

The Experience of Dementia in Ireland: A Snapshot in Time

September 2023



Plain Language Summary



THE Alzheimer
SOCIETY OF IRELAND

Background

- Approximately 64,000 people are living with dementia in Ireland, and we expect this number to rise to 150,000 by 2045. In recent years, there has been a welcome increase in funding for dementia services and support, but there are still not enough to meet the needs of rising numbers of people living with dementia and carers.
- The Cost of Living Crisis is deeply affecting people across Ireland. There is a growing gap between service availability and the need for services. Although the Irish State has strongly invested in dementia-specific home care in recent years, the home care staffing crisis is now reducing this already over-stretched service.
- It is well known that people living with dementia and carers face isolation, declining health, fear, stigma, stress and burnout. Dementia is a life-changing and devastating diagnosis. However, the right services and support have the power to ease this journey.
- We all have a role to play in supporting people living with dementia and their families. However, strong and sustained funding is essential to make this happen and prepare for future developments in therapies, service needs and care.

Aim

The Alzheimer Society of Ireland (The ASI) set out to get an understanding of what it is like to be affected by dementia in Ireland in 2023. This report details the findings of this national research and reflects the experiences of people living with dementia and carers.

What we did

Who

72 people living with dementia

597 current carers

How

Paper, online and telephone anonymous surveys

When

May – June 2023

Profile of respondents

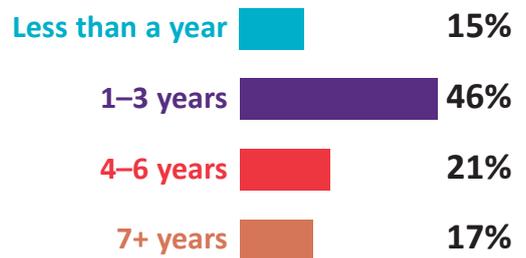
Profile of respondents with dementia



‘What type of dementia do you have?’

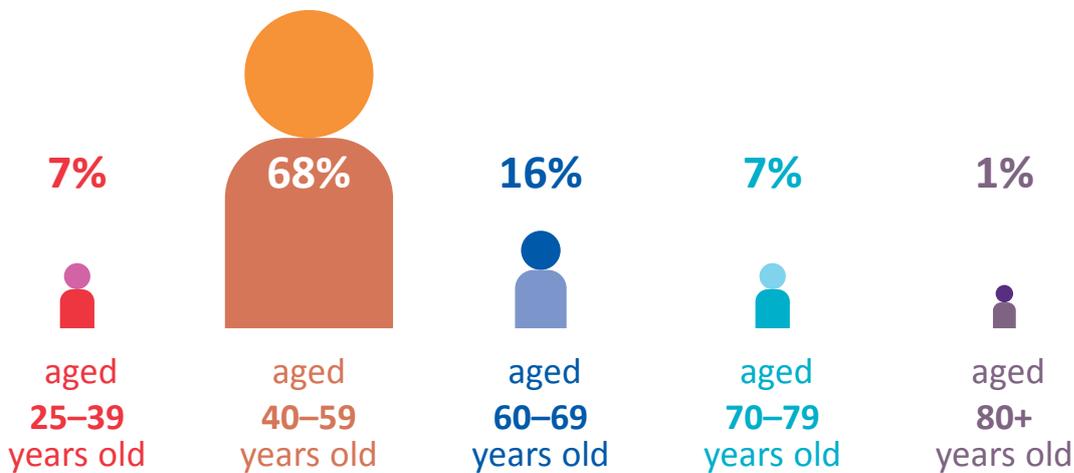
Alzheimer’s Disease	42%
I do not know my specific type of Dementia	21%
Vascular dementia	15%
Mixed Dementia	9%
Frontotemporal Dementia	8%
Lewy Body Dementia	4%
Another type	0%

‘Time since receiving your diagnosis of dementia?’



