THE Alzheimer SOCIETY OF IRELAND

The Experience of Dementia in Ireland:

A Snapshot in Time:

November 2026



Plain Language Summary

2nd Edition

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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.

Acknowledgements

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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/**.

Background

About 70,000 people live with dementia in Ireland. We expect that by 2050 there will be 150,000. In recent years, funding for dementia services and support has increased, but there is still not enough for the needs of the rising numbers.

The Cost of Living Crisis impacts many people living with dementia and carers. This is due to costs such as heating and fuel.

People living with dementia and carers often feel isolated, lonely and experience stigma. Community supports and services make a big difference. They help people to connect, be active and part of their communities.

A diagnosis of dementia is very difficult for individuals and families. The right supports and services can help them through the diagnosis and support them beyond that.

Aim

The Alzheimer Society of Ireland (The ASI) wants to understand what it is like to be affected by dementia in 2026. This report sets out what we found out about the experiences of people living with dementia and carers.

What we did

Who: **117** people living with dementia

776 current carers

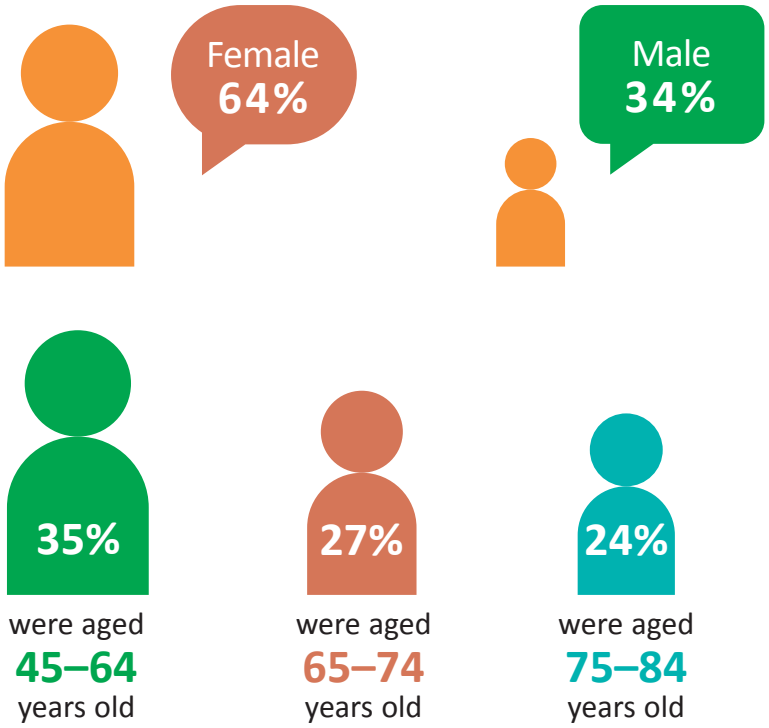
How: Paper, online and telephone anonymous surveys

When: April – July 2026

How to read the numbers

These findings describe the people who answered the surveys. They do not necessarily describe everyone affected by dementia in Ireland.

Profile of Respondents with Dementia



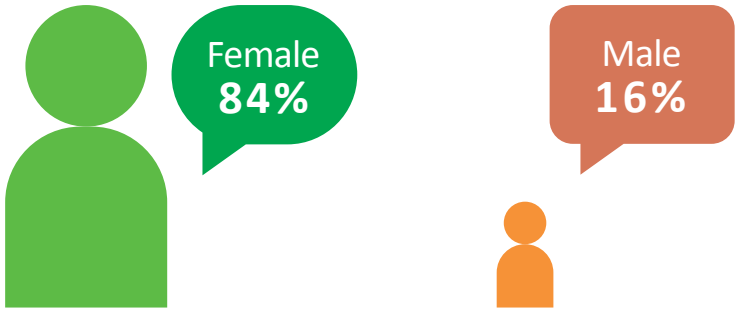
People live with these types of dementia:

