



The Cost of Living while Caring

A brief report on the financial situation of family carers of people with dementia in Ireland



Introduction

There are over 64,000 people living with dementia in Ireland, which is expected to double to 150,000 by 2045¹. Over 180,000 people in Ireland are or have been carers for a family member or partner with dementia, with many more providing support and care in other ways. **The Alzheimer Society of Ireland (The ASI)** works in communities across Ireland to provide essential dementia-specific services and supports to people living with dementia and their families.

The Irish health and social care system is dependent on family carers who provide the lion's share of care to people with dementia. The value of this work to the State is estimated to be in the region of €804m per annum². In June 2022, Family Carers Ireland published the second national State of Caring report, which captures a snapshot of what life is like for family carers in Ireland. This includes data from 129 individuals who were caring for a person living with dementia. Family Carers Ireland is the national charity supporting 500,000+ family carers nationwide, including those supporting people living with dementia.

Caring in Ireland has long been associated with poor health outcomes such as stress, burnout and illness³. The prevalence of clinical depression for family caregivers of persons with dementia is three times the Irish national average. Unmet needs of the carer can significantly impact their quality of life, including loss of self, loss of companionship/friendship, and loss of freedom⁴. Irish research funded by The ASI highlighted that one in three spousal carers had clinically significant symptoms of depression, and the prevalence of these symptoms did not decrease among those who were no longer providing care at follow-up. 65% of respondents were women, and the majority (79%) reported providing 81-100% of care for their spouse.

¹ Alzheimer Europe (2020) Estimating the prevalence of dementia in Europe, Available: https://www.alzheimer-europe.org/sites/default/files/alzheimer_europe_dementia_in_europe_yearbook_2019.pdf

² The Alzheimer Society of Ireland (2022) Pre Budget Submission 2022.

³ Brennan et al. (2017) De-Stress: A study to assess health and well-being of spousal carers of people living with dementia in Ireland.

⁴ Hazzan, A. A., Dauenhauer, J., Follansbee, P., & Hazzan, J. O. (2022). Family caregiver quality of life and the care provided to older people living with dementia: qualitative analyses of caregiver interviews. *BMC Geriatrics*, 22. <https://bmccgeriatr.biomedcentral.com/articles/10.1186/s12877-022-02787-0>

The current cost of living crisis is deeply impacting communities across Ireland. In a report published by The ASI, families affected by Younger Onset Dementia highlighted the financial burden of supports and interventions during this challenging economic climate⁵.

This document highlights the financial challenges faced by 129 family carers of people with dementia. 122 respondents provided care to one person, while seven provided care to two or more people with dementia. This anonymised dementia-specific data has been extracted from survey data collected by Family Carers Ireland as part of The State of Care 2022 report. The online survey was completed by 1,484 current family carers who shared their views and experiences of what life is like for family carers in Ireland in 2022.

Demographic information

Age	Average age: 53 years old Ranging from: 22 -79 years old
Gender	Male (n=17): 13.2% Female (n=95): 73.6% Prefer not to say (n=2): 1.6% Missing (n=15): 11.6%
Length of time caring	Between 5 and 9 years (n=50): 38.8%
Hours spent caring per week	140-168 hours (n=57): 44.2%
Person they are caring for	Parent /Parent-in-Law (n=91): 70.5% Spouse/Partner (n=27): 20.9%

The majority of respondents were female carers, with an average age of 53 years old. Most were long-term carers of their parents/parents-in-law or spouse/partner. Over 44% of carers stated they spent between 140 and 168 hours per week caring. These findings, in particular identifying women as the primary carer, align with existing literature⁶ and Census data⁷.

⁵ Kilty, C., Curtin, C., & Fox, S. (2022). Harnessing community information and support for People with Younger Onset Dementia and their families. The Alzheimer Society of Ireland

⁶ Lafferty, A., Fealy, G., Teahan, A., McAuliffe, E., Phelan, A., O’Sullivan, L., O’Shea, D. (2016) 153 Profiling family carers of people with dementia: Results from a national survey, *Age and Aging*, 45 (2), ii13-ii56.
<https://doi.org/10.1093/ageing/afw159.151>

⁷ Central Statistics Office (2016) Census of Population, Available:
<https://www.cso.ie/en/releasesandpublications/ep/p-cp9hdc/p8hdc/p9cr/#:~:text=Increase%20in%20carers,the%202011%20figure%20of%2018%2C112.>

Respondent's financial situation

52.7% (n=68) were in receipt of Carer's Allowance. Of those who disclosed their income, almost one in three earned <€20,000 per annum (31.8%, n=41). Carers often have to leave their paid positions or work in a part-time capacity in order to support their loved ones living with dementia.