- Responses across 19 counties in Ireland

Profile of carers

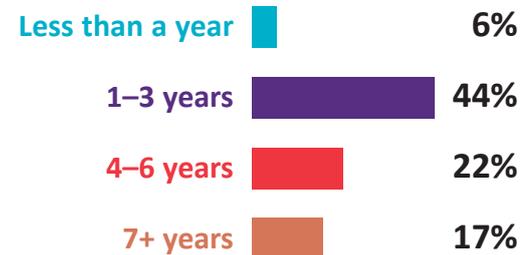


‘What is your relationship to the person you are caring for?’ (They are my)

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

*In Laws

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



- Responses across 25 counties in Ireland

Access to services and supports

- Dementia-specific services are essential to support people with dementia to remain at home in their communities, with many having an additional benefit of providing respite to carers. Similarly, carer-specific services are critical to support carers to continue providing care and protect their mental and physical health.
- 47% of people living with dementia and 52% of carers said they had access to some of the services they need
- 33% of people living with dementia and 26% of carers said they did not have access to the services they need

Many people spoke about their challenges in accessing services, including lengthy waiting lists and a lack of availability. It is important that help and advice are available from the day of diagnosis. Respondents also shared their need for support in the evenings and weekends.

Urban / Rural Divide

The urban/rural divide further impacts people's ability to access services, particularly if there are poor or no transport options available. There are areas in Ireland with no home care workers available to support people with dementia.



Home Care

Accessing home care was highlighted as a particular struggle, especially as respondents don't receive the number of hours they need. This causes stress and frustration, leading many carers to seek out additional home care through private providers.

- Of the 236 people who are in receipt of home care, 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.

Some carers said that they are considering long-term care options due to a lack of services, even though their preference is to support the person with dementia living at home.

