

Engaging the Voice of Family Carers:

The Development of a Dementia Carers Campaign Network

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There are approximately 48,000 people living with dementia in Ireland and approximately 50,000 family carers¹. The Alzheimer Society of Ireland (ASI) is committed to ensuring that the voice of the person with dementia and the family carer is heard. We facilitate the Irish Dementia Working Group and the Dementia Carers Campaign Network (DCCN). The DCCN is an opportunity for people who care for someone with dementia to meet and discuss issues which affect them and to campaign for change.

¹Figures from Cahill, S. & Pierce, M (2013) *The Prevalence of Dementia in Ireland*. Genio Dementia Learning Event.



Dorothy Mooney, Member of the Dementia Carers Campaign Network Committee, poses with her husband Eric for the ASI's 'Still' public awareness campaign, April 2015

DEVELOPING A DEMENTIA CARERS CAMPAIGN NETWORK IN IRELAND

- ASI has a long history of working with carers to raise awareness of issues facing families affected by dementia and to lobby for policy change.
- In 2013 ASI began to explore the possibility of developing a campaign network to support and facilitate carers who were engaged or interested in advocacy work.

Éamon O'Farrell, Member of the Dementia Carers Campaign Network, Helen Rochford-Brennan, Chair of the Irish Dementia Working Group, and Dorothy Mooney, Member of the Dementia Carers Campaign Network Committee, outside the Irish Parliament, October 2014



First Steps

- Discussions were held with carers who had been involved in ASI advocacy campaigns in the past and with groups representing carers around Ireland.
- ASI staff and branch members working in local communities provided their input on the need for a carers campaign network.
- We received advice and support from Alzheimer Scotland's National Dementia Carers Action Network, which allowed us to gain further insights into the potential of forming a similar network in Ireland.
- An exploratory meeting of Ireland's Dementia Carers Campaign Network was held in December 2013 and this was followed by two regional meetings.
- At these meetings carers discussed the aim of the network, how carers would like to be involved and the potential barriers to involvement, the main activities of the network, the key issues the network should focus on, and the role of ASI.

THE ROLE OF NATIONAL ALZHEIMER'S ASSOCIATIONS

- Alzheimer's associations have a vital role to play in supporting the voice of family carers.
- During the initial meetings of the Dementia Carers Campaign Network, there was general agreement that ASI should be the driving force behind the network.
- We stand 'shoulder to shoulder' with carers, taking a supportive and facilitative role.
- ASI is committed to supporting the Dementia Carers Campaign Network to represent, raise awareness and campaign on the distinct needs of people who care for someone with dementia.



Sean Donal O'Shea, Member of the Dementia Carers Campaign Network Committee, in ASI's 'Stigma' campaign advertising poster, June 2015

"Joining the DCCN is a great opportunity to share experiences and help plan some hopefully relevant campaigns"

DCCN Committee Member



Sean Donal O'Shea, Member of the Dementia Carers Campaign Network Committee, addressing political representatives at an ASI information event at the Irish parliament, March 2015

DEMENTIA CARERS CAMPAIGN NETWORK

STRUCTURE & ACTIVITIES

- The Dementia Carers Campaign Network is open to anyone in the Republic of Ireland who has experience of caring for someone with dementia.
- There is a core committee of eight to ten carers who take responsibility for driving the network forward. Membership of the committee and of the wider network is fluid as carers become more or less involved as their situations change.
- The main obstacles to carers becoming involved in the Dementia Carers Campaign Network are location and the responsibilities attached to their caring role. Some members find it difficult to attend meetings, but are anxious to remain involved in the group in other ways.
- The network has become very active over the past year and has been involved in the implementation of Ireland's first National Dementia Strategy. Members have also raised awareness at national conferences, spoken powerfully on radio and television and lobbied Government and senior officials on the needs of family carers.

THE FUTURE

- The Dementia Carers Campaign Network will launch their first campaign in November 2015. This campaign will focus on the impact of caring and will allow the network to:
 - (1) highlight the impact of caring on dementia carers;
 - (2) share tips and advice from network members to support carers; and
 - (3) highlight to political representatives the value of family carers to the State.
- Regionalisation of the Dementia Carers Campaign Network is an issue that will be considered over the coming year. The committee is currently examining ways to increase membership of the network and to ensure that carers in remote parts of Ireland can become active in the group.

FOR MORE INFORMATION PLEASE CONTACT

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