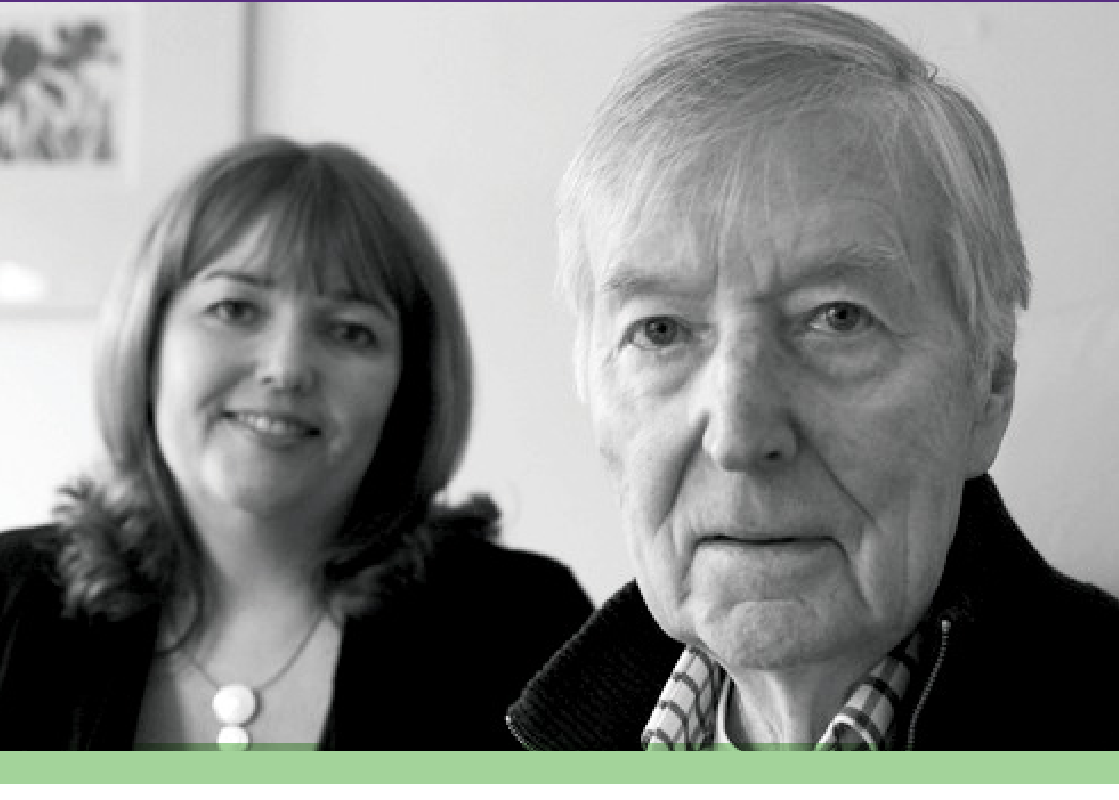
The Impact of Caring

DEMENTIA CARERS CAMPAIGN NETWORK



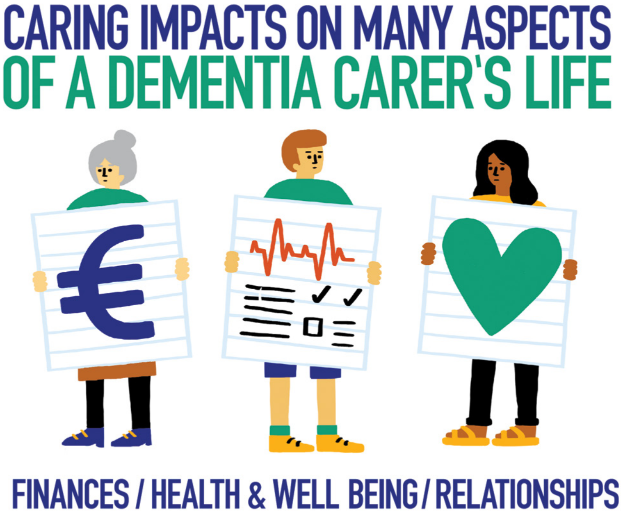
THE ALZHEIMER SOCIETY of IRELAND

Cover image:
Judy and Norman Williams.
Courtesy of Richard Kendrick.

DEMENTIA CARERS CAMPAIGN NETWORK

There are approximately 48,000 people living with dementia in Ireland and approximately 50,000 family carers[1]. Caring for a loved one with dementia takes time, energy and, above all, love. It can be a long and emotional journey but with the proper support, it can be a rewarding one too.

The Dementia Carers Campaign Network (DCCN) aims to represent, raise awareness and campaign on the distinct needs of people who care for someone with dementia. The group was established in 2013 and is supported and facilitated by The Alzheimer Society of Ireland (ASI). In this booklet, six DCCN members share their experience of caring for a loved one with dementia.



