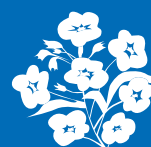


# The Experience of Dementia in Ireland: A Snapshot in Time

September 2023



THE Alzheimer  
SOCIETY OF IRELAND



## Foreword

I am delighted to present this timely report which captures the experience of living with dementia in Ireland in 2023. The report lays bare the multi-faceted complex challenges faced by people living with the condition and those who care for and support them. The lived experience regarding services, immense need, mental and physical health must be heard.

We at The ASI are grateful for the critical input of the Dementia Research Advisory Team (DRAT) and proud of the fact that this report was developed in collaboration with PPI contributors. In total, 72 people living with dementia and 597 current dementia carers took part in this work. These considerable numbers mean this is a robust piece of work that meaningfully captures the real-life experience of dementia in Ireland.

It is clear from this report that people are grappling with serious issues such as burnout, isolation, mental and physical health issues, and ever-increasing financial issues. The scale of need throughout the country is immense and services must step up to offer meaningful support. We know the right services at the right time have the power to ease the journey for people with dementia and their families.

The dementia landscape is changing, especially with the recent publication of the Model of Care for Dementia in Ireland setting out targets and practice recommendations to advance the diagnosis, treatment care and support of people with dementia and their families. We must now turn to implementing this ambitious model, as implementation has the potential to alleviate many of the serious challenges outlined in this report.

In recent times we have seen examples of good practice, and these must be harnessed and multiplied to give comfort to more people with dementia and their carers, so they are not alone on this often-cruel journey. We are at a critical juncture in dementia in Ireland and I believe one of immense opportunity to deliver the Model of Care and the framework it provides. The ongoing support from the government and Minister Mary Butler, the HSE National Dementia Office and The All-Party Oireachtas Group on Dementia combined with robust funding can ensure a more hopeful future.

Finally, to people living with dementia and family carers and supporters and in particular those who filled out the survey for this report – thank you for putting these issues into sharp focus. You have improved our understanding of what is needed in communities throughout Ireland, and we will continue to lobby for those supports on your behalf. Your voice has been heard and we will ensure your views are present in our advocacy work now and into the future.

I sincerely thank the authors of this work, Dr Laura O’Philbin and her dedicated Research and Policy Team Dr Diane O’Doherty and Ms Cíara O’Reilly here at The Alzheimer Society of Ireland and all those who provided their time and expertise to bring this work to fruition, particularly those who helped disseminate the survey and made this report possible.

A handwritten signature in blue ink, appearing to read 'Andy Heffernan', written over a light blue circular watermark or logo.

Andy Heffernan  
CEO, The Alzheimer Society of Ireland

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## About The Alzheimer Society of Ireland

The Alzheimer Society of Ireland is the leading dementia-specific service provider in 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. Our vision is an Ireland where people on the journey of dementia are valued and supported.

## Section 1:

# About this research



## Who

**72** people living with dementia

**597** current carers

## How

Paper, online and telephone anonymous surveys

## When

May – June 2023

**Dementia describes a range of cognitive, behavioural, and psychological symptoms that can include memory loss, problems with reasoning and communication, and changes in personality that impair a person's ability to carry out daily activities<sup>1</sup>.**

**Carer refers to a person who provides regular, unpaid personal assistance to a friend or family member with a long-term illness, health problem or disability<sup>2</sup>.**

In Ireland, we primarily use the term family carer. However, some carers and care recipients may see this definition as exclusionary of the care provided by neighbours, friends, unmarried partners and others. In this report, we use the term carer to include all those who provide regular unpaid care or support to a person living with dementia.

The Alzheimer Society of Ireland (The ASI) set out to capture a snapshot of living with dementia in Ireland in 2023. People living with dementia and (informal) carers shared their experiences and perspectives on services, supports, challenges, needs, and their mental and physical health. This report details the findings of this national research and reflects the experiences of people living with dementia and their carers. The *Experience of Dementia in Ireland* surveys were developed in collaboration with Person & Public Involvement<sup>3</sup> (PPI) Contributors from the Dementia Research Advisory Team<sup>4</sup> and piloted before the survey was formally launched. There were two versions: one for carers and a shortened version for people with dementia. The surveys were open to any person living with dementia or any current informal carer of a person with dementia in the Republic of Ireland over 18 years of age. Links to the survey were distributed through The ASI's TeamUp For Dementia Research service, face-to-face services, networks, and social media advertising. Potential participants were offered a choice of completing the survey online, on a hard printed copy or over the phone with a member of the research team. The vast majority of participants completed the survey online. Responses that were less than 50% complete were excluded from the analysis. Percentages have been rounded to the nearest whole number except in cases where rounding would eliminate a respondent group.

This report contains information and discussion about difficulties and challenges relating to living with dementia and supporting person with dementia which some readers may find upsetting or distressing. If needed, details of our National Helpline is available on 1800-341-341 are available on the last page of this document.

1 National Institute for Health and Care Excellence (2018). <https://www.nice.org.uk/guidance/ng97/chapter/About-this-guideline#:~:text=Dementia%20is%20a%20term%20used,%2C%20washing%2C%20dressing%20and%20cooking>.

2 HSE (2023). <https://www.hse.ie/eng/services/publications/olderpeople/model-of-care-for-dementia-in-ireland.pdf>

3 Person & Public Involvement (PPI) is 'research carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.'

4 The Dementia Research Advisory Team is a group of people living with dementia and carers/supporters who are involved in dementia research as co-researchers. These Experts by Experience influence, advise, and work with researchers across Ireland in a PPI capacity (<https://alzheimer.ie/creating-change/research/ppi/>)

## Context

Approximately 64,000 people are living with dementia in Ireland, and this number is expected to rise to 150,000 by 2045<sup>5</sup>. For every person with dementia, it is estimated that three others support that person and provide care<sup>6</sup>. Dementia care in Ireland costs over 1.69 billion euro per annum, with 48% of this attributable to family care and 43% to residential care. Formal health and social care contribute 9% to the total cost<sup>7</sup>.

There has been a welcome increase in investment in dementia services and support in recent years. However, a historical culture of scarcity in dementia service provision means there is significant ground to make up. There is not yet an adequate level of services and support to meet the needs of people living with dementia and carers. In 2020 and 2021, the COVID-19 pandemic illuminated the sparse and scarce nature of dementia service provision, while lockdowns and service closures did serious harm to the mental and physical health of people with dementia and their families. As dementia continues to proliferate against the backdrop of the escalating Cost of Living Crisis, so too does the gap between services and needs. Although the Irish State has strongly invested in ringfenced dementia-specific home care in recent years, the home care staffing crisis is now decimating this already over-stretched service.

It is well established that people living with dementia and carers face isolation, declining health, fear, stigma, stress and burnout. There is no doubt that dementia is a life-changing and devastating diagnosis, both for the person and their loved ones, however, the right services and support have the power to ease the journey. The person with dementia is not the cause of the immense difficulties experienced by carers. It is the scarcity of dementia-specific services and supports across Ireland. There are pockets of good practice across the country, but in many areas, there continue to be major challenges in accessing services for people with dementia. Considering this research was carried out by The ASI, the largest dementia-specific provider in Ireland, it is likely that service access is even lower than it appears in this report.

The national and international dementia landscape is changing for the better with the recent publication of the landmark *Model of Care for Dementia in Ireland*<sup>8</sup> which sets out targets and practice recommendations to advance the assessment, treatment, care and support of people with dementia and their families in Ireland. Implementing this ambitious model is of critical importance as it has the power to alleviate many of the challenges faced by people living with dementia and carers. Internationally, there is a growing evidence base on the potential for risk reduction and prevention in parallel with innovations in disease-modifying therapies and diagnostics<sup>9 10</sup>.

We all have a role to play in supporting people living with dementia and their families, but strong and sustained funding is essential to make this happen. There is an urgent need for planning and investment to support people with dementia and their carers to live as well as possible and to prepare for future service needs, care innovations, and treatment developments.

