THE Alzheimer SOCIETY OF IRELAND

The Experience of Dementia in Ireland:

A Snapshot in Time:

November 2026



2nd Edition

THE Alzheimer
SOCIETY OF IRELAND

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

We are very grateful to all the people living with dementia and carers who took the time 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 Kevin Cullen, Ms Katrina Foley and Dr. Ruth Forrest (members of the Dementia Research Advisory Team) who were PPI Contributors. 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, Dr Sally Yalley, Ms Cíara O'Reilly and Ms Sarah McDonnell. We would also like to acknowledge the support of our research interns Yasmin, Carolina, Lily and Finn.

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.

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Foreword



I am pleased to present this report which provides timely insights into the experiences of people affected by dementia in Ireland. This 2026 report comes at a critical juncture, as demand for services, support and information continues to grow. Findings from this report highlight the multifaceted realities of living with dementia and of providing care, underscoring the increasing need for person centered supports. I welcome the strong contribution of lived experience which remains central to the core of this report.

The ASI would like to thank members of the Dementia Research Advisory Team (DRAT) for their input but also collaborative Person and Public Involvement (PPI) work in shaping this research from the initial stages to dissemination. Your insights as PPI contributors have helped to sharpen our focus in all aspects of this report. In total, we had 117 people living with dementia and 776 carers take part in this work, which is a significant increase from our 2023 report. The strong level of engagement with the survey provides a solid foundation for the report's conclusions.

Whilst we have seen positive improvements since our 2023 report, we know that there are a significant number of people affected by dementia that continue to struggle with the Cost of Living crisis and worry about how best to support their loved ones with dementia. This has become all the more prominent for those affected by a Young Onset Dementia diagnosis, which brings about its own set of challenges. As dementia prevalence continues to rise, The ASI continues to advocate for the expansion of existing services and supports. Access to these services and supports gives carers much-needed respite. It also gives people living with dementia the opportunity to share their experiences, socialise with others and helps reduce stigma.

The Model of Care for Dementia in Ireland has set targets and recommendations on the diagnosis, treatment, care and support of those living with dementia. We have seen real progress, in conjunction with the support from successive governments over the last three years which has allowed The ASI to expand our existing supports and services to more and more people affected by dementia in Ireland. We've also had opportunities to introduce new services, such as our Activity Clubs, which cater to those living with early stage and young onset dementia. Services that best support people of all ages and stages help maintain levels of independence, quality of life and support overall wellbeing. To this end, a special thanks to Minister of State for Mental Health Mary Butler TD, (former Minister for Older Persons), and to the current Minister of State for Older People and Housing Kieran O'Donnell TD for their commitment.

In addition, a sincere thanks to the HSE's National Dementia Services and the All Party Oireachtas Group on Dementia who continue to support our work so we can collectively continue to bring about changes for all those affected by dementia in Ireland.

To finish, I would like to thank all those who took the time to complete the survey or those who supported a loved one to have their voice and experience heard. It is only through your words that we can truly see where we can effect real change for people affected by dementia in Ireland. We will continue to ensure that your voices are heard by those in government through our advocacy efforts.

I would also like to thank all of those involved in this report: Dr. Laura O'Philbin for spearheading this work along with the team, Dr. Diane O'Doherty, Dr. Sally Yalley, Ms Cíara O'Reilly and Ms Sarah McDonnell at The ASI. A special thank you also to The ASI staff and research interns who supported data collection and all those who helped to bring this 2026 report to fruition.



Andy Heffernan
Chief Executive
The Alzheimer Society of Ireland



Section 1:

About this research



Who

117 people living with dementia:
(182 recorded responses)

776 current carers
(1,183 recorded responses)

How

Paper, online and telephone anonymous surveys

When

April – July 2026

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[1].

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[2]. In this report, we use the term *carer* to refer to anyone who provides regular unpaid care or support to a person living with dementia.

The Alzheimer Society of Ireland (ASI) set out to capture a snapshot of the day-to-day experiences of living with dementia in Ireland in 2026. People living with dementia and carers shared their experiences and perspectives on services and supports, challenges and needs, physical and mental health, financial circumstances, community and social supports, stigma, and of navigating legal decision-making frameworks. Given the increasing numbers of people living with young onset dementia (YOD) and the unique challenges they may face, the survey also included a dedicated section on YOD.

1 The Alzheimer Society of Ireland. What is Dementia and Types of Dementia – Alzheimer [Internet]. The Alzheimer Society of Ireland [cited 2026 Oct 1]. Available: **https://alzheimer.ie/about-dementia/what-is-dementia-and-alzheimers/**
2 Health Service Executive. The Model of Care for Dementia in Ireland [Internet]. 2023 [cited 2026 Oct 1]. Available: **lenus.ie/server/api/core/bitstreams/8dde18e2-7e28-454d-95fe-03da43a28f8c/content**

This report presents the findings of this national survey and provides an overview of the experiences and perspectives shared by people living with dementia and carers across Ireland. Surveys were co-developed with Person and Public Involvement[3] and were piloted prior to their national launch. Two versions of the survey were developed: a longer version for carers and a condensed version for people living with dementia. They were open to people aged 18 years and over who were living with dementia or providing current unpaid care to a person living with dementia in the Republic of Ireland.[4] The ASI's TeamUp for Dementia Research service, face-to-face services, organisational and community networks, and social media. Surveys were also shared through The ASI networks with links to the populations being surveyed. Participation was monitored throughout the data collection period including geographical representation. The research team visited dementia cafés, day centres and activity clubs to support participation among people who may have been less likely to be reached through online or network-based recruitment. 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. Most participants completed the survey online.

The survey for people living with dementia received 182 responses, of which 117 were included in the analysis. The carer survey received 1,183 responses, of which 776 were included. Completion of the pre-specified age question was used as the inclusion criterion for analysis. As this item appeared after eligibility screening and was not considered sensitive, it was deemed an appropriate indicator of sufficient survey completion. 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 a person with dementia which some readers may find upsetting or distressing. Our National Helpline is available on 1800-341-341. More details are available on the last page of this document.

3 The Alzheimer Society of Ireland. PPI [Internet]. 2026 [cited 2026 Oct 1]. Available: **https://alzheimer.ie/creating-change/research/ppi/**

4 The Alzheimer Society of Ireland. TeamUp for Dementia Research [Internet]. 2026 [cited 2026 Oct 16]. Available: **TeamUp for Dementia Research – Alzheimer**

Context

Dementia is a growing health concern, with approximately 9.1m people estimated to be living with dementia in the EU today[5]. There are approximately 70,000 people living with dementia in Ireland with these figures set to increase to over 151,000 by 2050. These numbers are important for us to understand how best to support people affected by dementia.

The cost-of-living crisis continues to impact households across Ireland, with very few homes being unaffected. Costs of basic necessities like food, electricity and home heating have skyrocketed, compounding existing challenges. People living with YOD are particularly vulnerable, as they may not meet thresholds for income support from government. As outlined in our recent Policy Evidence Paper[6], the drop from an average weekly wage of €1012 to a disability payment of €254 can cause financial hardships. Dementia care in Ireland costs over €1.7 billion annually[7], with our health and social care largely dependent on informal or family carers to fill the gaps in service provision, taking on the bulk of caring responsibilities. Research undertaken by The ASI and Family Carers Ireland[8] found that family carers are disproportionately impacted by increases in the costs of living.

Since the publication of our Experience of Dementia 2023 report[9], Ireland has moved from a starkly negative, post COVID-19 pandemic era, to one of more optimism. Funding has increased for supports and services and the new services like The ASI's YOD Activity Clubs have come onstream.

But with every positive news story, we continue to see people affected by dementia struggle with finances, loneliness and social isolation. We must also consider what appears to be a growing loneliness epidemic in Ireland. Our 2023 report highlighted loneliness amongst carers and people living with dementia alike. European Commission research found Ireland to be the EU's loneliest nation[10], with 20% of the population feeling lonely most, or all, of the time, in comparison to a 13% EU average. As part of this report, we utilised a UCLA score on loneliness, which creates a discussion around the self-reported loneliness of people living with dementia and carers.

We are at an important juncture in the dementia research landscape, with the emergence in recent years of the first disease-modifying therapies of their kind in over twenty years, with many more in the clinical drug pipeline. Equally, the development of blood-based biomarkers to support the diagnosis of dementia is very promising for people in early stage dementia or living with mild cognitive impairment. The ASI recognises, however, that these developments do not meet the needs of everyone affected by dementia. We will therefore continue to advocate for sustained, long-term funding to ensure that across Ireland, people living with dementia and their families have access to the services and supports they need to live well. We now present our findings from our second edition of our Experience of Dementia in Ireland: A Snapshot in Time.