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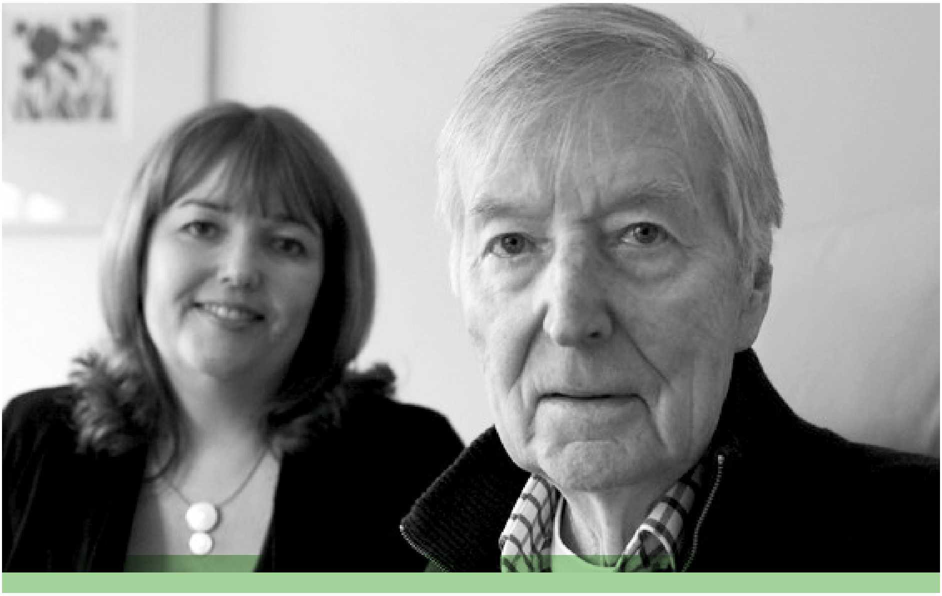
[1] Pierce, M., Cahill, S. and O'Shea, E. (2014) *Prevalence and Projections of Dementia in Ireland, 2011 – 2046*.



Judy with her father Norman

‘I hope things improve for family carers in the future’

I was caring full-time for my lovely father Norman for four years until he died aged 81. Dad had dementia and Parkinson’s Disease. I wanted to care for Dad as I knew how important it was for him to remain in his own environment. He was much happier and less anxious at home and he liked to be surrounded by his own possessions. Being a carer is hard work, and very tiring, especially if you are being woken in the night, as I was. It is very demanding and if the right support is not there for you, it can have a negative effect on your health. I wouldn’t change a day of my time with Dad, but I hope that things improve for family carers in the future and that the Government makes more provision for carers while they are in their caring role and supports them after their caring role comes to an end.

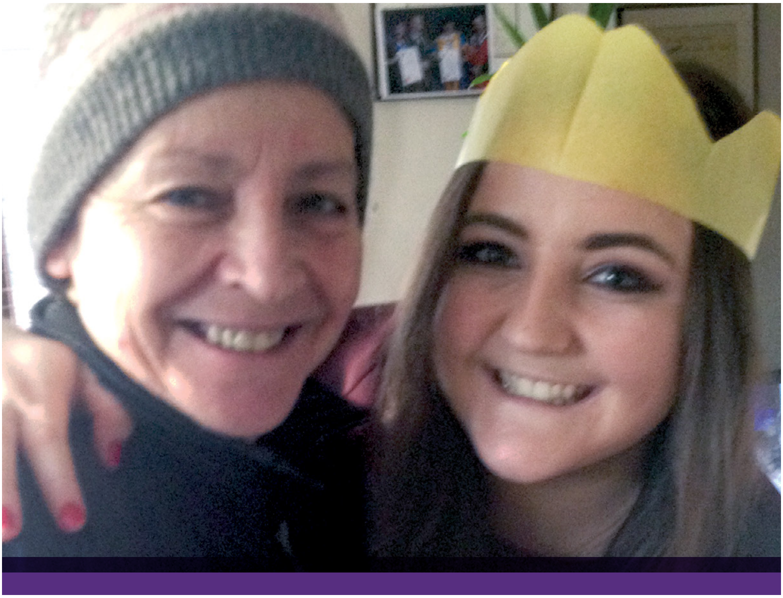
Judy Williams, Family Carer

Teresa with her husband Derek

‘Take control of the things you can control now, it does help. Above all things be open about the condition’

I can honestly say that my husband’s diagnosis was like a bomb went off in our lives. We had planned a long life and lots of adventures together, but, alas it was not to be. To say it is difficult to watch your husband slowly unravel and forget who you are is an understatement. I washed, dressed and took care of his every need. It was extremely challenging work. Derek eventually moved on to full-time care where he is well looked after, but I miss him every day. Take control of the things you can control now, it does help. Above all things be open about the condition, don’t be afraid to tell people what it is, there is no shame in it.