5 HSE & National Dementia Office (2020). <http://dementiopathways.ie/permacache/fdd/cf3/792/e223695cf65ee173882bdc394de3a8fc.pdf>

6 Cahill S, O'Shea E & Pierce M (2012) [https://dementia.ie/wp-content/uploads/2020/01/future\\_dementia\\_care\\_in\\_ireland.pdf](https://dementia.ie/wp-content/uploads/2020/01/future_dementia_care_in_ireland.pdf)

7 Trépel, D., Crean, M. & Begley, E. (2018). <https://alzheimer.ie/wp-content/uploads/2018/12/Economic-Analysis-of-Home-Care-Services-Summary-Document.pdf>

8 HSE (2023). <https://www.hse.ie/eng/services/publications/olderpeople/model-of-care-for-dementia-in-ireland.pdf>

9 Livingston et al. (2020). [https://doi.org/10.1016/S0140-6736\(20\)30367-6](https://doi.org/10.1016/S0140-6736(20)30367-6)

10 Cummings J et al. (2023). <https://doi.org/10.1002/trc2.12385>

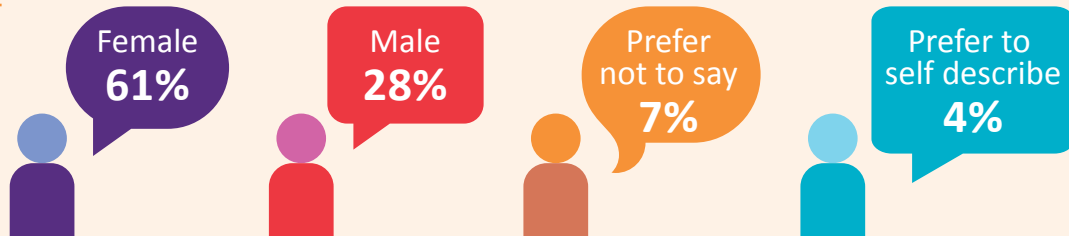
Section 2:

# Profile of respondents

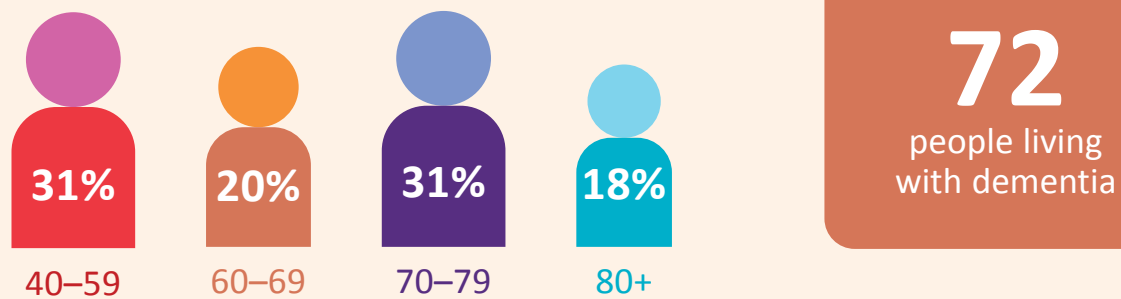


# Profile of respondents with dementia

## Gender



## Age



## 'What is your sexual orientation?'

Straight / Heterosexual	92%
Gay man	4%
I prefer not to say	3%
'I use a different term'*	1%
Lesbian / Gay woman	0%
Bisexual / pansexual	0%
Asexual	0%

\*Abrosexual

## 'What is your ethnicity?'

Irish	89%
Any other white background	7%
Irish Traveller	3%
Please write in description	1%
Any other Asian background	0%
Chinese	0%
Any other black background	0%
African	0%

## 'What type of dementia do you have?'

Alzheimer's Disease	42%
I do not know my specific type of Dementia	21%
Vascular dementia	15%
Mixed Dementia	9%
Frontotemporal Dementia	8%
Lewy Body Dementia	4%
Another type	0%

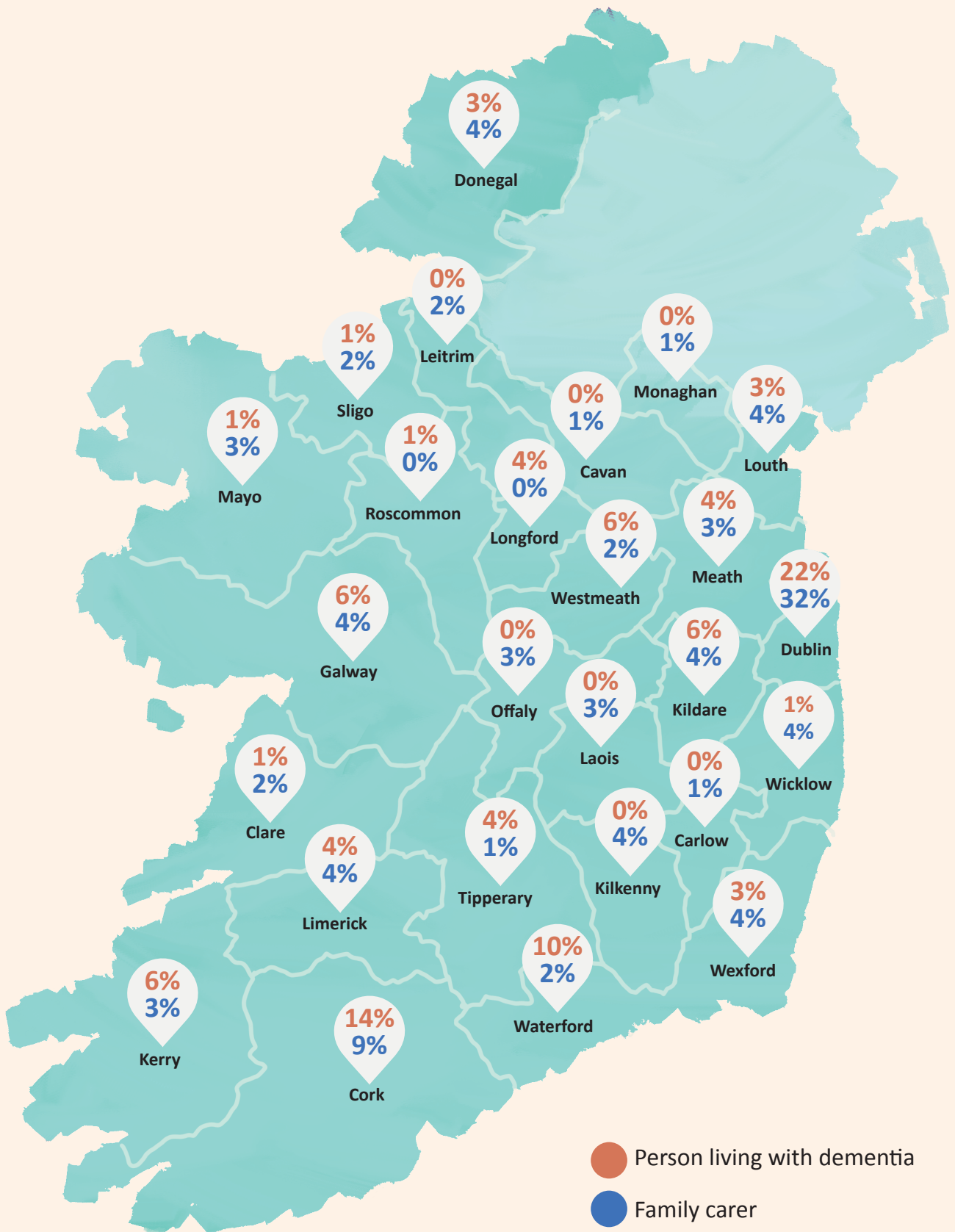
## 'Time since receiving your diagnosis of dementia'





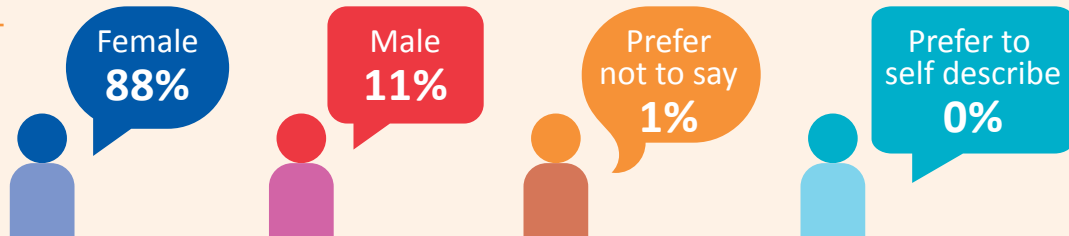
2: Profile of respondents

What county do you live in?

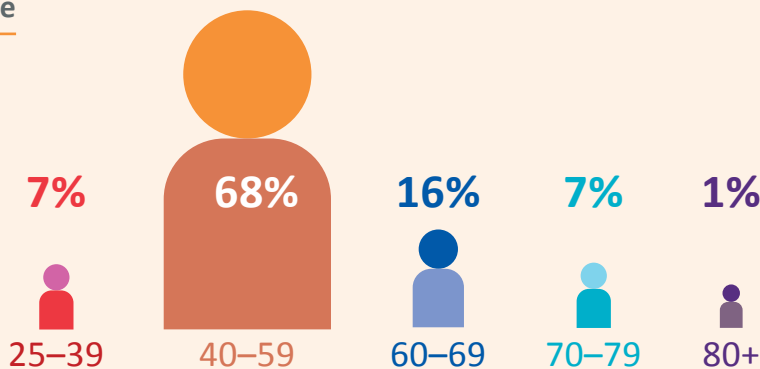


## Profile of carers

### Gender



### Age



**597**  
current carers

### 'What is your sexual orientation?'

Straight / Heterosexual	<b>92.5%</b>
I prefer not to say	<b>3.5%</b>
Lesbian / Gay woman	<b>1.4%</b>
Bisexual / pansexual	<b>1.0%</b>
Gay man	<b>0.9%</b>
'I use a different term'	<b>0.5%</b>
Asexual	<b>0.2%</b>