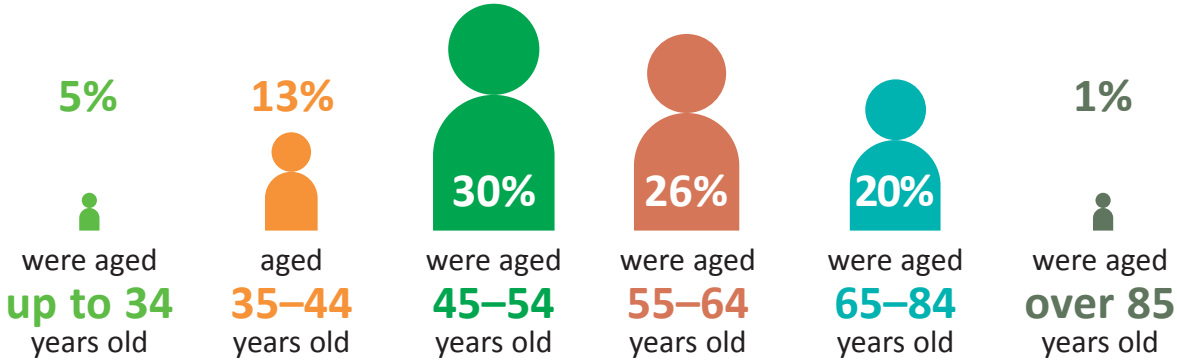
37%	Alzheimer's Disease
20%	Vascular Dementia
10%	Lewy Body Dementia
7%	Frontotemporal Dementia
4%	Mixed
3%	Unsure of their type of dementia

35% of people said they received a diagnosis **before the age of 65 years old**.

13%	of people had been diagnosed less than a year
38%	of people had been diagnosed within the last 1–3 years
38%	of people had been diagnosed in the last 4–6 years
11%	within 7-10 years or more

Profile of Carers





59% said they were caring for a parent,
25% caring for a spouse/partner.

21% said they were caring for a person diagnosed with Young Onset Dementia.

45%	of carers self-identified as being the primary carer
17%	of carers equally share caring duties with another person / people

Others said they were not the primary carer and care shared amongst extended family.



Access to services and supports

Specific services designed for people with dementia can help them to live at home for longer and stay part of their community. Carers also get a break from caring. The right services at the right time are important to improve wellbeing. Almost 50% of people living with dementia say that these services have had a positive effect on how they are feeling.

- The services most used by carers included homecare / home support **20%**, day centre attendance **13%**, family carer training **10%**, dementia adviser service **10%**.
- The services most used by people living with dementia included homecare / home support **21%**, day centre attendance **19%**, activity club social group **12%**, Other* **10%**, and Alzheimer Cafe **7%**.
- **Almost 60%** of carers and **47%** of people living with dementia said it is difficult to access the services they need.

Many people said it is hard to access services because of long waiting lists and not enough availability. Transport was also a problem in both cities and in the countryside. Carers said they need care support in the evenings and weekends.

Home Care

Access to home care was highlighted as a hardship. People said that they do not receive the number of hours they need. This causes stress and frustration. Carers often have to go to private providers for additional home care.

Carers described problems with the availability and the delivery of care services. This included getting the allocated number of care hours due to staff shortage, the person receiving support refusing care, issues with the timing and scheduling of care visits.

Young Onset Dementia

Young Onset Dementia means the person has received a diagnosis before the age of 65. The biggest difficulty for carers of people with Young Onset Dementia is finding services that suit a younger person. They have unique support needs for to their age and life stage.

- People living Young Onset Dementia reported concerns about their loss of independence, changes in their relationships, money worries and difficulties accessing supports.
- They said new services that could help their families included counselling / family support groups.
- There is a need for a whole-family approach. This includes having the right information available for the person with the diagnosis. Children need information designed for their age. Partners need more respite.



Health and Wellbeing

Caring responsibilities are difficult and can impact carer's physical and mental health.

