual Launch of Hear Our Voice! Guidelines for involving people with dementia in policy, advisory, consultation and conference activities on ***Friday, June 5th 11am-12 noon***.

**Speakers:**

* ***Kathy Ryan****, Chair IDWG*
* ***Dr Helen Rochford Brennan*** *Steering Group IDWG, Chair European Working Group of People with Dementia*
* ***Dr Emer Begley****, Senior Project Manager, The National Dementia Office*
* ***Mary Cunningham****, Supporter of the IDWG and Guidance Document Contributor*
* ***Dr Fiona Keogh****, Senior Research Fellow, Centre of Economic and Social Research on Dementia*
* ***Pat McLoughlin****, CEO The Alzheimer Society of Ireland*

There are ***154 registered*** for the event so far. There are people registered from the following organisations: The National Dementia Office, the HSE, The Disability Federation of Ireland, Nursing Homes Ireland, Dublin City University, University College Cork, Trinity College Dublin, County Councils, the Gardai, Age and Opportunity, The National Safeguarding Office, The Irish Centre for Social Gerontology, Local Link, Community Development organisations, Active Retirement Ireland and HIQA. There are also many individual interested parties and some international guests from Notre Dame University, Bradford University and the Dementia Voices Empowerment Project in the UK.

***The Alzheimer Society of Ireland CEO, Pat McLoughlin said:*** *“Authentic participation of people living with dementia does not just happen; it takes planning, capacity building and robust support. I know policy makers want to involve people living with dementia and I believe this document can support them to do so. I have learned so much from people living with dementia during my time with The Alzheimer Society of Ireland and people living with dementia inform everything we do and are at the core of the organisation. If we listen to people living with dementia, they can support us to create a better and more inclusive network of dementia supports.”*

***Senior Research Fellow, Centre for Economic and Social Research on Dementia at NUIG, Dr Fiona Keogh said:*** “*We have been working with the members of the Irish Dementia Working Group and The Alzheimer Society of Ireland for many years now and have learned so much about what works best in terms of involving people with dementia as equal partners in our work. Co-producing the guidelines* *was a wonderful opportunity to bring all of that learning and experience together so that it can be shared more widely to increase the ways in which people with dementia are involved in policy and providing advice and expertise to a wide range of other organisations.”*

**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)

***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 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*

**Website:** www.alzheimer.ie

***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, 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

***About The Centre for Economic and Social Research on Dementia (CESRD):***

The CESRD will develop and facilitate new thinking on dementia in Ireland that focuses on personhood within dementia and a resource allocation process that maximises the capabilities and well-being of people with the disease and their family carers in an efficient and effective way. The Centre will provide the research framework to support the implementation of the National Dementia Strategy in Ireland. Researchers at the Centre will offer support in terms of social audit, economic evaluation and both quantitative and qualitative analysis of dementia care in Ireland. The CESRD will focus mainly on exploring non-pharmacological approaches to the care of people with dementia. [www.cesrd.ie](http://www.cesrd.ie)

***About the Irish Dementia Working Group (IDWG):***

The IDWG is an advocacy group of people with a diagnosis of dementia who work to share their experiences and highlight issues important to them. By amplifying the voice of people living with dementia they aim to improve understanding of the condition and supports for those affected by dementia. The IDWG works to influence public policy, raise awareness, engage in political advocacy and destigmatise dementia by speaking publicly and in the media.

**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.*