### 'What is your ethnicity?'

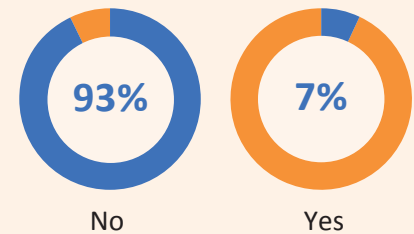
Irish	<b>94.4%</b>
Any other white background	<b>4.6%</b>
Irish Traveller	<b>0.4%</b>
Other	<b>0.4%</b>
Any other black background (outside of African)	<b>0.2%</b>
Chinese	<b>0.2%</b>

## Caring profile and service users

**‘Are you the primary carer of the person living with dementia?’**



**‘Are you caring for more than one person with dementia?’**



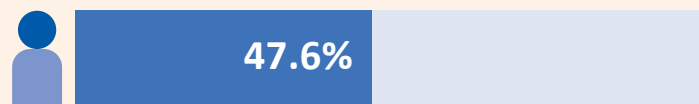
**‘What is your relationship to the person you are caring for?’**

[They are my]

Parent	74%
Spouse / Partner	18%
Other*	3%
Sibling	2%
Friend / Neighbour	2%
Uncle / Aunt	1%
Grandparent	1%

\*In laws

**Mean percentage of time spent supporting the person with dementia per week**

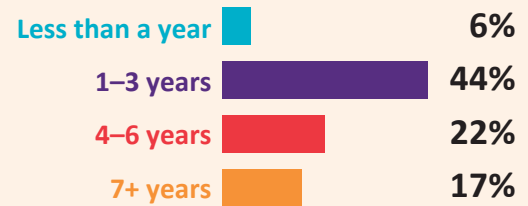


**‘What type of dementia does the person you are caring for have?’**

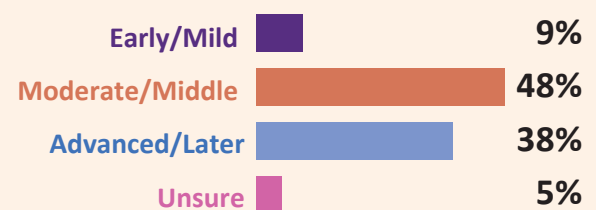
Alzheimer’s Disease	38%
I do not know my specific type of Dementia	21%
Vascular dementia	17%
Frontotemporal Dementia	10%
Mixed Dementia	6%
Lewy Body Dementia	5%
Another type*	3%

\*Posterior Cortical Atrophy

**‘How long have you been caring for or supporting this person?’**



**Approximately what stage of dementia do you think the person is at?**



## Section 3: Findings



3: Findings

63%

of carers reported difficulty accessing services, with

25%

experiencing 'great difficulty'.

57%

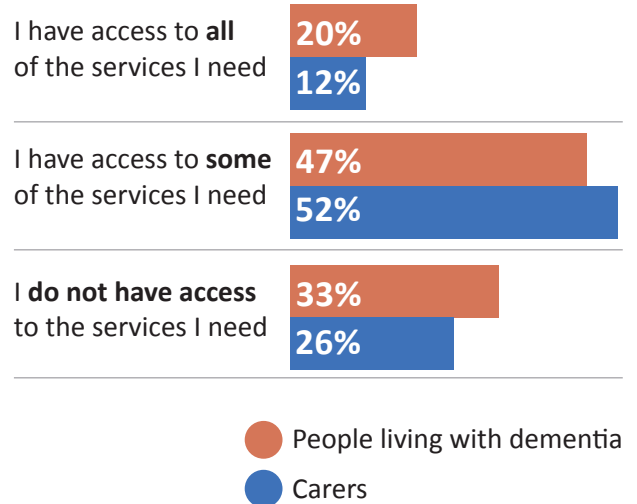
of respondents with dementia reported difficulty accessing dementia-related services, with

30%

reporting 'great difficulty'.

## Access to services and supports

In Ireland, the majority (64%) of people with dementia live at home<sup>11</sup>. In this research, 90% of respondents with dementia report living at home, while 80% of carers support a person with dementia who is living at home. Dementia-specific services are essential to support people with dementia to remain at home in their communities, with many having a dual benefit of providing respite to carers<sup>12</sup>. 33% of respondents with dementia said they currently use/attend dementia services. Similarly, carer-specific services are critical to support carers to continue providing care and minimise challenges that could impact their mental and physical health. Dementia is a complex condition, and as such, a suite of services is required to provide adequate support to people living with the condition and their carers.



“Access is provided to what is available, not to what is needed. Home care does not cover the evening. Residential respite requires that one of us be there to support my parents at mealtimes. Actual home care is not possible through statutory services, only available privately which is overwhelmingly expensive. Fair Deal system makes nursing homes the only option.”

11 Pierse, T., O’Shea, E., & Carney, P. (2019). <https://pubmed.ncbi.nlm.nih.gov/31187725/>  
 12 Pierce, M., Cullen, K. & Wynne, R. (2020). [https://alzheimer.ie/wp-content/uploads/2022/05/ASI\\_22\\_Day\\_Care\\_Report\\_Final-2-1.pdf](https://alzheimer.ie/wp-content/uploads/2022/05/ASI_22_Day_Care_Report_Final-2-1.pdf)

## Services accessed by people living with dementia

### What services do you use?

Dementia Adviser Service	17%
Local Day Centre	17%
Homecare / Home Support	15%
Support Group	13%
Other*	9%
Community / Public Health Nurse	6%
Occupational Therapy	6%
Meals on Wheels	6%
Respite Care	4%
Day Care at Home	4%
Social Worker	2%

\*Other responses listed were North Cork Dementia Alliance and activities with Engaging Dementia

## Services accessed by carers

### What dementia services do you and the person with dementia use?

Homecare / Home Support	52%
Community / Public Health Nurse	44%
Other*	23%
Local Day Centre	23%
Occupational Therapy	19%
Dementia Adviser Service	17%
Respite Care	12%
Family Carer Training	9%
Meals on Wheels	9%
Family Carer Support Group	8%
Day Care at Home	8%
Support Group (for the person with dementia)	7%
Social Worker	6%

\*Other responses included private home support, speech and language therapy, private live in carers, and befriending services. The majority listed 'none' or 'nursing home care'

## Lack of access, waiting lists and administrative burden

Respondents report significant challenges in accessing services, with the gap between services and needs evidenced by extensive waiting lists and a lack of availability. They report an administrative burden and stress in having to *'fight'* for services and support. They feel the system is *'complex'* and *'confusing'* and that there is a lack of information. One carer commented that they feel *'defeated'* by fighting for services. Many say they are currently on waiting lists but express frustration and feel *'forgotten'* as they wait months or even years for support. Frustration is also expressed with the difficulty of navigating multi-disciplinary services and there is a perception that there is a disconnect across services. Many respondents commented on problems accessing their Public Health Nurse.

“At every turn of our dementia path, we struggled to get any help/information for Dad especially as he lived alone. We basically were banging our heads off a wall at every turn.”

“Impossible to get a carer. Mum was assessed for 20 hours a week, she gets 5. It took 18 months to get it. Everything Mum is entitled to from the HSE is a fight and a battle getting OT, physio, carer, public health nurse, equipment, aids. Adapting the bathroom for her needs from CoCo took 18 months with 20 pages of a form to fill out.”

“I'm not completely disabled but we fight for every support and they forget we exist.”

“Not sure what services there are available so therefore cannot ask for specific assistance.”

“The caring part is certainly tough, but I do it because I love my Mom; what is more difficult, and makes it more stressful is dealing with PHN and other services to try to get some support to help keep Mom at home.”

Accessing home care is a particular struggle, and respondents highlight a large discrepancy between the number of hours needed, the number of hours granted and the number of hours received. People with dementia and their families feel they do not have access to enough day services, and many who attend day centres desire additional hours. Respite options are limited, and some respondents feel they are not suitable for people living with dementia. Furthermore, many dementia services are provided during the standard working day; however, respondents highlight the urgent need for support in the evenings and at weekends.

“I feel frustrated and tortured dealing with this disease and feel I had to fight all the time to get anything for Mam which was so difficult as I had no fight left in me while trying to manage Mam as well.”

“When we used day services they were over-subscribed and hard to find a place.”

“Not enough local day care centres for me to enjoy and give my family some time to themselves.”

“Rejected for home care support by HSE on grounds of family members living nearby. The fact that we family members have other full-time jobs and other family responsibilities was not taken into consideration. My father gets absolutely no support from the state other than a periodic memory clinic appointment. The memory clinic has been supportive with letters to HSE requesting care hours but to no avail. It’s appalling.”

“Not enough help out there! Was very anxious and couldn’t get support needed.”

“Suitable respite places are very scarce for patients. And private respite is expensive and not always suitable to meet patients’ needs.”

“There is no support for me and my family, we are currently on waiting lists for emergency respite, day care, home help and any other support. To date, we have had nothing despite applying for everything.”