5 Alzheimer Europe. Dementia Prevalence Report [Internet]. 2025 [cited 2026 Oct 1]. Available: **alzheimer-europe.org/sites/default/files/2026-01/alzheimer_europe_-_dementia_prevalence_report_2025_-_final_-_digital.pdf**

6 The Alzheimer Society of Ireland. Policy Evidence Paper: Pre-Budget Submission [Internet]. 2025 [cited 2026 Oct 1]. Available: **ASI-Pre-Budget-Submission-2027-Policy-and-Evidence-Paper-1.pdf**

7 The Alzheimer Society of Ireland. Policy Evidence Paper: Pre-Budget Submission [Internet]. 2025 [cited 2026 Oct 1]. Available: **ASI-Pre-Budget-Submission-2027-Policy-and-Evidence-Paper-1.pdf**

8 The Alzheimer Society of Ireland & Family Carers Ireland. The Cost of Living While Caring [Internet]. 2023 [cited 2026 Oct 1]. Available: **The Cost of Living while Caring FINAL.docx**

9 The Alzheimer Society of Ireland. The Experience of Dementia, A Snapshot in Time [Internet]. 2023 [cited 2026 Oct 1]. Available: **alzheimer.ie/wp-content/uploads/2023/09/The-Experience-of-Dementia-in-Ireland-2023.pdf**

10 Berlingieri, F., Colagrossi, M., Mauri, C. Loneliness and social connectedness: insights from a new EU wide survey [Internet] European Commission, 2023[Accessed 2026 Oct 1]. Available: **JRC Publications - Loneliness and social connectedness: insights from a new EU-wide survey**

Section 2:

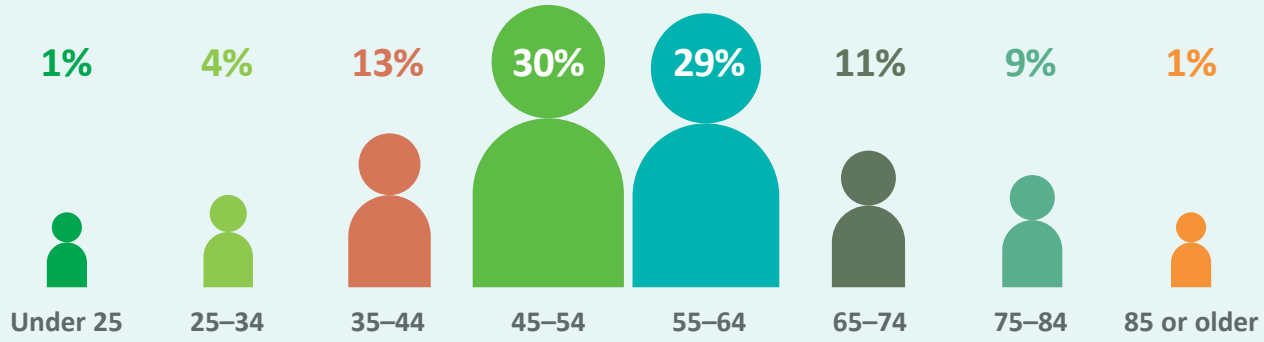
Profile of Respondents



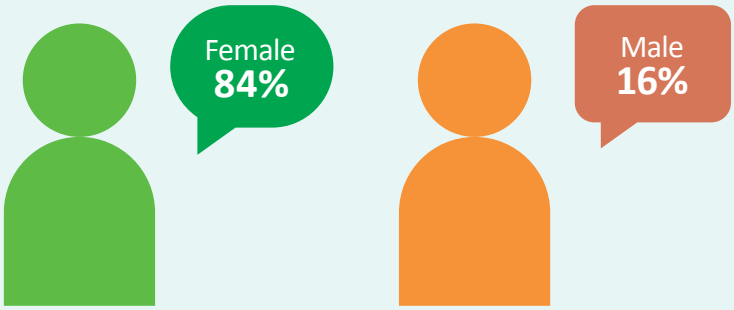
Profile of carers

Please note that n=776, but not all participants answered each question.

Age



Gender



Sexual Orientation

Straight / Heterosexual	**92%**
Gay or Lesbian	**2%**
Bisexual	**2%**
Another sexual orientation	**4%**

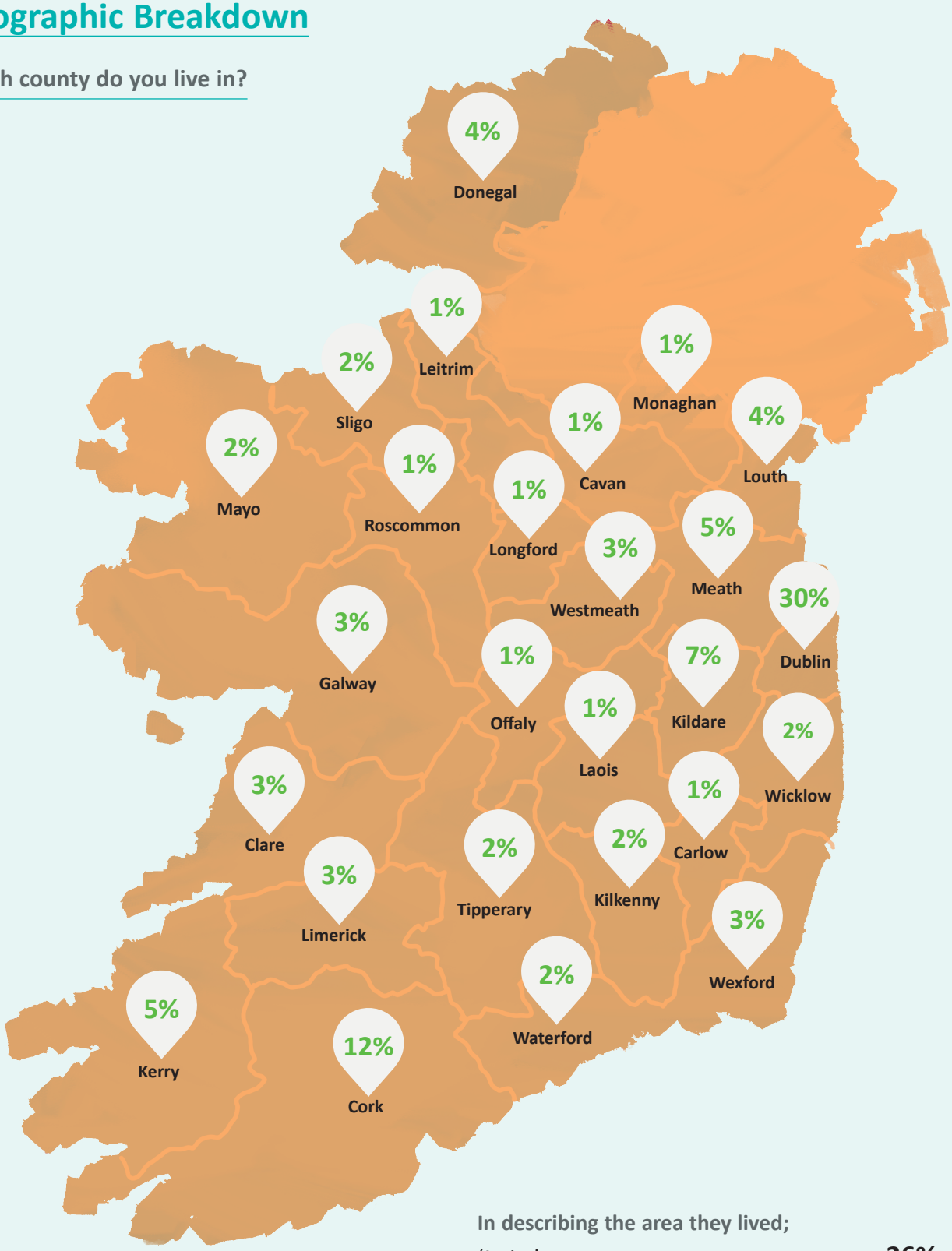
Ethnic Background

White Irish	**95%**
Any other white background	**4%**
Mixed or multiple ethnic backgrounds	**1%**
Prefer not to say	**1%**

There was also one person from 'Asian or Asian Irish' background, 'Black or Black Irish' and 'White Irish Traveller' respectively who completed the survey.

Geographic Breakdown

Which county do you live in?



Largest cohorts:

Dublin	**30%**
Cork	**12%**
Kildare	**7%**

In describing the area they lived;

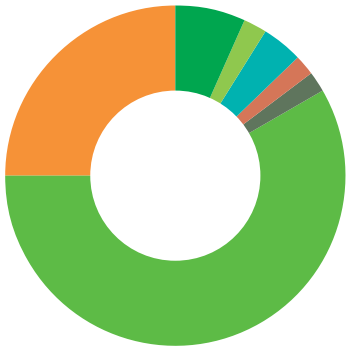
'A city'	**26%**
'A large town'	**24%**
'The countryside / rural area'	**23%**
'A village'	**14%**
'A small town'	**14%**

Caring Profile

59% of respondents stated they were caring for a parent, with 25% caring for a spouse or partner. 'Other' responses included in-laws, daughter, and cousin.