- Loneliness is a concern for both people living with dementia and carers. **72%** of carers and **53%** of people living with dementia said they felt lonely at least some of the time.
- Carers experience a sense of grief when providing care to their loved one, however caring is a described as incredibly meaningful and worthwhile.
- **33%** carer are 'Struggling' with their caring responsibilities, **41%** of carers reported an 'Average' feeling. **25%** of carers felt they were coping 'well' or 'very well'.
- Carers said small changes could make a big difference to their health and wellbeing. Help would look like counselling, taking a short break or holiday, time for regular exercise and getting enough sleep.
- People living with dementia reported their physical health is better than mental health. **57%** said their physical health was 'good 'or 'very good', **48%** said their mental health as 'good' or 'very good'.

"It can be a sad and lonely task as the individual loses ability bit by bit. But very rewarding to know I am helping to maintain dignity and independence."

"It would be a lot easier if I didn't love them so much. I take it all so seriously and would do anything for them... The hopelessness I feel is overwhelming but I keep going. I will continue to keep going."

Financial Impact

- **38%** of carers reported some difficulty of making ends meet. Worry about finances increases stress.
- **25%** of carers have reduced their working hours and **almost 20%** have left employment.
- **56%** of carers said they did not receive any social welfare payments or supports.
- **24%** of people living with dementia access Disability Allowance.
- **48%** carer said they were sharing a home or financially involved with their loves one's dementia care.

"Very difficult to live on 270 a week after having a full time wage. Using savings to pay bills with cost of living."

"Our home needs to be warm all the time and fuel costs are so expensive now and I get no help. Everything costs more and we just about get by."

Many people said that they manage by drawing on savings, spending less on everyday expenses, or with help from family and the State. For others, the financial impact was more difficult, and with real fears about making ends meet.

Both carers and people living with dementia shared how dementia affects their day to day lives, as well as their finances. Dementia can lead to extra costs, changes to how carers work, increased caring responsibilities and difficulties in maintaining independence.

Community Supports

- **51%** of carers who knew about services did not participate in community-based initiatives / activities for people affected by dementia.
- **27%** were aware and participate (with or without loved one).
- **44%** of people living with dementia find local community initiatives / activities helpful.

The top 3 community initiatives carers found most helpful:

1. Alzheimer / Dementia Cafes
2. Daycare
3. Choir / Singing for the Brain

What made taking part in community supports difficult?

- Carers struggled to find time to attend initiatives due to unsuitable times and transportation difficulties.
- Stigma around 'dementia-specific' supports is still an issue for some people with a diagnosis of dementia. They are less likely to engage in a service.
- People who decided not to get involved in organised groups said they prefer their own hobbies and interests, spending time at home or with family.
- **77%** of people living with dementia and **82%** of carers said that dementia awareness and inclusion training for local business staff would make them more likely to engage with that business.

Understanding decision making arrangements

The survey asked about the Assisted Decision Making (Capacity) Act 2015.

- **45%** of people living with dementia and **17%** of carers have not hear of the Act.
- **46%** of carers have a basic understanding of the Act.
- **13%** of carers have heard of it but do not understand it.

Carers and people living with dementia experience difficulties putting legal decision-making arrangements in place. This includes finding a professional to support the process, costs difficult online processes. Suggested improvements include earlier awareness, accessible information and face to face workshops with professionals (rather than an online system).



What do people with dementia and carers need?



Homecare



Day services



Respite



Transport



Services that support social connection, companionship and meaningful activity

Recommendations

We have listened to the dementia community and used their experiences to create a list of recommendations with linked actions.

1.
Secure incremental, **sustained funding for services** and to support the **implementation of the Model of Care for Dementia** in Ireland.

2.
Provide improved access to **home care support hours**.

3
Address **loneliness and isolation** as a growing public health concern and brain health priority.

4
Develop **Young Onset Dementia Supports** that encompass the whole family.

5.
Expand **post-diagnostic education** and information sharing initiatives for people with dementia and their carers.

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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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Facebook: TheAlzheimerSocietyofIreland

Instagram: @Alzheimersocirl

Bluesky: @alzheimersocirl.bsky.social

@The Alzheimer Society of Ireland

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

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

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