## 3: Findings

## The urban/rural divide

The urban/rural divide compounds service access issues in rural areas through reduced availability of services, staff, and wider catchment areas. The lack of transport to and from services is a significant challenge for people with dementia and carers. The impact of no longer being able to drive can also be seen here, as people with dementia struggle with *“getting around”* and having issues with public transport *“no direct bus to city”*. Several respondents, particularly from rural areas, cited the need for help with transport to access support in their communities. There are areas in Ireland with no home care workers available to support people with dementia.

“Mam lives in South Galway. Prior to moving into the nursing home we did avail of what we could re public health. However, it can be hard to get appointments due to too few nurses, chiropodists, etc., across a wide geographic area.”

“Because we live in the West it is next to impossible to get any services. Most aren’t available or prioritised for rural areas or anywhere outside of Dublin/Cork.”

“(I) live in a rural area, although we qualify for home help, no person available to come and carry out tasks, even for 45 min twice weekly.”

“There is a complete absence of support and care in rural areas. As a carer, I am totally burnt out.”

“On a waiting list for nearest day care centre, (I) have to travel 30 miles to present care centre.”

“I have to be able to drop and collect my husband to day care as they don’t have sufficient transport, this was very difficult while I working full time.”

“We have 1 centre here in Waterford city, I live 17 miles outside of the city, so access to same is difficult as I am dependent on family to bring me. Secondly, only a small number of places are available, so access is restricted, and no 3, I have mobility issues, need to use a walking aid and find that a barrier to attending the service.”

“Home help approved no staff available. No transport to day centre my Mum wants to attend. No home support available.”

## Impact of the Home Care Staffing Crisis

The Home Care Staffing Crisis continues to diminish home care provision. There is unequal pay and conditions between the HSE and nonprofit sector, making recruitment and retention a significant obstacle in the latter. Dementia-specific home care is complex and requires specialised competencies and skill sets, which are often not reflected in remuneration.

“Person has been sanctioned full home care package, i.e. 3 visits daily, this has never been fully supplied due to staff shortage, holiday cover is missing as often as not and worse, we’re often not informed.”

“I only have 3 hours support despite being allocated 7 hours.”

“Regular home help went on a week’s hols (holidays) and didn’t come back for 9 weeks, we were left without for 6 of those with no explanation to where home help was. We were new to service.”

“Challenges getting care staff; this group rotate frequently and often comment on pay and poor travel fees; inconsistent agency supply, especially at weekends and public holidays.”

“We have had to wait for weeks and weeks to get the care we were approved for. Everyone is so nice and kind and trying their best, and we are lucky that my mother and sisters are all well educated and well able to keep going to get all that Daddy is entitled to, but I think it must be very difficult for people who aren’t used to all the paperwork etc.”

Many respondents regularly receive markedly fewer hours than allocated as there simply are not enough staff to deliver them. This is causing significant stress and frustration, and several carers have felt forced to seek out additional home care hours with a private provider so they can continue to work. A lack of cover for sick leave and holiday leave can result in the person with dementia being left without home care, often for weeks on end. This induces stress and anxiety, with many carers reporting *‘fear’* that nobody will turn up to care for their loved one. Continuity of care is essential for providing quality dementia-specific home care; however, the home care staffing crisis prevents this due to increasingly high staff turnover.

“Our carers are constantly changing which causes trouble for my Dad. We had a great relationship with some of them and then they get pulled from us. This means my Dad then struggles with some and, as a result, doesn’t always cooperate with the care.”

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**Of the 236 respondents who are in receipt of home care**, almost two-thirds (**63%**) have experienced a delay or a reduction in the delivery of home support hours or a home support package due to a shortage of home care workers.

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## 3: Findings

## Admission to long term care

Some carers report that a lack of access to services is pushing them to consider long-term care options, even though their preference is to support the person with dementia living at home.

“In the early stages it got impossible to get home care two hours a week. I am an only child, my Dad passed away ten years ago, Mam moved very quickly to next stage, eventually had to let her go to nursing home, broke my heart and the guilt if only I got more help.”

“Home Help support not available in our area with the result that when Mom’s mobility deteriorated, she had to go into care when she could have stayed at home if we had the correct home help support in place.”

“My parent doesn’t wish to go into a home, and I don’t want to resort to it. We just need more help to keep them at home.”

“HSE home helps are unreliable. Nursing home is the only option in my opinion. We would love to keep Mam at home but supports were not enough.”

## Service suitability

**Person-centred care means the person is ‘viewed, treated and valued as an individual with dignity and respect’<sup>13</sup>.**

Recognising and supporting equality and diversity is essential to the provision of person-centred care as it facilitates a more inclusive approach to care by identifying and removing barriers to access and participation, enabling individuals to use a wide range of services and facilities while valuing and supporting everyone who avails of that care<sup>14</sup>.

Some respondents from minority backgrounds commented that culturally sensitive dementia support is lacking.

“The ONLY LGBTQI+ dementia service in Ireland is underfunded and hanging by a thread.”

“Culturally competent dementia service in Ireland is not readily available, so I access it elsewhere.”

“There’s nothing out there for travellers like me.”

“I don’t seem to be able to find any information about support services for my parents who don’t have perfect English.”

13 HSE (2023). <https://www.hse.ie/eng/services/publications/olderpeople/model-of-care-for-dementia-in-ireland.pdf>

14 Walsh, M., Millar, E., Rowe, J., Mitchell A. (2012). Health and Social Care Level 2 Dementia Care Award and Certificate. Collins Education, London.

## 3: Findings

**Young Onset Dementia occurs in people under 65 years of age.**

It is well established that people affected by Young Onset Dementia (YOD) have unique support needs due to their age and stage in life<sup>15</sup>. Many are in employment when symptoms arise and have active social lives with financial and family responsibilities. In this research, 29% of respondents with dementia and 14% of carer respondents are impacted by YOD. They convey frustration with a lack of YOD-specific services suitable for their needs. This cohort is particularly vulnerable to access issues as they are often not entitled to access existing dementia services due to their age, and those they can access are unsuitable for their needs. One respondent highlighted how people with Down Syndrome and dementia fall through the cracks.

“There are no appropriate supports for early onset Frontotemporal Dementia in our area and no day care services. Respite services are not appropriate for under 65’s and are hard to access if the person with dementia is not bedridden.”

“He is too young to be eligible for most services.”

“My sister has Down Syndrome. Because she is early onset dementia, Public Health is not interested as she is under 65. She was discharged from ID [Intellectual Disability] services because she had a Dementia diagnosis. This cohort of people (i.e. Down Syndrome and Dementia) need to have an agreed pathway.”

“We were also told that most of the support groups are for much older people, that would be depressing even more for my father.”

“My mother doesn’t want any help for Dad because she doesn’t really accept/understand that he is ill.”

A commonly cited frustration of carers is that the person with dementia does not want to attend certain services or is unwilling to accept support in their home. People living with dementia commented that some services are not suitable for their needs and, therefore, will not attend. Indeed, there is a cohort of people for whom services are not of interest due to their personal preferences, highlighting the importance of maintaining a suite of options for people with dementia. Some carers mentioned that the person living with dementia is unwilling to acknowledge their diagnosis and, therefore, not willing to seek help.

“The help that’s available is not applicable to my needs. It’s just a one size fits all.”

15 Kilty, C., Curtin, C. & Fox, S. (2022). [https://alzheimer.ie/wp-content/uploads/2022/09/ASI\\_22\\_YOD\\_Report\\_LR.pdf](https://alzheimer.ie/wp-content/uploads/2022/09/ASI_22_YOD_Report_LR.pdf)

# The role of local community

## Engaging with communities

Ireland is well known for its strong and welcoming community culture, particularly in more rural areas. 24% of people with dementia engage with community initiatives they find helpful for dementia, such as age-friendly clubs, cafes, boules, men's sheds, choirs, sewing groups etc. Several respondents with dementia voiced their need to continue attending local community groups and initiatives such as local GAA clubs, social clubs and singing groups. Similarly, 18% of carers said that they, or the person they support, engage with community initiatives that they find helpful for dementia.

"Making Connections choir in St Raphaela's in Stillorgon is great."

"I'm a member of a gospel choir which meets weekly, the support of this group of fantastic, friend family helps take my mind to better places. I've even brought my patient to practice when unable to arrange cover and they were welcomed with open arms."

"I used to be very actively engaged with all local groups GAA, active retirement, community alert, historical committee, War of Independence commemorations, political party activist. But when I was diagnosed with dementia, all that stopped because I thought it was the end. Until I met [an occupational therapist] and her team. After the first six weeks course, they gave my confidence back and the courage to get up and start living again."

"One very good thing that has happened is a volunteer, (from a local organisation called 'Contact' whom I phoned myself), who comes for about an hour once a week. I also go to Western Alzheimer's carer support group when I am in Galway and can go; I've also gone to one or two Alzheimer's (Society of) Ireland monthly meetings in Galway."