The mean number of hours spent caring or supporting this person was 50 hours per week.

What is the relationship to the person you are caring for?



Other	7%
Friend / Neighbour	2%
Sibling	4%
Uncle / Aunt	2%
Grandparent	2%
Parent	59%
Spouse / Partner	25%

Type of dementia of person being cared for:

Alzheimer's disease (AD) was the most reported form of dementia for which people are providing care. Alzheimer's disease is also the most common form of dementia in Ireland[11]. Other responses included primary progressive aphasia. 21% of respondents stated that the person they were caring for/ supporting was diagnosed with YOD (before the age of 65).

AD:	41%
'Unsure'	18%
Vascular:	16%
Mixed Dementia:	10%
Frontotemporal Dementia:	5%
Lewy Body:	5%
Another type:	4%

Was the person diagnosed before the age of 65?

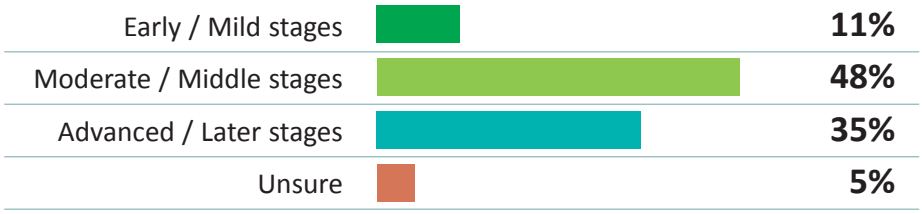


Yes	21%
No	78%
Unsure	1%

11 Health Service Executive (2026) Symptoms [Internet]. 2026 [cited 2026 Nov 12]. Available: **https://www2.hse.ie/conditions/alzheimers-disease/**

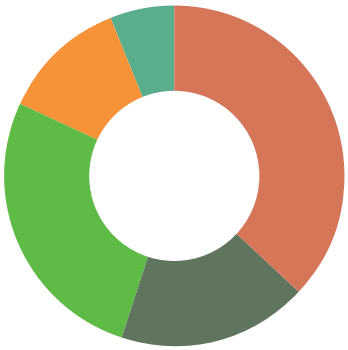
Stage of Dementia

At approximately what stage of dementia is the person that you care for (to the best of your knowledge)?



Living Situation

Where does the person you are caring for or supporting live?



We live together	37%
They live in a nursing home or other	18%
They live with another family member	27%
They live alone	12%
Other	6%

Primary Carer



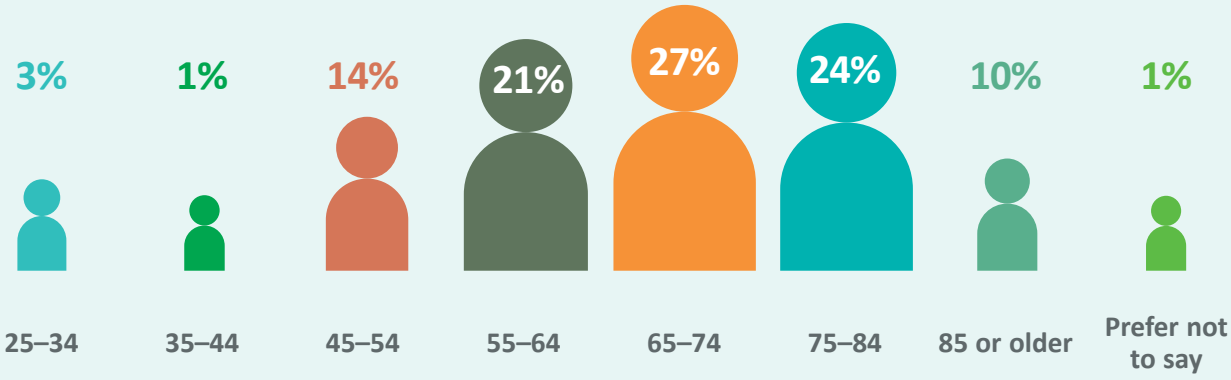
Yes:	45%
No:	29%
Caring duties are shared equally with another person/other people:	17%
Other: These included living alone with family nearby, having a live-in carer, extended family, with spouse / partner and in a hospital setting.	9%

Profile of respondents living with dementia

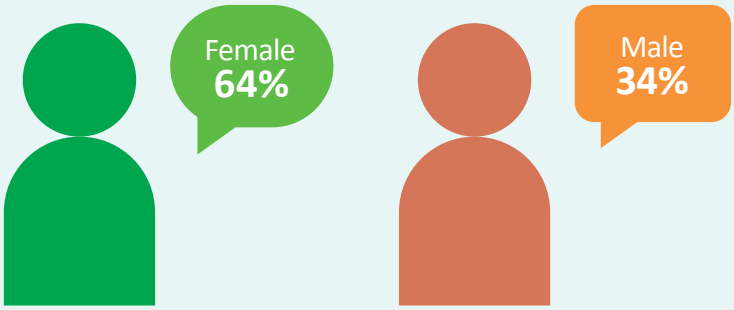
Please note that n=117, but not all participants answered each question.

48% of respondents self-identified as living with dementia, and 52% were supporting a person with dementia to complete this survey.

Age



Gender



Sexual Orientation

Straight / Heterosexual	**97%**
Gay or Lesbian	**2%**
Prefer not to say	**2%**

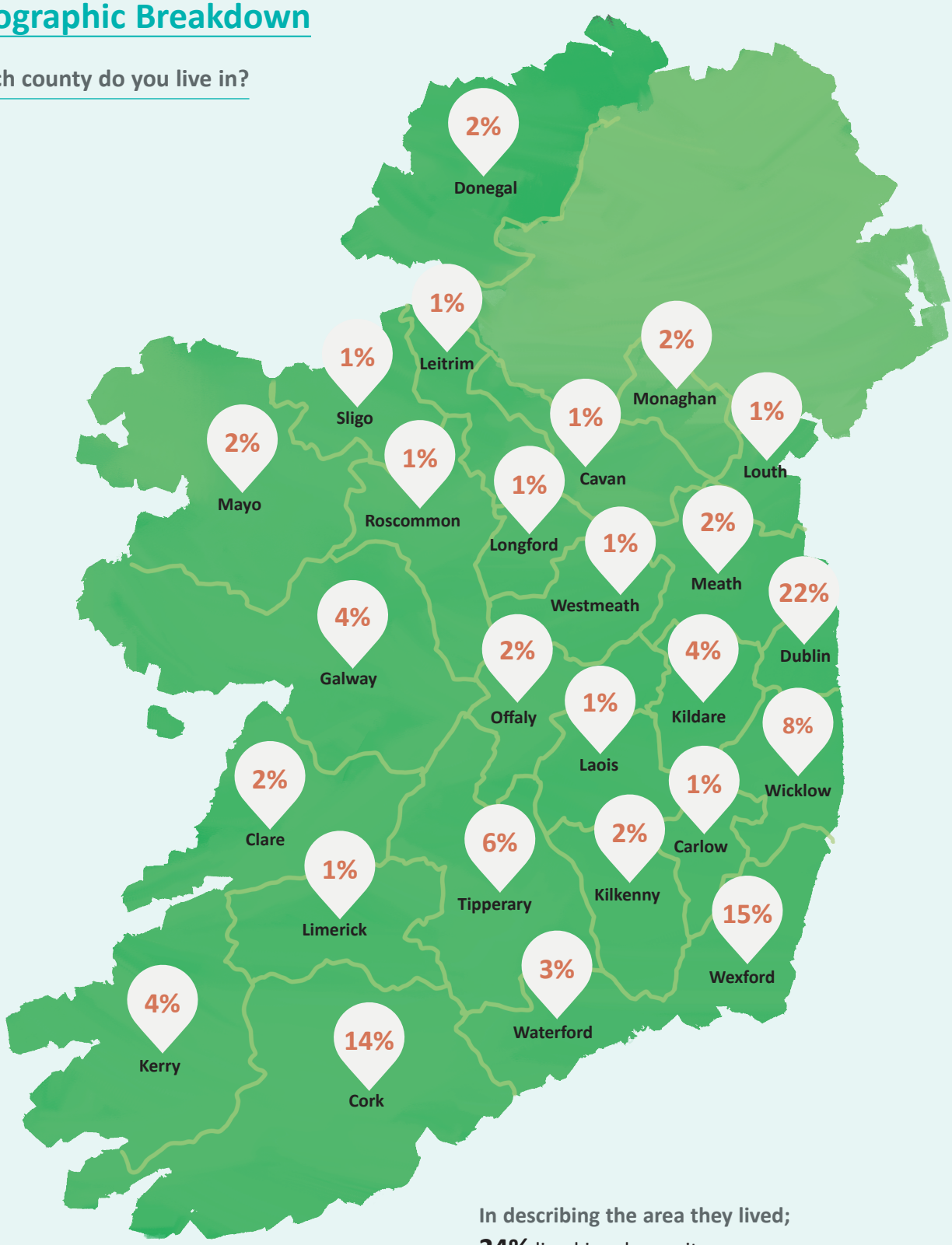
Ethnic Background

White Irish	**91%**
Any other white background	**6%**
Asian or Asian Irish	**1%**

One respondent identified themselves as ‘Indian’.