Managing the cost of caring

- 55% (n=71) of carers said they are having difficulty making ends meet. Notably, 12% (n=15) of family carers state they are having *great difficulty* making ends meet.
- 17.8% (n=23) of family carers also stated they were cutting back on household essentials.
- 22.5% (n=29) have had to cut back on seeing friends and family.
- In some cases, financial difficulties were so impactful that people had fallen into arrears with mortgage payments (4.7%) and utility bills (5.4%).

Perceived value in society

The majority of respondents (77%) feel that their value in the role of a carer is not recognised by society. Again, this data is supported by existing literature both nationally⁸ and internationally⁹.

⁸ Lafferty et al. (2022) Making it work: a qualitative study of the work-care reconciliation strategies adopted by family carers in Ireland to sustain their caring role, Available:

<https://www.tandfonline.com/doi/epdf/10.1080/13668803.2022.2043826?needAccess=true&role=button>

⁹ UNECE (2019) The challenging roles of informal carers, Available:

https://unece.org/DAM/pau/age/Policy_briefs/ECE_WG1_31.pdf



This data paints a stark picture of carers (generally women) who are struggling financially, limited in their social interactions with friends and family and not feeling valued for the work that they do in society. This situation is likely to have a detrimental impact on mental health and lead to burnout. The impact of the COVID-19 pandemic and lockdowns can be viewed as a contributing factor to the current situation as it continues to proliferate globally three years later. Research undertaken by The Alzheimer Society of Ireland (2021)¹⁰ during the peak of the global pandemic highlighted the profound impact of public health measures and closure of services amongst people living with dementia and those in a caring role. Research indicated that many family carers continue to remain at ‘breaking point’ with their mental and physical health suffering, and relationships and other priorities coming under strain.

Need for investment in financial supports

The well-being of people who care for and support loved ones living with dementia is at serious risk of deteriorating as Ireland navigates the current cost of living crisis. An already stressful and complex situation with significant health risks is being exacerbated by financial strain. The ASI and Family Carers Ireland’s teams throughout the country are meeting family carers struggling daily and this paper seeks to amplify their precarious situation. Calls to The Alzheimer Society of Ireland’s National Helpline that

¹⁰ The Alzheimer Society of Ireland (2021) Caring and Coping with Dementia: During Covid-10: Experiences of People living with Dementia and Family Carers. Available: https://alzheimer.ie/wp-content/uploads/2021/06/ASI_Covid_Report.pdf

were related to financial advice and concerns more than doubled in the first three months of 2023 compared to 2022. The vast majority of carers are very willing to provide care for their loved one with dementia, but they cannot do this without financial and psychosocial support. The Alzheimer Society of Ireland advocates for investment in psychosocial supports for family carers of people living with dementia through our Pre-Budget Submissions^{11 12} (e.g. counselling, support groups, education). It is now equally critical that there is continued and enhanced investment in financial support as carers contend with the cost of living crisis. We call on the government to:

- Include Carer's Allowance as a qualifying payment for Fuel Allowance to provide support for the rising cost of fuel and household bills and increase the capital disregard for those under 70 to €50k in line with the disregard for persons aged over 70.
- Increase the weekly rate of the Carer's Allowance to support people affected by dementia adequately. The once-off payments allocated in Budget 2023 are very welcome, but the weekly rate remains insufficient to meet the needs of struggling carers.
- The €200 cost of living lump sum due to be paid to long-term social welfare recipients in April 2023 should include carers who receive the annual Carer's Support Grant as a standalone payment, as was the case with the cost of living payments in November 2022.
- Recognise the costs of caring in the allowable deductions for Carer's Allowance, including medical expenses and fuel, and assess income on net value.

Acknowledgements

The ASI are grateful to Family Carers Ireland, particularly Dr Nikki Dunne, for providing anonymised dementia-specific data to develop this document. The Family Carers Ireland State of Caring Report can be read [HERE](#).

For information and support, please contact The Alzheimer Society of Ireland's National Helpline on 1800 341 341 or visit www.alzheimer.ie

¹¹ The Alzheimer Society of Ireland. (2021). Pre Budget Submission 2022. Retrieved from <https://alzheimer.ie/wp-content/uploads/2021/09/The-Alzheimer-Society-PBS-2022-Long-Document.pdf>

¹² The Alzheimer Society of Ireland (2022). Pre-Budget Submission 2023. Retrieved from <https://alzheimer.ie/wp-content/uploads/2022/07/The-Alzheimer-Society-of-Ireland-Pre-Budget-Submission-2023.pdf>