"They are not dementia-friendly, but activities that Mam did before diagnosis, so she was well-liked within the groups, and they look out for her, which means she's been able to continue on with them."

## 3: Findings

## Barriers to access

However, 72% of people living with dementia and 80% of carers say they do not engage with community supports. 18% of carers said there were no available community-based initiatives in their area while 37% of people with dementia said there were no community supports available in their area that were of interest to them. Of great concern is that 18% of carers and 35% of people with dementia say that local community groups in their area are not dementia-inclusive, which is a barrier to attending.

Other barriers to accessing community supports include the person with dementia's symptoms being too advanced, lack of awareness of what's available, no time, physical mobility issues, fear of socialising, lack of trust, and sensory impairment. One person with dementia commented that they live in a nursing home but would still like the opportunity to access community groups.

"She was asked not to come back to her local community group as it was too hard to keep an eye on her wandering."

"Not sure they would be okay there."

"I don't know if any initiatives in our area, but transport would be an issue and they need someone to accompany them to everything."

"[I am] quite deaf and a bit shy."

"Prefer to spend time with people I know and trust."

"I'm working full time, as are my brothers, and it is all we can do to keep the basics going."

"And even when he wasn't too bad, there were very few people willing to help take him (I work fulltime) and my Mum couldn't lift or change his pad etc). If he did soil his pad, in (the) middle of (an) event, then that ruined it for everyone! Easier to stay at home."

"He was never keen on joining in to community-type events, groups of people are too noisy for him. One-on-one care and attention and entertainment would be brilliant for him (i.e. music)."

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A lack of transport is a barrier for **21% of carers and 27% of people with dementia** in attending services both in urban and rural areas.

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## 3: Findings

Stigma, lack of awareness, and discrimination against people living with dementia, have a detrimental psychological, social and emotional impact on them and their carers<sup>16</sup>. This can lead to those diagnosed with dementia and carers withdrawing from their usual social activities and limiting their interactions with local communities. Some carers discussed this further:

“It is a huge strain on us all...It has devastated us completely and we find that many people avoid Mam and Dad because they don't know how to deal with it.”

“Lack of simple contact with others dealing with dementia – stigma is part of this.”

“It's (dementia) poorly understood by the community in general so I find it very lone(ly) and isolating to be coping.”

“Lack of understanding of the disease in the general realm.”

Considering that there has been strong investment in anti-stigma and awareness campaigns by the HSE and The ASI, the level of perceived stigma present in this research data is somewhat surprising. Stigma and poor awareness of dementia compounds barriers to accessing dementia supports and services.



16 World Health Organisation (2021). <https://www.who.int/publications/i/item/9789240031531>

3: Findings

16%

of respondents receive **Carers Allowance.**

3%

of respondents receive **Carers Benefit.**

14%

of respondents receive the **Annual Carers Support Grant.**

8%

of respondents receive **Fuel Allowance.**

67%







of respondents report that they receive **none of the above benefits.**

(From 335 respondents).

## Caring and financial challenges

The Irish health and social care system is dependent on carers who provide the majority of care to people with dementia. The value of this work to the State is estimated to be in the region of €804m per annum<sup>17</sup>. The escalating Cost of Living Crisis is now exposing an already vulnerable cohort to more difficulty due to the cost of care and a reduced ability to work.

### How well is your household able to make ends meet?

Very easily		7%
Easily		10%
Fairly easily		33%
With some difficulty		30%
With difficulty		11%
With great difficulty		9%

308 respondents report being involved in financial aspects of caring for the person with dementia, such as paying for all/some of their expenses, financing care etc. Of these, 269 disclosed their average household income. According to the most recent CSO figures, the average household income is €46,999; however, one in three respondents report an average household income below €30,000 per year<sup>18</sup>. Many carers have reduced their working hours or left their work entirely to provide support and care to the person with dementia. 36% of carers report needing to make work adjustments ‘all of the time’ (20%) or ‘most of the time’ (17%) to provide care for the person with dementia.

17 Connolly, S., Gillespie, P., O’Shea, E., Cahill, S., Pierce, M.(2014). <https://pubmed.ncbi.nlm.nih.gov/24381036/>

18 Central Statistics Office (2022). [https://www.cso.ie/en/releasesandpublications/ep/p-silc/surveyonincomeandlivingconditionsilc2022/householdincome/#:~:text=Nominal%20Household%20Income&text=The%20median%20nominal%20household%20disposable,%25\)%20from%20the%20previous%20year](https://www.cso.ie/en/releasesandpublications/ep/p-silc/surveyonincomeandlivingconditionsilc2022/householdincome/#:~:text=Nominal%20Household%20Income&text=The%20median%20nominal%20household%20disposable,%25)%20from%20the%20previous%20year)



3: Findings

## Struggling to make ends meet

These difficulties were most pronounced in households earning less than €30,000 per annum. However, financial challenges are not limited to lower-income households. Only households reporting income of €150,000 and above reported no difficulties in making ends meet. It should be noted that these difficulties are not limited to people caring for a person with dementia who lives in the community and are felt strongly by those supporting a person living with dementia in a nursing home too. (Figure 1).

**50% of carers** report having difficulty making ends meet. Notably, more than one in ten report having ‘*great difficulty*’ making ends meet.

Figure 1: Ability to make ends meet broken out by living situation

### The person lives in their own home (with me or with visits from me)

Very easily	6%
Easily	10%
Fairly easily	35%
With some difficulty	29%
With difficulty	9%
With great difficulty	9%
Don't know/prefer not to say	5%

### The person lives in a nursing home or other long term care facility

Very easily	1%
Easily	8%
Fairly easily	26%
With some difficulty	26%
With difficulty	13%
With great difficulty	13%
Don't know/prefer not to say	14%

### The person lives in my home

Very easily	14%
Easily	11%
Fairly easily	23%
With some difficulty	23%
With difficulty	14%
With great difficulty	11%
Don't know/prefer not to say	5%

### The person lives with another family member (with visits from me)

Very easily	5%
Fairly easily	32%
With some difficulty	36%
With difficulty	9%
With great difficulty	9%
Don't know/prefer not to say	9%

## 3: Findings

## Financial realities

Carers describe difficulties keeping up with mortgage repayments, bills, and buying food. Many rely on family members' loans or erode their savings just to stay afloat. They report consistent worry and guilt about their own and their children's futures.

"I can't work full-time as my Mam and aunts need so much attention with constant phone calls etc., however, I'm over the thresholds for government support so I am the working poor living paycheck to paycheck, also with Fair Deal every penny of my mother's and aunts goes to the nursing home and their care even though the family home with my 90 year old father still needs to be maintained and ran."

"Most of my father's pension now goes towards nursing home fees, my mother struggles to make ends meet without him."

"My savings have gone."

"Going without. Late payments on bills. Needing to borrow."

"We have 3 children. We can manage to pay for care for Dad for a while because we have a cushion but if it goes on for years the kids suffer."

"Difficulty paying the additional charges from the nursing home and ability to make repayments on a life loan."

"Travelling every weekend to care for mam, cost of diesel."

"Fear as disease progresses what options we will have full-time care is too expensive."

"Uncertainty about the future and how to fund care."

The rising cost of living goes hand in hand with a rising cost of providing care and support to people with dementia, the effects of which are being felt deeply by carers. One person stated that they could no longer afford to make regular visits to their relative with dementia due to the cost of petrol.

"My father doesn't know how to judge money. We subsidise everything other than his phone credit he pays for himself and if he buys any treats from the shop and his lottery ticket. He contributes nothing to food, electricity, bins etc. The sanitary pads he wears are heavy. It all adds up."

## Intensifying the challenges of caring

Carers experience more stress and burnout in addition to poorer physical and mental health outcomes than the general population. Financial challenges intensify the stress, burnout and health challenges they already experience. Many respondents report cutting back on socialising, hobbies, and what they deem *'non-essentials'*. However, these are the very things that can support people to maintain their mental health, reduce feelings of loneliness and isolation and even provide some reprieve from stress and anxiety.

These findings align with 2022 data published by The ASI and Family Carers Ireland, which highlighted the same financial challenges faced by carers of people with dementia as they contend with the Cost of Living Crisis<sup>19</sup>. This research clearly shows that, one year on, carers continue to experience financial hardship and intensified stress, worry and anxiety on top of their caring role.



19 The Alzheimer Society of Ireland & Family Carers Ireland (2023). <https://alzheimer.ie/wp-content/uploads/2023/03/The-Cost-of-Living-while-Caring-FINAL.docx.pdf>

## The experience of living with dementia in Ireland

Dementia is a life-changing diagnosis, both for the person receiving it and their families. People living with dementia and carers participating in this research opened up about their daily lives and challenges. This section reflects the experience of both cohorts.

The greatest challenges reported by respondents with dementia are (a) difficulty accessing supports and services, (b) the impact of dementia on mood, memory and independence, and (c) loneliness and isolation.

The greatest challenges reported by carers are (a) balancing caring responsibilities with employment and/or raising children, (b) financial strain, (c) difficulties accessing services, (d) poor mental and physical health, (e) loneliness and isolation, and (f) not understanding dementia as a condition.