Geographic Breakdown

Which county do you live in?



Largest cohorts:

22% living in Dublin

15% in Wexford

14% in Cork

In describing the area they lived;

24% lived in a large city,

25% lived in a large town,

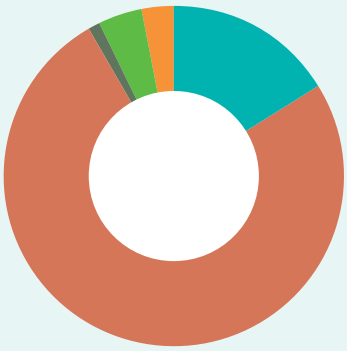
20% in the countryside / rural area,

18% a small town and

14% a village

Living Situation

What is your living situation?



I live alone	**16%**
I live with family	**75%**
I live with friends	**1%**
Other	**4%**
I live in a nursing home	**3%**

Forms of dementia

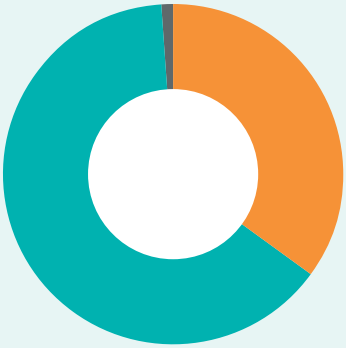
AD:	**37%**
Vascular:	**20%**
Lewy body:	**10%**
Frontotemporal:	**7%**
Mixed:	**4%**
Another type:	**3%**
Unknown:	**19%**

Time since diagnosis

Approximately, how long has it been since you received your diagnosis of dementia?

Less than a year	**13%**
1–3 years	**38%**
4–6 years	**38%**
7–9 years	**8%**
10 years or more	**3%**

When asked if received diagnosis <65 years of age



Yes	**35%**
No	**64%**
Not Sure	**1%**

Most respondents (75%)
stated they lived with family.

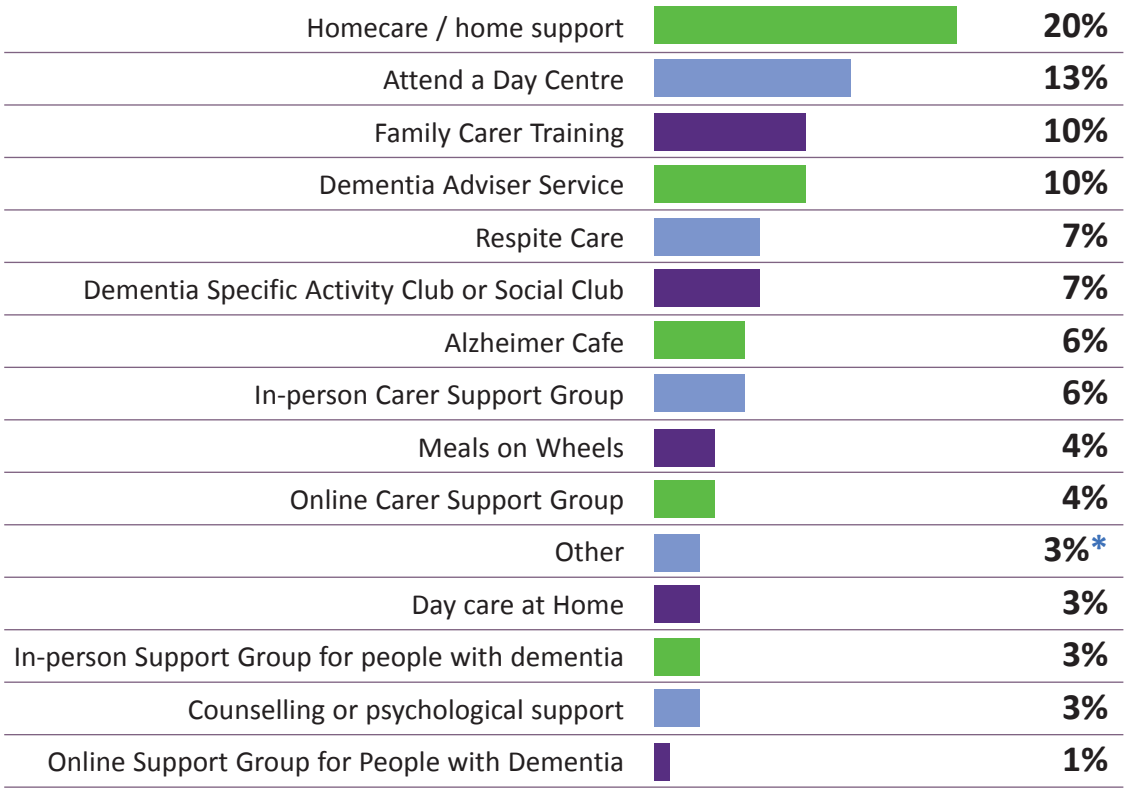
Section 3:

Findings



Theme 1:
Services and Supports

Services accessed by carers and or / the person living with dementia (from the carer's perspective)



*Other services included exercise classes, social activities, exercises for the brain, dementia cafes, local and public health nurses.

Most utilised services reported by carers include:

Homecare / home support:	**20%**
Attending day centre:	**13%**
Family carer training:	**10%**
Dementia adviser service:	**10%**

When asked, how often do you use these services (given the top three answers);

Once off / rarely;

Family Carer Training	**25%**
Dementia Adviser Service	**22%**
Respite Care	**20%**

Weekly basis:

Attend a day centre	**28%**
Homecare/Home Support	**21%**
Dementia specific activity club or social group	**18%**

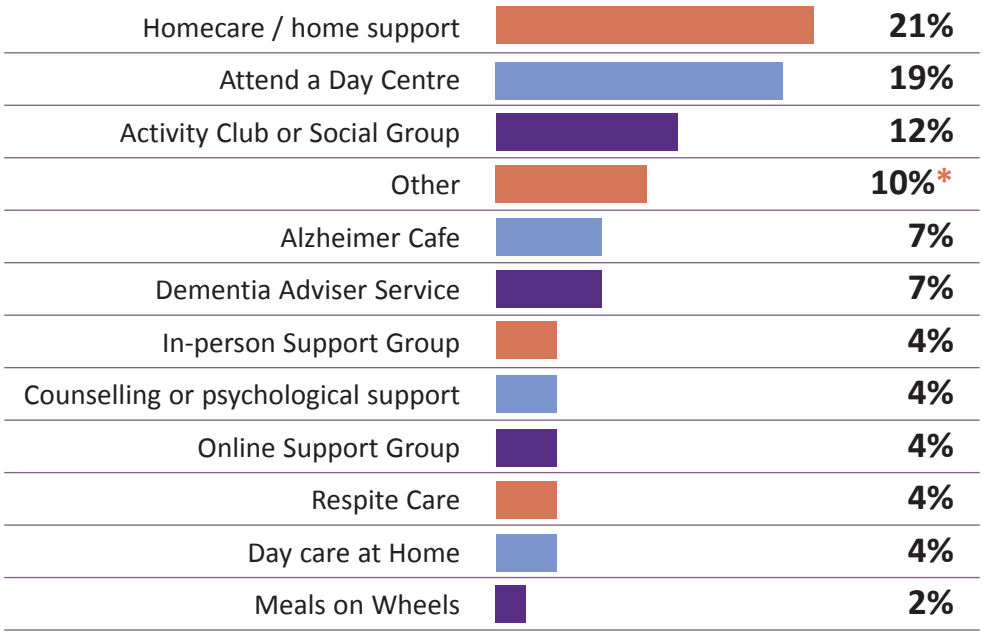
Monthly basis:

Alzheimer Cafe	**30%**
In-person carer support group	**16%**
Dementia Adviser Service	**10%**

Several times per week:

Homecare/ Home Support	**27%**
Attend a day centre	**17%**
Meals on Wheels	**12%**

Services accessed by people living with dementia:



Most utilised services reported by carers include:

Homecare / home support:	**21%**
Attending day centre:	**19%**
Activity Club or social group:	**12%**

Impact of services

When asked how have these services impacted your life as a carer / supporter:

	Improved	The Same	Worsened
My Stress Levels	**58%**	29%	13%
My Wellbeing	**47%**	40%	12%
My Sleep	23%	59%	17%
My ability to continue caring	**48%**	42%	10%
My ability to balance caring with other responsibilities	42%	42%	16%

When asked how have the services impacted the life of the person living with dementia:

	Strongly Agree	Neither agree nor disagree	Strongly Disagree
Supports them to be more independent	31%	53%	16%
Supports them to stay living at home	**56%**	33%	11%
Meets their needs	39%	43%	17%
Reduces potential of crisis situations (e.g. unexpected hospital trips, high levels of distress)	36%	48%	17%

When asked how have these services impacted your life as a person living with dementia:

	Improved	The Same	Worsened
My Stress Levels	41%	46%	14%
My Wellbeing	**49%**	40%	12%
My Sleep	28%	57%	15%

The right services at the right time play an important role in improving overall wellbeing, with almost **50% of people living with dementia** reporting that services had a positive effect on their wellbeing.