Teresa Dillon, Family Carer

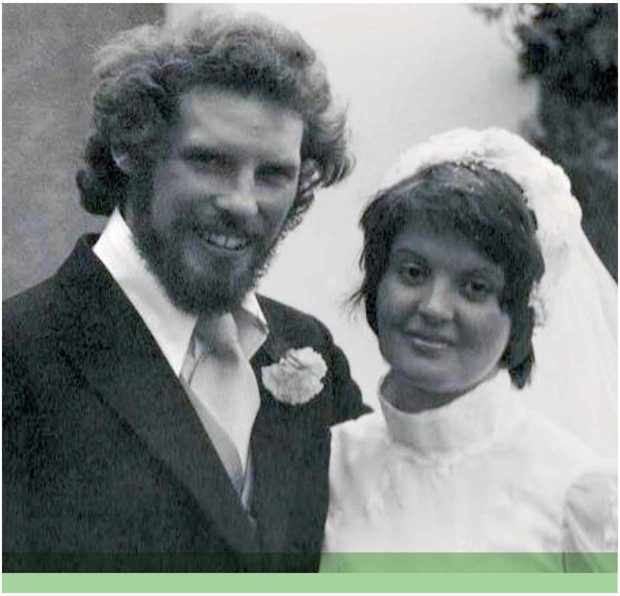


Katie with her mother Loretta

‘My love and respect for her strength has expanded beyond comprehension’

In the summer of 2010, when I was 18-years-old, my mother, Loretta, was diagnosed with early onset Alzheimer’s disease. Since then we have watched her condition progress steadily and substantially. To this day, I know mom still cares about us so much. She lights up when we walk into the room, and is so full of hugs and kisses. Caring for mom has been a challenge. She can no longer do anything for herself and her limited words makes it difficult to anticipate her needs. She has occasional moments of realisation too, and nothing makes me sadder than seeing her tears. In these moments, we hug her and return her words “I love you”.

Katie Moran, Family Carer



Dorothy with her husband Eric

‘If only the powers that be could walk in my shoes, just for a day, and witness what is required in the care of a loved one with this disease’

Forty two years ago my husband Eric came into my life. He loved and cared not only for my sons and me, but for my late parents too. Then, nine years ago, the insidious disease that is Alzheimer’s made an appearance in our lives. I am caring for someone who bears no resemblance to the man I married with one exception, I believe he still feels and understands love. Besides experiencing the emotional, psychological and loneliness of caring I also bear the brunt of it physically, but as a carer your pain and needs go on the back burner. More effort must be put into acquiring additional supports for carers and their loved ones and most crucially more funding must go towards scientific research in support of dementia. We have got to think of future families.

Dorothy Mooney, Family Carer

Laura with her mother Nora

‘Keeping life normal is the ultimate struggle and fighting for needed resources is often a battle in itself’

Growing up I was blessed to benefit from Mam’s unfaltering care no matter what hardships life brought. Even after my father passed away Mam was always there. She was the ultimate carer. Early Onset Dementia is not an illness that you contemplate in your 50s and the role of a carer isn’t straightforward or easy. Keeping life normal is the ultimate struggle. The Government needs to do more to enable people to keep living in their homes and to resource their caregivers to provide much needed care. Caring for Mam has taught me how to find my voice as a carer and to use it to fight for what she needs.

Laura Reid, Family Carer

Bernie with her mother-in-law Frances

‘It is a relief for us knowing she is being well cared for’

My mother-in-law Frances was diagnosed with dementia nearly five years ago. At the time her GP said she would need help with the day to day running of her life. We contacted ASI and found out what services were available and found places where Frances felt comfortable, but as time went on her dementia worsened. The appointments and notes I wrote in her diary would be forgotten. On a few occasions she went out and couldn’t find her way home. I was concerned for her safety all of the time and the worry took its toll on the whole family. We just couldn’t look after Frances at home anymore, so a decision was made to look for residential care. Frances moved into a lovely nursing home not too far away, so we can all visit regularly.

Bernie Donoghue,
Family Carer

KEY FACTS ABOUT DEMENTIA

- 48,000 people are living with dementia in Ireland
- There are 50,000 dementia family carers in Ireland
- There are an estimated 4,000 people aged under 65 in Ireland living with younger onset dementia[2]
- The majority (63%) of people with dementia live at home[3]
- Carers for people with dementia save the Irish Government €807 million each year[4]
- 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[5]

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[2] Pierce, M. Cahill, S. and O'Shea, E. (2014) *Prevalence and Projections of Dementia in Ireland 2011 – 2046.*

[3] Ibid.

[4] Cahill, S., O'Shea, E. and Pierce, M. (2012) *Creating Excellence in Dementia Care; A Research Review for Ireland's National Demetia Strategy,* TCD/NUIG.

[5] Ibid.

THE ALZHEIMER SOCIETY OF 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. We work to ensure the voice of people with dementia and family carers are heard. The Dementia Carers Campaign Network is open to anyone in the Republic of Ireland who has experience caring for someone with dementia. It is a national campaigning group, raising awareness of issues facing families affected by dementia and lobbying for policy change. If you would like further information about the Dementia Carers Campaign Network please contact us at advocacy@alzheimer.ie.

CONTACT US:

Email: advocacy@alzheimer.ie

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Alzheimer National Helpline **1800 341 341**

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