“The toll on my mental and physical health has been almost to the point of catastrophic both prior to and following diagnosis. I am on antidepressants following psychotherapy and am now dealing with a cancer diagnosis.”

“I recently started having stress-induced panic attacks.”

“I’ve had to avail of counselling to help me cope.”

### Deteriorating mental and physical health

Both people with dementia and carers report grappling with deteriorating mental and physical health. Memory loss, worsening symptoms and declining physical health impact the person with dementia’s ability to remain independent and create feelings of anxiety about the future. The emotional impact dementia has on people living with the condition is multi-faceted. They report experiencing feelings of “*confusion*” and “*depression*” as their condition progresses alongside a “*loss of self*.” Respondents with dementia also cite difficulties with their physical health bringing about reduced independence. They highlight challenges with their mobility and finding themselves “*unsteady*” on their feet, requiring “*mobility assistance*”. Many carers report seeking treatment for mental health issues and suffering a range of stress-related illnesses, including high blood pressure, panic attacks and, in one case, premature labour. Others have cancelled surgical procedures or are using their sick leave entitlements to provide care, leaving them in a vulnerable position.

3: Findings

34%

of carers reported below-average physical health, with

12%

experiencing poor physical health.

43%

of carers had visited a healthcare professional in the past month on account of their health.

43%

of carers reported below-average mental health, with

16%

experiencing poor mental health.

14%

of carers report feeling depressed 'most of the time', and

6%

report feeling depressed 'all of the time'.

4%

of carers report that they 'never' feel cheerful

"My confidence is gone."

"I am no longer self-sufficient, can't remember how to do basic tasks."

"The stress was so unbearable I went into premature labour."

"I have had to take 3 months off work to be able to cope and to try to get my own health back on track as I ended up with dangerously high blood pressure from stress."



"I have developed high blood pressure and my husband has developed IBS from the stress of caring for our loved one."

"My physical, mental and emotional health has been very much negatively impacted by the stress and distress of caring."

"I had to give up work because of anxiety and depression issues and there was no free external help for grief counselling or financial advice."

9%

of carers report they 'never' feel they are enjoying life

31%

of respondents with dementia rated their mental health as poor while

32%

rated theirs as fair.

46%

of carers felt worried or anxious often in the last week.

20%

of respondents with dementia said that, in the last week, they have not felt like they are enjoying life at all.

58%

of respondents with dementia rate their physical health as below average, with

32%

of respondents rating it as 'poor'.

## Loneliness and isolation

Loneliness describes how someone feels when they lack meaningful social or emotional connections. It is recognised as a public health issue that impacts both at an individual and societal level<sup>20</sup>.

Loneliness is an internationally recognised public health risk that has long been associated with poor health and higher rates of mortality<sup>21</sup>. People living with dementia cited struggles with “making conversation” and “engaging with others.” Communication also affects the person living with dementia’s ability to socialise as some experience confusion or “can forget what I am trying to say sometimes.” Experiencing “frustration with language/vocabulary” can negatively affect the person’s ability to communicate and engage socially. Respondents also referred to a lack of “stimulation”. One person called for “social activities the family can do” while another mentioned the challenge of “socialising as I depend on my children who work busy jobs.” Similarly, many carers report that the person they support is experiencing loneliness and point to a need for increased opportunities for people with dementia to socialise with people in their communities who understand their condition.

“It’s a very lonely journey.”

**55% of respondents with dementia** said they have felt lonely in the last week, with **30%** feeling lonely ‘a lot’ in the last week.

“I live on my own... I’m very lonely and vulnerable. When I go out, I stop traffic. If someone was with me, they could help with this situation.”

“[My biggest challenge is the] General feeling once a person is diagnosed with dementia, they are given up on.”

**21% of carers** say they are ‘never’ feeling close to other people.

As a person living with dementia’s care needs increase, so too is this impact felt by the carer. Responsive behaviours, a dearth of nearby services and a lack of understanding by the public can mean less time spent in the community and more time confined to the home. A common challenge cited by carers was the impact caring has on their family situation and home life. Notably, references were made to “family feuds” and siblings becoming “estranged.” Carers noted having to cut back on hobbies, physical exercise, and opportunities to engage in social activities due to their caring role.

“When you’re in an isolated area and everything is so far away. It feels like if you’re out in the country, it’s like you don’t exist.”

20 Institute of Public Health (n.d.). <https://www.publichealth.ie/loneliness>

21 Hawkey, L.C. (2022). <https://doi.org/10.1038/s41572-022-00355-9>

3: Findings

“Very restricted to house and listening to him repeat 100 times a day and he’s bad with anxiety in the evening makes it worse.”

“It’s the loneliest road you will ever travel.”

“Finding it difficult dealing with care 24/7 do feel the loss of my independence and time to myself and not seeing friends and the lack of conversation about simple everyday things.”

“It seems like no one cares.”

“Miss my hobbies.”



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**18% of carers** say they ‘never’ feel they have somewhere to turn to for support.

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## Fear and worry about the future

Respondents expressed feelings of fear, apprehension and worry about the future. People living with dementia worry about their ability to maintain independence and are concerned about what their future looks like. Many carers are worried about their own health and their ability to continue providing care as they age, and care needs increase. Others worry about needing to give up work to provide care, and the mental health and financial challenges this will bring.

“I worry greatly about the future and having to give up work.”

“Short-term memory is going fast, living alone. Wondering how long I will be able to do that.”

“As her condition progresses, I know both (of us) will begin to suffer more and that does concern me. As her sole carer it’s a very big responsibility.”

“Definitely becoming more tiring and physically demanding. Inform myself as much as possible but the future and what it holds weighs heavy sometimes.”

“I worry about my capacity to sustain the level of care I give her as her needs increase and my own energy levels diminish with age.”

“Constantly worrying about them and their future.”

“Worried that anything should happen to me who will care for my husband.”

“Worry about end-of-life care.”

“Worrying about where my parent will be looked after if we cannot manage at home.”



## 3: Findings

9%

of carers say their sleep is disturbed *'always'*, while

24%

experience disturbed sleep *'most of the time'*.

41%

of carers feel they have less time to spend with other family members *'all of the time'* (15%) or *'most of the time'* (26%).

"It's extremely difficult to look after my own health as I work full time, have a young family and also spend a full day each weekend caring for my parents. When not there I am every day sorting things out with their carers, medical appointments, managing their household etc. by phone and email. It's endless."

**Almost one in three carers** who took part in this research spend more than **80%** of their time supporting a person living with dementia, equating to over 134 hours per week.

## Carer exhaustion and burnout

Carers have noted the full-time nature of supporting a loved one with dementia, referring to providing care "24/7," being "always on call" and "alert." Carers describe struggling to meet the demands of their caring role, particularly when combined with competing responsibilities such as raising children and working. They expressed feeling "drained," "guilty," "exhausted," and "burnt out." In most cases, they feel unable to prioritise their mental and physical health. The majority of carers (~85%) are of working age and 72% are supporting a parent living with dementia. Adult children carers are uniquely impacted as they are typically juggling unpaid care with other demanding life roles such as paid employment and/or raising children.

"I have no time to put myself first between caring for my Mam and small children. There is no time to put my needs first."

"I work full time, and spend some evenings and most weekends caring. I find it exhausting and my own home and health is getting neglected."

"(I) want to be able to help care for my mother as much as possible but I am overwhelmed and exhausted from worrying about her and trying to meet her needs while keeping on top of my children's needs too."

**38% of carers** say they struggle to cope with their caring responsibilities.

## 3: Findings

## Carer guilt and grief

Respondents report attempting to temper emotionally intense feelings of frustration with patience, whilst also contending with guilt and grief. These feelings are multi-faceted; they experience anger at themselves for losing patience, feel like they aren't doing enough for the person, and worry about the impact on other family members. It is important to remember that carers are experiencing intense overwhelm, distress, worsening health, guilt and fear in the context of grieving because a person they love is diagnosed with a progressive and life-changing disease. Many report feeling a strong sense of loss already.

"Losing my love for my mother."

"Feeling guilty or useless."

"Feeling angry at yourself for not having patience."

"I feel I have lost my Dad already."

"Our mother is very angry all of the time, nothing we do makes her happy. We're heartbroken and really stressed."

"Trying to find the hours in the day to do what's needed and feeling like a failure because I can't fit it all in."

"Finding very emotional the changes in my husband and dreading the future"

"The desperate years of feeling like you're grieving a desperate loss but still must get on with life, work, responsibilities without any real understanding/leeway given."

"I get upset easily. Experiencing a loss even though he is still with me."

"Feeling guilty at time away from my children."

"Guilt at my Mam being in a nursing home, but not enough support for her at home."

## Managing well and acceptance

A small number of carers report that they are managing reasonably well and can feel close to the person they are supporting. It is not possible to discern the specific reasons for this in the data. However, there is a positive correlation between feeling there is access to services needed and better physical and mental health. There were no significant differences between spousal carers and adult children.