Respite

When asked whether they had availed of respite care, almost two-thirds of carers **(64%)** said they had not.

Respite can take many forms, from formal services provided by the HSE and The ASI to informal support from family and friends. Some carers chose to pay for private respite themselves.

Most of the respite reported was provided by family members or paid for privately by carers, so that they could take a break or go on holiday.

Some comments included:

> "It was a big deal to get respite for my dad...I was trying to book 4 months before date I needed again, I didn't get. So, I took just a random date they had. And not much information provided how it works, what to expect."

> "We have received two weeks of respite for Dad this year, having cared for him ourselves for over 8yrs. It was like winning the lotto! Otherwise, family members provide the respite by taking over, spending the night etc. We have had to pay someone privately to stay overnight once in order to attend a family funeral. And on occasion for a few hours here and there. Otherwise Mum and the family do our best, some pulling more weight than others, as you can imagine."



Challenges accessing services

Almost **60% of carers** reporting having some difficulty accessing the services that they need.

Do you have any difficulty accessing the dementia services you need?



Yes, a great deal	**18%**
Yes, some	**41%**
No	**42%**

Issues reported included inadequate transport, poor timing of services, lack of physical movement and hoist usage, carers reporting how limited time they had available to attend services and refusal to attend services by the person living with dementia. Carers also reported the high demand for accessing services, with waiting lists being many months. A poor understanding of what services are available and who to contact about these services was also reported.

> "I don't know how to access them."

> "I don't know what's available."

> "Most of this was organically learned throughout the process. I wish there was something more formal to say here is the journey (everyone is different). Here are the supports you have access to. Here is what you need to pay and ultimately your options. It's more worrying having to figure each part out yourself."

When we examined responses by area, we found similar challenges in accessing services across rural areas as well as in cities and large towns. This suggests that access to services is a nationwide issue, rather than one limited to specific locations.

When asked to identify three services you feel would be most helpful to you and / or the person living with dementia, carers reported;

1. Day care
2. Home care
3. Respite

For the person living with dementia, they noted:

Do you have any difficulty accessing the dementia services you need? (e.g. waiting lists, transport, etc.)



Yes, a great deal	**19%**
Yes, some	**28%**
No	**53%**

Respondents identified a broad range of services and supports they felt they needed, with several common priorities emerging. These included greater access to home care and practical supports to maintain independence, opportunities for social connection, meaningful activity and companionship, accessible transport, day services and respite, and access to allied health and therapeutic supports. Respondents also highlighted the importance of dementia-specific knowledge and training among service providers, alongside timely information and support following diagnosis.

There was a strong desire for supports that enable people living with dementia to continue participating in everyday life and doing the things that are important to them. Respondents described wanting support not only with personal or household tasks, but also to exercise, socialise, pursue interests, access healthcare and remain connected to their communities.

1: Maintaining Independence / Practical supports to live independently

Responses in relation to requests for home care and home help were often framed around remaining independent and managing everyday life. Respondents mentioned support with domestic chores such as cleaning, shopping, preparing meals and personal care, but some also stated a preference for assistance that would enable them to continue doing things that mattered to them personally: *"Visits to help me do my pastimes, not just cleaning or showers"* a *"Cooking Course"* and *"More activities such as painting and creativity".* Individuals are not necessarily seeking more care hours; rather, they are asking for the right kind of support to continue participating in their own routines and interests: *"Someone to come so we can walk with my dog."*

2: Transport and access to community

Transport was repeatedly identified as a need however, responses suggest that transport is not just a logistical issue; the ability to travel determines whether people can access healthcare, day services, exercise, social activities and engage in community life. Individuals cited rural locations as a barrier to accessing services, getting to hospital appointments and even attending Mass, and suggested *"Perhaps someone who could travel to several locations would solve that."* For people living with dementia, transport is an enabler of independence, social connection and access to healthcare and meaningful activity.

3. Social connection, companionship and meaningful activity

Services which support social interaction, companionship and meaningful activity are at the forefront of what will support people living with dementia's needs. Meaningful activity includes *"social interaction with like-minded people"* and *"Being able to get to the gym every day"*, as well as traditional community initiatives such as a day centre: *"We have some craic (at the Day Centre)! We do singing classes and music. There's a guy who comes who tells stories."* The social connection of being around other people underpinned this desire to access services. For people living with dementia, the desire for *"company"*, *"to have the bit of chat and hear what's going on"* and *"have a laugh"* is inherent to their wellbeing. These responses suggest that the value of services extends beyond structured activities: friendship, conversation, humour, belonging and having something to look forward to are important outcomes.

Transport Challenges

Transport presented some degree of difficulty for 41% of respondents. Limited public transport and rural location were among the most frequently selected barriers, alongside anxiety about travelling. Loss of driving ability could result in increased reliance on family members. Similar responses elsewhere described feeling "stuck" after giving up driving or being unable to go out unless a spouse or family member was available to provide transport. This suggests that being able to get somewhere does not necessarily equate to being able to travel independently.

The experience of travelling itself could also present challenges. One respondent described wearing a hidden disabilities sunflower lanyard when travelling, explaining that it provides a visual indication that they may need "support and calm directions".[12] The sunflower lanyard is a way to share to others that you may have a disability or condition that is not always visible and you may need a helping hand or support or extra time. This complements reports of anxiety about travelling and highlights the importance not only of transport availability, but of transport environments that are understandable and dementia inclusive.

> "Our parent is no longer able to drive and has mobility issues that require one of the family to be available to drive to all appointments, support activities and outings. No appropriate public transport available in the area."

How easy or difficult is it for you and the person you care for to get where you need to go? (For example, appointments, shops, social activities.) [Carers]



Very difficult	**22%**
A little difficult	**34%**
Somewhat easy	**26%**
Very easy	**18%**

How easy or difficult is it for you to get where you need to go? (For example, appointments, shops, social activities.) [Person living with dementia]



Very difficult	**20%**
A little difficult	**21%**
Somewhat easy	**32%**
Very easy	**27%**

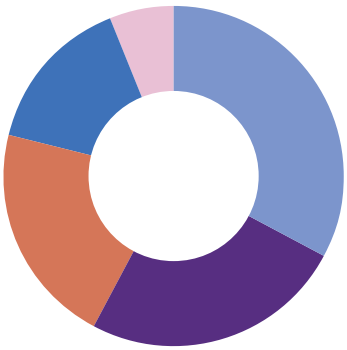
12 Hidden Disabilities. What is the Hidden Disabilities Sunflower? [Internet]. 2026 [cited 2026 Oct 16]. Available: **https://hdsunflower.com/**

What are the main transport challenges you face? [Carers]



Anxiety about travelling	**21%**
Rural location	**17%**
Other (please input below)	**17%**
We do not experience transport difficulties	**14%**
Transport not dementia friendly	**12%**
Limited public transport	**9%**
Cost of transport	**6%**
No challenges	**4%**

What are the main transport challenges you face? [Person living with dementia]



Other (please input below)	**33%**
Limited public transport	**25%**
Rural location	**21%**
Anxiety about travelling	**15%**
Cost of transport	**6%**

When asked how easy it was for carers to get to key places such as appointments, shops and social activities with the person they cared for, 18% said it was very easy, 26% said it was somewhat easy, 34% said it was a little difficult and 22% admitted it was very difficult. This reflects that more than half of carers are experiencing varying degrees of difficulty in this regard. The most commonly listed challenge among carers was anxiety around travelling or leaving home. Other transportation challenges included living in a rural location, limited public transportation options and transportation options not being dementia-friendly.