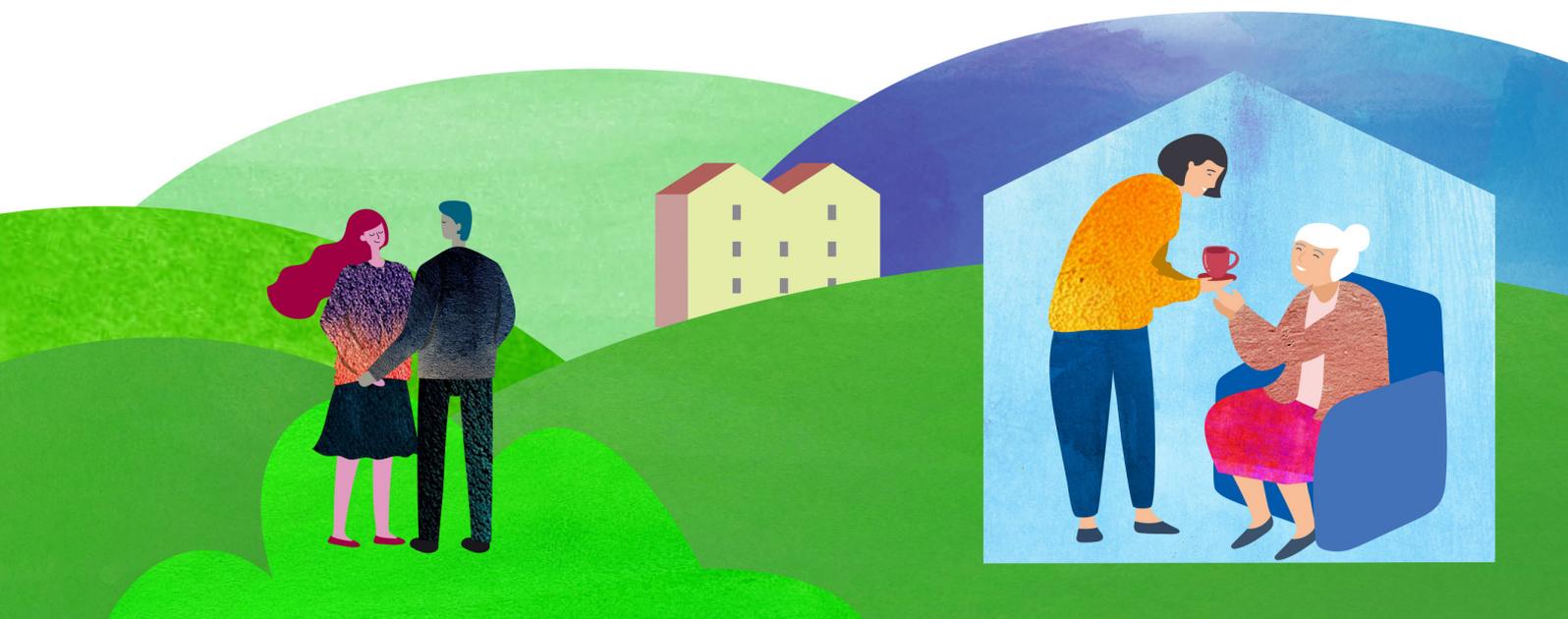
Service Suitability

Some respondents from minority backgrounds commented that culturally sensitive dementia support is lacking. It is important to recognise and support equality and diversity so that everyone is supported and enabled to attend services and facilities.

Those living with Young Onset Dementia have unique support needs due to their age and stage in life. Many are in employment and have young families when symptoms begin.

- 29% of respondents with dementia and 14% of carer respondents are impacted by Young Onset Dementia

Some people are not interested in attending specific services due to their personal preferences, so it is important to have a variety of options for people with dementia and carers.



The role of local community

In many instances, people affected by dementia voiced their need to continue attending local community groups such as GAA clubs, social clubs and singing groups.

- 24% of people living with dementia engage with community initiatives they find helpful for dementia. This include age-friendly clubs, cafes, boules, men's sheds, choirs, sewing groups, etc.
- 18% of carers said that they or the person with support engages with community initiatives that they find helpful for dementia.

Barriers to engaging with local communities

Barriers to engaging with local community

- 18% of carers said there were no available community-based initiatives in their area; 37% of people with dementia said there were no community supports available in their area that were of interest to them.
- 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.
- A lack of transport is a barrier for 21% of carers and 27% of people with dementia in attending local services both in urban and rural areas.

Stigma, lack of awareness, and discrimination against people living with dementia have a negative impact.



“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.”

Caring and financial challenges

- 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.
- 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.
- 50% of carers report having difficulty making ends meet.
More than one in ten report having 'great difficulty' making ends meet.

Many carers described their difficulties in keeping up with mortgage payments, bills and buying food. Some comments included:



**"My savings
have gone."**



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

Carers experience more stress and burnout, as well as poorer physical and mental health outcomes than the general population. Financial pressures increase stress, burnout and the health challenges they already experience.

Many respondents report cutting back on socialising, hobbies, and what they deem 'non-essentials'. However, these are things that can support people to maintain their mental health, reduce feelings of loneliness and isolation and provide a break from the stress of caring.

From 335 responses from carers, we learned:

- 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.

These research findings are in line with data from 2022 published by The Alzheimer Society of Ireland and Family Carers Ireland (*The Cost of Living while Caring Report*).

The experience of living with dementia in Ireland

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 informal caring responsibilities with employment and/or raising children,
- (b) financial strain,
- (c) difficulties accessing services,
- (d) poor health and feelings of loneliness and isolation, and
- (e) not understanding dementia as a condition.

Exhaustion and burnout

Almost one in three carers who took part in the Experience of Dementia in Ireland survey spend more than 80% of their time supporting a person living with dementia which is more than 134 hours per week.

- 38% of carers say they struggle to cope with their caring responsibilities.
- A large proportion of carers (approximately 85%) are of working age, while 72% (n=413) are supporting a parent living with dementia.

“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.”

Deteriorating mental and physical health

Carers:

- 34% of carers reported below-average physical health, with 12% experiencing poor physical health
- 43% of carers reported below-average mental health, with 16% experiencing poor mental health.