“It was a shock to the system initially. After almost 3 years, I am taking it day by day.”

“Can be overwhelming at times, but mostly okay.”

“It’s tough, but what’s the alternative?”

“It is difficult at times, but I’m aware of taking care of things.”

“Hills and hollows, you grieve on the move, you get up, and you keep going.”

“We have organised and managed a good home care team, paid for by my parents, with tax relief, so that my caring is not a burden but more of an opportunity to spend quality time with both my parents.”

“While there are challenges, I love looking after my mother. She is an incredible woman. There is a privilege to this time. An opportunity to say all the things that we want to say. I am lucky.”



Section 4:

# What do people with dementia and carers need?



Respondents were asked to list the services they feel they need the most. This included services they have access to or services they feel they need.



### Home care / home support:

The most common responses among both people with dementia and carers were home support and home care *“to ensure they live their best life in their own home”*. Respondents with dementia used terminology like home ‘visits’ and ‘support’, indicating a need for support rather than the personal care typically associated with home care<sup>22</sup>. Services such as Day Care at Home which provide variety, stimulation and personalised activities to the person with dementia in their home can likely meet this need. This is likely reflective of the profile of respondents with dementia who are earlier in their journey. Many people living with dementia need home support but are denied it because they do not require personal care. Both people living with dementia and carers highlighted the need for flexibility in service provision, both in timing (i.e. outside standard working hours) and responsiveness to specific needs. Home care is in crisis due to staffing issues, yet it is one of the most urgently needed services for people with dementia and their families. *“We have a wonderful carer from Home Instead, paid for by the HSE, who is so good with my mother and it is because of her that my mother can continue to live happily at home”*.



### Day services:

Day services (both Day Centres and Day Care at Home) were highlighted as critical support for people living with dementia, with the dual benefit of providing respite to carers. Like home support, they enable the person with dementia to remain at home in their communities for as long as possible while providing opportunities for socialising and stimulation with trained staff.



### Stimulation and opportunities to socialise:

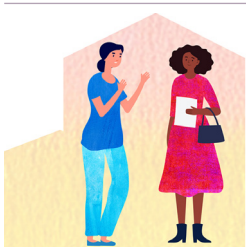
People with dementia wish to have more opportunities to socialise, meet new people and spend time with people in a similar position to themselves. They describe *‘lost confidence’*, and the importance of having the opportunity to have a judgement-free space to socialise and *‘somewhere to stimulate my mind’*. They mention the need for *‘companionship’* and *‘social stimulation’*. Opportunities for the person with dementia to socialise were also strongly cited by carers, many of whom were worried about the person feeling lonely and isolated.

22 Day care at Home is a service provided by The Alzheimer Society of Ireland. For further information visit [www.alzheimer.ie](http://www.alzheimer.ie)



## Better access to health and social care professionals:

People with dementia and carers strongly highlighted the need to engage more with healthcare professionals such as Occupational Therapists, Physiotherapists, Dentists, Public Health Nurses and Chiropodists. Respondents express concern about the lack of dementia-specific support/awareness among the healthcare professionals and staff they encounter. They feel this is a barrier to diagnosis and quality care *'Lack of education/training of people in contact with my mum'*. Many commented on the need for professionals to visit the person with dementia in their home where possible.



## Education, information and advice:

Carers highlighted the need for education, training and advice. In fact, a lack of knowledge of dementia was one of the most commonly cited challenges by carers. Respondents describe how this induces anxiety, apprehension and fear about the future. Carers describe feeling *'helpless'* when trying to support the person living with dementia as they don't understand how to help manage symptoms and unmet needs. Carers highlight the need for information and advice on future planning and end-of-life care. Some spoke about the challenge of *'Ensuring safety, dignity and respect for our loved one as the condition worsens'*.

The Assisted Decision-Making (Capacity) Act was signed into law in December 2015. The Act recognises that, as far as possible, all adults have the right to play an active role in decisions that affect them. These decisions can be about their personal welfare and property and affairs.

**47% of respondents with dementia** and **41% of carers** say they are not aware of the recently enacted Assisted Decision (Capacity) Act 2015.



## Psychological support:

People living with dementia describe the need for psychological support to come to terms with their diagnosis (*help with accepting that I have "it"*), and manage their feelings around the changes to their life and worsening symptoms. Carers describe deteriorating mental health and reaching *'breaking point'* as they try to care for their loved one while managing their own lives.

**36% of carers** said they would *'definitely'* want to avail of counselling services if provided, while **35%** said they *'probably'* would. **Almost half of respondents with dementia (49%)** said they would like to avail of counselling services, while **35%** they might like to avail of counselling.



## Meal preparation or meal delivery:

Support with meal preparation or meal delivery was frequently cited as a need by people living with dementia and carers. People living with dementia felt that cooking was a challenge for them as their disease progressed, while carers worry about the person not eating or forgetting to eat. Those living further away from the person with dementia feel that support with meals would help ease their caring load. Many respondents commented that a Meals on Wheels provider is not currently available in their area, with just 13% of respondents with dementia and 9% of carers reporting they use the service.



## Respite:

The need for respite options was strongly highlighted by carers who report feeling exhausted, burnt out and approaching crisis. The current waiting lists for respite were also highlighted as an issue if suitable beds were even available in the local area. *“Applied for respite and waiting 3 months for word back”*.



## Young Onset Dementia specific services:

Those impacted by young onset dementia were asked if there is a new service (not already available to them) that they would like to see. Of 59 responses to this question (17 people with dementia, 42 carers), most respondents reiterated the need for age-specific services, particularly age-specific day centre days with age-appropriate activities, a YOD memory cafe and YOD-specific support groups. Counselling and psychotherapy were also highlighted as a need, as well as more professional knowledge in the healthcare sector and YOD-specific information, advice and support. Those with YOD also highlighted the importance of their local communities and awareness of dementia as a disease that can impact younger people. These findings align with national and international research on YOD, including Irish research published by the National Dementia Office in 2020<sup>23</sup> and The Alzheimer Society of Ireland in 2022<sup>24</sup>.

23 Fox, S., Cahill, S., McGowan, K & Kilty, C. (2020). <https://dementia.ie/wp-content/uploads/2020/12/Youngonsetdementia.pdf>

24 Kilty, C., Curtin, C. & Fox, S. (2022). <https://alzheimer.ie/wp-content/uploads/2022/07/CK-et-al-2022-Harnessing-community-information-and-support-for-people-with-young-onset-dementia-and-their-families.pdf>

## Section 5:

# Recommendations





**5: Recommendations**

This research highlights the long-standing challenges faced by people living with dementia and carers. Difficulties accessing services combined with financial challenges, declining health, loneliness and stigma have created an unsustainable and devastating trajectory for people living with dementia and their families. Dementia is a life-changing illness, but appropriate action and investment in services and support can help ease the journey and support both people living with dementia and carers to live as well as possible for as long as possible. The following recommendations should be acted upon to address the urgent needs of people living with dementia and carers.



**Improve access to services and plan for the implementation of the Model of Care for Dementia in Ireland**

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**Open up local communities to address loneliness and isolation**

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**Provide psychotherapeutic support and education to people with dementia and carers**

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**Provide sustainable financial supports to carers**

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**Generate awareness of prevention and prepare for innovations in Disease Modifying Therapies**

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## Improve access to services and plan for the implementation of the Model of Care for Dementia in Ireland

There has been enhanced investment in dementia-specific services and supports in recent years. However, a low base, rising prevalence and growing need means there are still serious support gaps in every county in Ireland. Sustained investment is essential to meet demand for services and supports. The implementation of the Model of Care for Dementia in Ireland is of critical importance as this ambitious and transformative model has the power to alleviate many of the challenges faced by people living with dementia and carers.

- Publish an implementation plan for the Model of Care for Dementia in Ireland.
- Standardise home care rates of pay and benefits across Ireland and introduce meaningful career progression opportunities to help address the home care staffing crisis.
- Increase investment in services that provide companionship, stimulation and support to the person living with dementia with the dual benefit of providing respite to carers (e.g. Day Care at Home, befriending, home support).
- Embrace and recognise diversity of experience and need by developing culturally sensitive materials that raise awareness and information about dementia care<sup>25</sup>. These should be communicated through community leaders and contacts, rather than relying on leaflets and posters.<sup>26</sup>
- Implement sustainable funding models for Meals on Wheels<sup>27</sup> providers to ensure consistent and wider coverage of this vital service.
- Map dementia-specific resource allocation and need to understand how to optimally target investment and allocate resources in communities that need it the most. The most recent mapping project was published in 2017<sup>28</sup>.