For people with mobility limitations, carers reported it wasn't always easy to find accessible taxis, or feasible transport options for people in more advanced stages of dementia. Some also felt they did not always find or qualify for accessible parking.

> "Getting a wheelchair in and out of car and no parking close to appointments."

The associated costs were prohibitively high, limiting travel to essentials like appointments.

> "We currently have a car but cost is high. Otherwise the only other option is a taxi which we cannot afford."

> "trips now limited to hospital visits (not family visits etc) this limits access for both patient and carers to many family events."

For others, it was difficult getting their loved ones to leave the house at all coupled with safety concerns around them being outside the home and the discomfort of being in a sensory-overloaded environment. This particularly increased the anxiety around travel.



Home Support

Appropriate home support is essential to allow people living with dementia to remain living at home in their communities for longer.

Main reasons for person with dementia needing home support:

Equal need for person care and support/companionship:	**40%**
Personal care:	**30%**
General support and companionship:	**19%**
*Other:	**12%**

***Other reasons reported the person living with dementia being at risk for falls, being vulnerable on their own and home support provided respite to the carer.**

Provider of Home Support	Carer	Person living with dementia
The HSE	**58%**	**49%**
The ASI	**18%**	**27%**
A private company / individual	**18%**	**12%**
Another organisation	**7%**	**12%**

	Carer	Person living with dementia
Average number of hours allocated	14 hrs per week	10.5 hrs per week
Average number of hours received	12.5 hrs per week	10 hrs per week
	(-1.5 hrs per week)	**(-0.5 hrs per week)**

> "The home helps are to come for 30 minutes each morning but they rush so fast to get out the door to get to their next client they usually spend 10 to 15 minutes max."

Carers reported challenges related to both the availability and delivery of formal care; accessing allocated number of care hours due to staff shortages, refusal of care by the person receiving support and dissatisfaction with the timing and scheduling of care visits.

> "Staff just don't stay. Once finished they leave. Even if they're finished after 20 mins."

Findings highlight that both the person living with dementia and carer reported receiving less hours of care than that which was allocated. Many carers expressed concerns that care staff were unable to spend the full time allocated with their family member, often leaving early to meet other clients. Respondents viewed this as a knock-on consequence of care providers not allowing sufficient travel time between visits.

Theme 2:
Young Onset Dementia

Young Onset Dementia (YOD) is characterised as a person who is diagnosed with a form of dementia before the age of 65 years old. As this is a growing cohort in Ireland, it is essential to understand the unique challenges faced by this group, and the many ways in which their needs differ from older people.

What have been the biggest challenges for your family in relation to the person with dementia being diagnosed at a young age?

Finding services that suit a younger person	**21%**
Emotional or mental health support	**15%**
Planning for the future	**11%**
Financial challenges	**10%**
Getting the right information	**10%**
Managing family and parenting responsibilities	**9%**
Feeling isolated or misunderstood	**9%**
Work problems	**9%**
*Other	**8%**

***Other challenges included having an awareness and acceptance, loss of independence by the person diagnosed at a young age, process of diagnosis and feelings of loneliness / guilt.**



Challenges in accessing information

When a loved one is diagnosed with a form of YOD, it can be a challenge to access information around diagnosis, what the next steps to take are, and general information around their specific condition.

Carers reported struggling to find information on:

General supports:	**46%**
Diagnosis:	**23%**
Legal or financial advice:	**23%**
Something else*:	**8%**

When carers were asked what supports did they feel children or young people need, they identified that peer support by others of the same age would be helpful. They also stated that age-appropriate support would be most suitable (for younger children for example) and more education and awareness and opportunities to have fun and be a child / teenager.

42% of carers reported that there were children or young people (under 25) in their family affected by the diagnosis.

When asked if there was one service or support that could be developed to make the greatest difference for families affected by YOD, what should it be?
Counselling / Family support groups

For those living with YOD;

What have been the biggest challenges for you in relation to being diagnosed at a young age?

Finding services that suit a younger person	**16%**
Work problems	**15%**
*Other	**13%**
Feeling isolated or misunderstood	**13%**
Getting the right information	**11%**
Emotional or mental health support	**10%**
Changing family dynamics	**8%**
Planning for the future	**6%**
Financial challenges	**6%**
Managing family and parenting responsibilities	**3%**

When asked are there children or young people (under 25) in your family affected by the diagnosis, 37% said 'Yes'. When asked about the challenges they face being diagnosed with YOD, respondents highlighted loss of independence and autonomy. They described *"loss of everything, freedom, independence"* and an *"inability to experience things I still want to do in the way I want to."*

The loss of driving was mentioned repeatedly and appears to represent more than a transport difficulty, affecting people's ability to participate independently in family and everyday life. Respondents described frustration at becoming more reliant on spouses and family members, including being less able to contribute to parenting and other family responsibilities: *"My wife is having to do so much. She takes the kids to all their activities. I feel frustrated that I can't do more. That I can't help."*

For those living with YOD, loss of independence, changing relationship dynamics, financial pressures and difficulties accessing appropriate practical support were recurring concerns. Respondents called for services that recognise the particular circumstances in which YOD can occur, including parenting dependent children, living alone, managing financial commitments and wanting to remain active and independent.

The loss of independence described as a challenge of YOD was reflected in respondents' priorities for future services, with calls for practical supports that would enable people to remain independent and live at home for longer, such as *"volunteer drivers"* and *"help around the home."*

A particularly strong theme was the need for a whole-family approach. Respondents highlighted the impact of diagnosis on spouses and children and identified a need for age-appropriate information, counselling and peer support for younger family members, alongside respite in an individual's home *"to allow carer time off"* and practical support for partners. When asked to consider what supports might benefit children and young people in their family, respondents identified counselling, accessible information, advice, education and opportunities to ask questions in a safe and supportive environment. Respondents also highlighted the importance of helping children understand the changes associated with dementia and of increasing awareness that dementia is not solely Alzheimer's disease. This response provides insight that a one-size-fits-all approach may not be appropriate for children and young people, rather that as needs vary considerably, an individualised / personalised support may be best.

Responses suggest that a whole-family approach to YOD should include proactive, age-appropriate support for children and young people, rather than relying on families to identify and source this support themselves. At the same time, respondents emphasised that services should not assume that everyone diagnosed at a younger age has family available to provide care.

"My wife is having to do so much. She takes the kids to all their activities. I feel frustrated that I can't do more. That I can't help."

Theme 3:
Health and Wellbeing

It is well recognised that the health and wellbeing of both the person living with dementia, and carers are impacted by a dementia diagnosis. Caring responsibilities can present significant challenges for carers, impacting both physical and mental health.

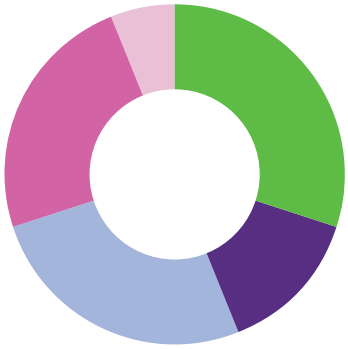
1 in four carers felt they were coping 'Well' or 'Very Well',
1 in 3 carers 'felt they were Struggling'.
2 in 5 carers reported feeling 'Average'
with regards to their coping with caring responsibilities

How would you rate your physical health at the moment?



Average	**27%**
Poor	**10%**
Fair	**19%**
Good	**33%**
Very good	**11%**

How would you rate your mental health at the moment?



Average	**30%**
Poor	**14%**
Fair	**26%**
Good	**24%**
Very good	**6%**

What would help to improve your overall health?

For many carers, relatively small changes could make a meaningful difference in their overall health and wellbeing. These included counselling, opportunities for respite through holidays or short breaks and adequate sleep. The carer role is characterised by many as all consuming, placing significant demands on carers' time, energy, emotional resources, contributing to feelings of strain and exhaustion.

"I have stopped going out for walks and really miss this."

Access to dementia-specific services including respite, day care and formal carers with specialist dementia training was identified as key factors in supporting both people living with dementia and family carers. Many carers also emphasised the importance of engaging in regular physical activity noting that opportunities to exercise would improve their mental wellbeing, reduce stress, and help maintain their physical health while managing the demands of caregiving.

"It's 24/7/365."

"Being responsible all the time."

"Main carer, bread winner, never off."

"Constantly on call"

"As a lone carer it's never being able to switch off. Everything all falls on me."

"My mental health was very poor during covid and with small kids – knowing my mum was really struggling to care for my dad was a huge burden. Exercise and being outdoors helped."

"I am limited to the HSE carer visits to get out and go for a run etc. I used to train with a club but I no longer can make any of the training sessions."

"Being 'on call' all the time."

"Non stop caring."

"Isolation and not being able to do things for myself eg personal fitness interests."