Persons living with dementia:

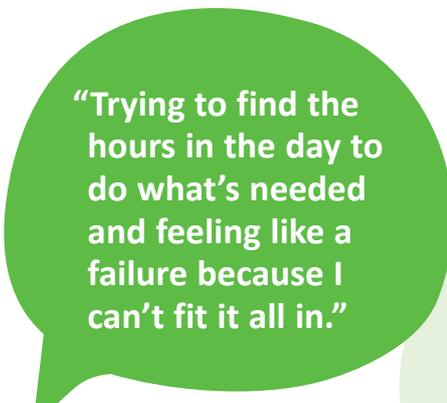
- 58% of respondents with dementia rate their physical health as below average, with 32% of respondents rating it as 'poor'.
- 31% of respondents with dementia rated their mental health as poor, while 32% rated theirs as fair.

Loneliness and isolation

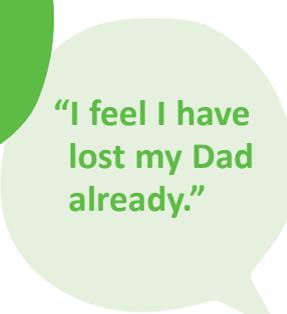
- 55% of respondents with dementia said they have felt lonely in the last week, with 30% feeling lonely 'a lot' in the last week.
- 21% of carers say they are 'never' feeling close to other people.
- 18% of carers say they 'never' feel they have somewhere to turn to for support.

Carer Guilt and Grief

Carers spoke about their feelings, from anger at themselves for losing patience, to worry about the impact on other family members on top of already feeling overwhelmed, stressed, guilt and fear.



“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.”



“I feel I have lost my Dad already.”

Fear and worry about the future

- Carers expressed feelings of fear, apprehension and worry about the future as the person's dementia progresses.
- People living with dementia worry about their ability to maintain independence and are concerned about what their future looks like.

Carer exhaustion and burnout

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

Acceptance

A small number of carers reported that they are managing reasonably well and feel like they can feel close to the person they are supporting. There is a positive connection between feeling you have access to services that you need and better physical and mental health.



What do people with dementia and carers need?

1. **Home care/home support**



2. **Day Services** (both day centres and Day Care at Home)



3. **Opportunities to socialise and social stimulation**



4. **Better access to health and social care professionals**
(particularly Occupational Therapists and Public Health Nurses)



5. **Education, information and advice**



6. **Psychological support** (e.g. counselling services)



7. **Meal preparation or meal delivery support**



8. **Respite**



9. **Young Onset Dementia specific services**



Recommendations

Using this research, we have created a list of recommendations with linked actions.



A

Improve access to services and plan for putting the Model of Care for Dementia in Ireland into effect



B

Open up local communities to address loneliness and isolation



C

Provide psychotherapeutic support and education to people with dementia and carers



D

Provide sustainable financial supports to carers



E

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

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.

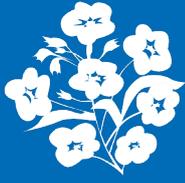
Support

**The Alzheimer Society of Ireland's National Helpline Service is open 6 days a week.
Call 1800 341 341 or email helpline@alzheimer.ie.**

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.

More information

If you have any questions about this plain language summary or would like to read the full report please contact research@alzheimer.ie or visit <https://alzheimer.ie/creating-change/research/>.



THE **Alzheimer**
SOCIETY OF IRELAND

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.



Phone: 01 207 3800



Web: www.alzheimer.ie



Twitter: @alzheimersocirl



Facebook: TheAlzheimerSocietyofIreland



Instagram: @Alzheimersocirl

**The Alzheimer Society of Ireland Helpline
is open six days a week**

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

Call 1800 341 341 or email helpline@alzheimer.ie

The Alzheimer Society of Ireland,
National Office,
Temple Road,
Blackrock,
Co Dublin.
A94 N8Y0