25 Alzheimer Europe (2020). [https://www.alzheimer-europe.org/sites/default/files/alzheimer\\_europe\\_policy\\_briefing\\_on\\_intercultural\\_care\\_and\\_support\\_for\\_people\\_with\\_dementia\\_and\\_their\\_informal\\_carers.pdf](https://www.alzheimer-europe.org/sites/default/files/alzheimer_europe_policy_briefing_on_intercultural_care_and_support_for_people_with_dementia_and_their_informal_carers.pdf)

26 Alzheimer's Society (2023). <https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/how-recruit-people-dementia/cultural-sensitivity-and-awareness>

27 National Meals on Wheels Network (2023). <https://mealsonwheelsnetwork.ie/>

28 The Alzheimer Society of Ireland & National Dementia Office (2017). <https://www.understandtogether.ie/training-resources/helpful-resources/publications/reviews-and-evaluations/dementia-specific-services-in-the-community-mapping-public-and-voluntary-services-2017-.pdf>



## Open up local communities to address loneliness and isolation

It is the preference and right of people living with dementia to remain living at home for as long as possible with access to their local communities. Social engagement supports the person living with dementia to maintain activities of daily living, an underpinning of independence. This research highlights the importance of local communities to people with dementia and their families, while also uncovering barriers to access and highlighting the detrimental impact of stigma.

The findings of this research add to the evidence that people with dementia and carers are more vulnerable to loneliness and isolation, which is associated with poor health outcomes and higher mortality<sup>29,30</sup>. Ireland has the highest rates of loneliness in the EU, and people living with dementia and carers are even more vulnerable to loneliness<sup>31</sup>. According to the Institute of Public Health, a public health approach to loneliness includes facilitating healthy social choices, making connecting with others easier and increasing opportunities to build trust and understanding. Previous research commissioned by The ASI states that people with dementia must be supported to continue engaging in meaningful social activities they enjoyed before their diagnosis and it is essential to raise awareness of dementia and caring<sup>32</sup>.

- Develop an action plan to address loneliness and isolation in line with the asks set out by the Loneliness Taskforce<sup>33</sup>.
- Continue investment in fostering dementia-inclusive communities so people affected by dementia and carers can keep up their usual social activities, access local amenities and business in addition to maintaining their social networks following a dementia diagnosis. The Dementia Understand Together Campaign<sup>34</sup> and community engagement initiatives are at the heart of this work<sup>35</sup>.
- Build on investment in public awareness campaigns (i.e. Understand Together) to address the stigma of dementia, and expand the remit to grow understanding of the experience of carers.
- Provide more opportunities for people with dementia and carers to develop social networks that foster social connection i.e. through the provision of support and interest groups. Facilitating attendance at these groups through provision of transport support is essential.

29 Hawkey, L.C. (2022). <https://doi.org/10.1038/s41572-022-00355-9>

30 Institute of Public Health (n.d.). <https://www.publichealth.ie/loneliness>

31 European Commission (2022). [https://joint-research-centre.ec.europa.eu/scientific-activities-z/loneliness/loneliness-prevalence-eu\\_en](https://joint-research-centre.ec.europa.eu/scientific-activities-z/loneliness/loneliness-prevalence-eu_en)

32 The Alzheimer Society of Ireland (2019). [https://alzheimer.ie/wp-content/uploads/2019/01/ASI\\_PP\\_DementiaLoneliness.pdf](https://alzheimer.ie/wp-content/uploads/2019/01/ASI_PP_DementiaLoneliness.pdf)

33 The Loneliness Taskforce is a coalition of organisations and individuals who work to address loneliness. The purpose of the Taskforce is to increase awareness of loneliness and advocate for policy change to address loneliness at local and national level. The Taskforce is chaired by Dr John Hillery, Chairperson of the Mental Health Commission with a broad membership <https://alone.ie/loneliness-taskforce-calls-for-e5m-funding-to-address-loneliness-in-budget-2024-as-action-plan-remains-on-the-shelf/>.

34 [www.understandtogether.ie/](http://www.understandtogether.ie/)

35 The Alzheimer Society of Ireland offers community engagement initiatives across the country to empower local communities to be more inclusive and aware of dementia and caring. Examples include a sporting memories reminiscence programme, a transition year awareness and anti stigma programme.



## Provide psychotherapeutic support and education to people with dementia and carers

People living with dementia and carers have poorer mental and physical health outcomes compared to the general population. This research brings forward clear evidence that people living with dementia and carers are struggling to cope, and their mental and physical health suffers as they try to navigate their diagnosis. Throughout the COVID-19 pandemic, The ASI highlighted that carers of people with dementia were at breaking point<sup>36</sup>. Although lockdowns and restrictions are behind us, carers and people living with dementia continue to struggle.

Counselling and psychotherapeutic services are a standard offering in many other health areas and have consistently stood out as a critical support gap for this cohort. Access to professional psychotherapeutic support and training for carers is urgently required, particularly in the face of the Cost of Living Crisis, which is intensifying stress. A lack of understanding of dementia compounds fear, anxiety and stress for both the person and the carer. Imparting education and skills can better equip families to cope and support the person with dementia. The ASI provides 78% of family carer training programmes in the Republic of Ireland, which are consistently oversubscribed. For example, in May 2023, 311 people were on a waiting list for family carer training. This research found that 47% of people with dementia and 41% of family carers are not aware of the Assisted Decision Making (Capacity) Act 2015 and this must be addressed.

- Invest in providing free psychotherapeutic services for people living with dementia and carers to address deteriorating mental health, including counselling services and more facilitated support groups.
- Increase investment in family carer training to reduce waiting lists.
- Continue efforts to raise awareness and understanding of the Assisted Decision Making (Capacity) Act 2015 among people affected by dementia and carers. The Dementia Carers Campaign Network and other carer organisations have highlighted concerns regarding the administrative burden involved in providing decision-making support, and this feedback must be considered.



## Provide sustainable financial supports to carers

There must be sustained and enhanced investment in financial support as carers contend with the Cost of Living Crisis. The findings of this research are aligned with data from 2022 published by The ASI and Family Carers Ireland<sup>37</sup>, and highlights the ongoing financial strain and resulting mental health implications faced by carers of people with dementia. The following recommendations from that report must be implemented urgently.

- 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.
- Recognise the costs of caring in the allowable deductions for Carer's Allowance, including medical expenses and fuel, and assess income on net value.



## Generate awareness of prevention and prepare for innovations in Disease Modifying Therapies

The dementia landscape is on the cusp of significant change with landmark innovations in Disease Modifying Therapies and Diagnostics. It is critical to prepare for the likelihood of at least some of these innovations reaching Irish shores<sup>38</sup><sup>39</sup>. There is a rapidly growing body of evidence on dementia risk reduction and prevention which must become part of public discourse<sup>40</sup>. While it is outside the remit of this particular research, brain health is everyone's business and educating the public on prevention must be prioritised.

- Fund a dedicated Project Manager role within the National Dementia Office to consider the Irish health system's readiness for Disease Modifying Therapies.
- Develop a brain health strategy with a commitment to dementia prevention and risk reduction for the general public to build on the commitment to brain health in the Model of Care for Dementia in Ireland.
- Invest in brain health and prevention awareness through public health campaigns and education.

37 The Alzheimer Society of Ireland & Family Carers Ireland (2023). <https://alzheimer.ie/wp-content/uploads/2023/03/The-Cost-of-Living-while-Caring-FINAL.docx.pdf>

38 Cummings J et al. (2023). <https://doi.org/10.1002/trc2.12385>

39 The Alzheimer Society of Ireland is currently collaborating with Trinity College Dublin on research investigating public attitudes towards Disease Modifying Therapies.

40 Livingston et al. (2020). [https://doi.org/10.1016/S0140-6736\(20\)30367-6](https://doi.org/10.1016/S0140-6736(20)30367-6)

## Acknowledgements

We are very grateful to all of the people living with dementia and carers who took the time and energy to share their personal experiences and stories with us. It is their efforts that have enabled us to produce this work. A special thank you to Mr John Crowley, Ms Janice Nolan-Palmer and Ms Alison McCarthy (members of the Dementia Research Advisory Team) who were PPI Contributors in this work. We would also like to acknowledge and thank ASI staff across the country who supported us in our efforts.

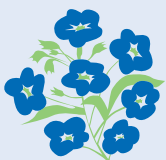
This research was carried out by The ASI Research & Policy Team Dr Laura O'Philbin, Dr Diane O'Doherty and Ms Cíara O'Reilly.

## Support

The Alzheimer Society of Ireland's National Helpline Service is open 6 days a week.

**Call 1800 341 341 or email [helpline@alzheimer.ie](mailto:helpline@alzheimer.ie).**

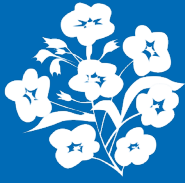
It is a confidential information and support service for people with dementia and their families, carers, anyone concerned about their memory and those working or studying in the field.



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## More information

If you have any questions about this report, or research at The Alzheimer Society of Ireland, please contact [research@alzheimer.ie](mailto:research@alzheimer.ie) or visit <https://alzheimer.ie/creating-change/research/>



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The Alzheimer Society of Ireland is a national service delivery and advocacy organisation. It is person centred, rights based and grassroots led with the voice of the person living with dementia and their carer at its core.



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**Monday to Friday 10AM – 5PM  
and Saturday 10AM – 4PM**

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