Person living with dementia:

How would you rate your physical health at the moment?



Poor	**12%**
Average	**18%**
Fair	**14%**
Good	**39%**
Very good	**18%**

Those living with dementia reported more positive physical than mental health. **Over half (57%)** rated their physical health as good or very good, compared with **48%** who rated their mental health as good or very good. Conversely, **26%** rated their physical health as fair or poor, increasing to **30%** for mental health.

> "I used to do personal training, one to one. I miss being able to do that."

When invited to share what would help improve their overall health in the open text option, respondents' comments demonstrated the interconnected nature of physical, psychological and social wellbeing. Social connection and emotional support emerged through requests for *"company," "access to other people,"* and "*counselling*," with one respondent stating a preference to *"remain at home with family"* for their mental health**.** Additional responses included reference to experiences of loneliness, frustration and boredom. Maintaining physical and meaningful activity was also important, including opportunities to continue forms of exercise that had previously been part of people's lives; "*I used to do personal training, one to one. I miss being able to do that."*

Physical health needs were not solely connected to exercise. Some responses included improved pain management, mobility support and access to routine healthcare, including *"GP visits and health checks in familiar, lower-stress environments."* Respondents also identified wider practical circumstances that could influence their wellbeing, including home support, appropriate housing adaptations, financial support and relief from caring responsibilities.

Importantly, experiences were not universally negative. Some respondents reported being satisfied with their current health, while others reflected positively on the benefits of previous physical activity; "*I was a PE teacher and I used to do quite a bit of athletics. This is standing to me now."* Overall, the responses suggest that supporting health and wellbeing for people living with dementia requires a holistic approach encompassing physical health, emotional wellbeing, social connection, meaningful activity and practical support to maintain independence.

Loneliness as a growing public health concern

Informal carers and people living with dementia are two vulnerable, at-risk groups for both loneliness and social isolation. Carers often must reduce hours in formal employment or take early retirement, taking on a role which can limit social interactions with their local community, family and friends. Moving from traditional paid employment to what is largely acknowledged to be an unpaid role can be difficult. Carers report that their own personal time or time for recreational activities effectively disappears when taking over a caring role, reducing their social circles and connections. This loss of personal identity and freedom was highlighted by carers.

For a person diagnosed with dementia, particularly for those with YOD, this can be a distressing experience. Those newly diagnosed have reported feeling in many instances that their local supports / services are not suitable for their age or stage. This can lead to a withdrawal from engaging in existing activities like Men's Sheds / Women's Collectives / local golf clubs / art classes etc.

Despite the challenges they face, carers described the importance of developing understanding, patience, and acceptance in adapting to dementia. Many demonstrated resilience and sought ways to maintain the wellbeing, dignity, and quality of life of the person with dementia while coping with their own challenges. Carers also sought to be better equipped to be sure they were providing the best care and meeting the needs of their loved one adequately.

"Being tied to the house."

"My world is getting smaller."

"No one to talk to or help with appointments or making decisions as it is only myself and my father living in the house."

"Our children are not near us – one many miles away, others in other countries and all are very busy with their own lives and families... Most days I don't see anyone except my husband."

"you're living two lives, yet no life of your own."

"Caring for someone with dementia is a lonely business in so many diverse ways, it is also scary for many reasons such as, dying before them, not knowing how to 'reach' them any more etc."

"Personal career and socialisation difficulties – feeling left behind."

UCLA Scale

The level of subjective loneliness was measured using the three-item UCLA Loneliness Scale[13]. The three items assess feelings of lacking companionship, feeling left out, and feeling isolated from others. The questions were measured on a 3-point Likert scale, with responses ranging from 1 (hardly ever or never) to 3 (often). Scores ranged from 3 to 9, with higher scores indicating greater loneliness. Scores were categorised as 3 – 4 (hardly lonely), 5 – 7 (lonely some of the time), and 8 – 9 (often lonely).

Findings suggest that loneliness is common among carers with almost three-quarters of respondents **(72%)** reporting feeling lonely at least some of the time, including **25.5%** who reported feeling lonely often. Just over one quarter **(27.7%)** were categorised as hardly lonely.

UCLA score category	%
Hardly lonely	**27.70%**
Lonely some of the time	**46.80%**
Often lonely	**25.50%**

Person living with dementia:

UCLA score category	%
Hardly lonely	**46.60%**
Lonely some of the time	**37.00%**
Often lonely	**16.40%**
Total	**100%**

More than half of respondents living with dementia (53.4%) reported feeling lonely at least some of the time, including 16% who were categorised as often lonely. However, 46.6% were categorised as hardly lonely. While loneliness is increasingly recognised as a broader societal issue in both Ireland and across Europe, findings suggest that caring responsibilities may create additional barriers to maintaining social connections and engaging in everyday activities. The results highlight the importance of considering social connection, respite, and access to support as part of a broader approach to the wellbeing of people living with dementia and carers.

Experiences of loneliness and social disconnection were relatively common among respondents. **60%** reported lacking companionship either some of the time or often, while **57%** felt left out and **59%** felt isolated from others at least some of the time. Approximately one in five respondents reported experiencing each of these feelings often.

Findings reflect themes emerging in this report where people living with dementia identified company, social interaction and access to other people as important to their overall health and wellbeing. Qualitative responses described experiences of loneliness, boredom and frustration, alongside a desire for opportunities to connect with others and engage in meaningful activity. When considered collectively, the findings highlight the importance of social connection as an aspect of living well with dementia.

13 Russell, D. UCLA Loneliness Scale (Version 3): Reliability, validity, and factor structure. Journal of Personality Assessment. 1996. 66, 20-40.

Feelings of life – Carer Perspective

	Always	Most of the time	About half the time	Sometimes	Never
My sleep is disturbed	12%	26%	19%	35%	8%
Caring brings me a sense of fulfillment	9%	23%	17%	41%	10%
I have less time to spend with other family members	23%	25%	16%	29%	7%
I am feeling close to the person I care for	27%	32%	14%	21%	6%
I am feeling depressed	3%	8%	13%	53%	23%
Caring has strengthened some of my relationships with family/friends	5%	11%	12%	42%	30%

Fear & Uncertainty

Many carers reported feelings of fear and uncertainty; for the future, for the unknown, about future care needs for their loved one and not having answers. The unpredictable nature of dementia can lead to these feelings around decision making, planning and coping ability for the future.

Ambiguous grief

Many carers experience and report what is often termed to be ambiguous grief. This sense of grieving for a person they once knew and the lives they may have had together, whilst the person with dementia is still physically present. Gradual changes in a loved one are witnessed first hand by carers providing informal care, leading to feelings of profound grief, confusion and loneliness.



Despite substantial challenges, many carers described caregiving as meaningful and worthwhile. They spoke of deep bonds, love, commitment, and satisfaction from being able to support a family member, preserve dignity, and enable the person with dementia to remain at home.

"Most carers will agree that people who do not have lived experience of dementia can never understand what it is truly like. While you dearly love your family member, the dementia changes them; you grieve over and over again for who they were."

"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."

"The fear of losing our loving relationship, after our life of 63 years together."

"At times very difficult, tiring, stressful but my mum has no worries or stress & wouldn't we all like to be cared for & loved if we were in that position?"

"While it has its challenges, emotionally, financially and the effect it has on your personal life, it is important to take joy and appreciate the smiles or few words that get spoken."

"My mother spent her life doing her best for us. It's time to give back. It's hard though."

"It is a privilege to help my mum in any way I can but sometimes I feel I fall short – but I do try to do my best."



Theme 4:
Financial Impact of Dementia

There was quite a dramatic divide in people's experiences with the perceived financial impacts of dementia. Many carers were not in receipt of any supports or social welfare payments in relation to their caring role, 44% were in receipt of one or more.

When asked about being in receipt of social welfare payments or supports they received in relation to their caring role;

56% said they did not receive any social welfare payments or supports

14% said they received the Annual Carers Support Grant

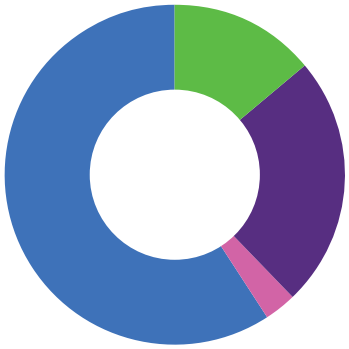
13% said they received a Carer's Allowance (including half rate Carer's Allowance)

6% said they received another social welfare payment or support. This included State Pension, Disability Payment, Domiciliary Care Allowance, Widows Pension, Invalidity Pension, Job Seekers Allowance and Living Alone Allowance.

6% said they received the fuel allowance

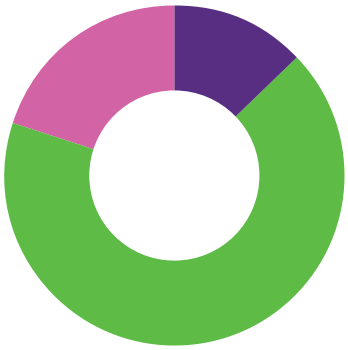
5% said they received Carer's Benefit

Are you in receipt of any social welfare payments by reason of having dementia? If so, which one(s)?



Invalidity Pension	**14%**
Disability Allowance	**24%**
Illness Benefit	**3%**
Other (please tell us)	**59%**

Have you ever made an application for a social welfare payment due to your dementia diagnosis that was rejected?



Yes	**13%**
No	**67%**
Not sure	**20%**

Among respondents who identified a specific dementia-related social welfare payment, Disability Allowance was most frequently reported, followed by Invalidity Pension and Illness Benefit. Several respondents reported receiving the State Pension, including some who had previously received disability-related payments before reaching pension age. Others indicated that they were receiving no payment or were not eligible, while some identified other forms of support such as Fuel Allowance or the Long-Term Illness Scheme. Findings suggest that financial wellbeing is influenced not only by supports available but also by eligibility, age-related transitions from one payment to another.

When asked "Have you ever made an application for a social welfare payment...", carers and people living with dementia noted:

> "Applied for supplementary allowance to purchase a chair (a durable dining chair with extra support and arms, like they have in hospital settings – HSE would not cover it, they advised applying this way) that would cost around 500 but they denied me because of credit union savings of 3,000."

> "I paid a lower stamp rate in PRSI so not able to avail of any social welfare payments – working a government dept for almost 20 years and served in the Naval service for 20 years."

When asked whether they had ever had an application for a social welfare payment due to their dementia diagnosis rejected, 13% said Yes, while 67% said No and 20% were unsure. As most payments are means tested, carers noted that they often were just above the means-test threshold. Other reasons included not being classified as a 'full-time carer', income from other means being over the threshold, insufficient contributions and being self-employed. In conjunction to struggling with accessing social protection supports, a challenge that many carers face is having to give up their formal employment, reduce their working hours and take early retirement. This can be a strain on their finances, particularly when they are financially involved or responsible for their loved ones' care.

1 in 4 carers have had to reduce their working hours.
Almost **1 in 5** have left employment.

Are you sharing a home or financially involved with aspects of the person living with dementia's care (e.g. paying for all / some of their expenses, financing social or health care etc.?



Yes	**48%**
No	**45%**
Prefer not to say	**7%**

Carers who reduce their working hours or leave employment struggle to access social protection and remain financially responsible for a loved one with dementia often face significant financial hardship.

38% of carers reported some difficulty of making ends meet. This increased overall stress and worry around finances.

The cost of living in Ireland has played a role in this, with the price of food and fuel having increased. CSO data indicates that overall consumer prices were approximately 7% higher in August 2026 than in December 2023, with food and non alcoholic beverages approximately 6% higher, housing, water, electricity, gas and other fuels approximately 10% higher. Carers reported being in mortgages arrears, balancing paying for care for their loved ones and finding money for food shopping.

Many carers reported cutting back on spending related to social and recreational activities. This reduction reflected both the financial and practical demands of caring and for some, contributed to becoming less socially engaged which has implications for carers' mental health and wellbeing.

"My professional work and salary is suffering."

"Financial challenges (with no income because I had to quit my job to be a carer) to afford respite, private home help, huge electricity costs re. extra heating, hospital equipment etc. and wheelchair accessible taxis"

"Expense of private care."

"... restricted the amount of fuel, heating only one room."

"I worry about financing caring needs going forward."

"Gave up work but because of husband's income I am not financially entitled to anything. I do provide care 7/8 hours a day so not entitled to carers allowance."

"I took special leave to care for them but it was unpaid so I had to go back to work."

Carers reported being in mortgage arrears, balancing paying for care for their loved ones and finding money for food shopping.

"I do whatever it takes to make sure the nursing home bills are paid first ie €300p/w excess whatever is left then I can use for our food, bills etc If there's food there I eat if not I drink water. I didn't have heating oil & come winter I'm unsure of how I'll afford this but not worrying ATM."

"I am stressed, anxious and seldom sleep well. It's just an ever present worry."

"I have very little for myself. Even my food budget is very limited."

"now can no longer have any social time in the evenings or weekends as can't afford to pay them."

"Delaying buying oil and sometimes good shopping."

"I've had to cut out all unnecessary expenditure, essential purchases only, don't buy new clothes."



Person living with dementia:

While the majority of respondents (69%) reported that their household was able to make ends meet fairly or very easily, 17% reported difficulty making ends meet or being unable to do so. When asked specifically about the impact of their diagnosis, one-third (33%) said that it had affected their ability to make ends meet, with a further 14% unsure.

The financial impact of dementia often extended beyond immediate financial strain, with respondents describing loss of employment following diagnosis.

"Had to leave my job I was 53yrs," "Giving up work, so loss of income is difficult as I was the main income earner," and *"I had to give up my full time job."*

In some cases, a spouse or partner also left work or reduced their hours to provide care, further affecting household income.

Respondents also described additional dementia-related expenditure, including private care, nursing home fees, medication and healthcare costs, transport and modifications to the home. For some, maintaining independence itself generated additional costs, particularly where transport, activities or future home-care support had to be privately funded. Others described relying on savings, pensions or social welfare supports to manage reduced income and increased expenditure.

When asked has the person's diagnosis of dementia impacted your ability to make ends meet, carers said:

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

Many respondents had to reduce their working hours, give up work or take early retirement to care for a loved one living with dementia, which had a negative impact on their financial stability and increased their stress around their finances. Carers also spoke about the extraordinary indirect costs associated with supporting a person with dementia which included ensuring their living space was suitable, extra equipment, personal care items and taxis to and from appointments.

In some instances, carers reported taking on the full financial responsibility of their loved one, including day to day expenses which is a toll on their own personal finances. Carers also reported having to dip into their life savings to cover costs. The cost of living was also highlighted as a financial strain for many carers, with the price of fuel being raised.

For others, it is a balancing act to ensure that their loved ones have the right care and for the carer to also live day to day.

> "My wife has had to cut down to two days a week so she has a lot of anxiety about the money. She was crying about it the other week."

> "My husband gave up his job... he doesn't want to leave me on my own."

> "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."

"The financial pressure has added significant stress and worry on top of the emotional impact of dementia caregiving. Increased costs related to care, transport, appointments, meals, safety needs, and reduced ability to work or rest have all had an impact. It has affected my mental well-being, sleep, and overall stress levels. There is also constant anxiety about future care costs and whether enough support will be available when needs increase further."

"We have old oil boiler that needs to be replaced and my mother afraid to turn on the heat in March and April due to increased cost of Kerosene. Heating bills now unaffordable. Difficulty paying bills and local property Tax Surcharges as we paid it late."

"We still have to pay a mortgage and support a person in college"

"Sometimes decisions are restricted on what we can afford to pay out for to help our person eg get personal care- eg getting chiropodist care over food bill for a week"



These findings suggest that the financial impact of dementia may not always be captured by whether a household is currently able to make ends meet. Some respondents remained financially stable while drawing on savings, reducing expenditure or relying on family and State supports, while others described significant financial insecurity. The responses highlight both the direct costs associated with dementia and the wider economic consequences of reduced employment, caring responsibilities and maintaining independence.

Theme 5:
Community Supports

Since our Experience of Dementia in Ireland report in 2023, there have been significant improvements in the availability and accessibility of supports at community level, which has been driven by The ASI and other organisations. We have seen improvements in overall general awareness and engagement.

Carer's awareness of community based initiatives or activities in local area for people affected by dementia:

51%	are aware but do not participate
27%	said they or the person they care for participate
23%	are not aware

People living with dementia also outlined their engagement with community initiatives or activities they found helpful:

Yes:	**44%**
No:	**56%**

Among those who participated, respondents identified both dementia-specific supports and mainstream community activities, including dementia cafés, day centres and Living Well programmes alongside swimming, gyms, choirs, social clubs, cultural and religious activities and informal socialising. These responses demonstrate the importance of having diverse opportunities that support social connection, physical activity (*"I like to go to the local pool. I would swim a couple of days a week"*), established interests *("I like being able to go for coffee with my friends")* and continued participation in everyday community life.

When carers were asked to list the top 3 community initiatives that they found most helpful, these included:

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



Barriers to accessing community initiatives

The most commonly listed reasons why carers struggled to access community initiatives were finding the time to attend, initiatives being held at an unsuitable time, and challenges with transportation to the venue. Carers found it difficult to carve out the time to attend as they were caring 24/7. For some, it was difficult to find someone else to care for their loved one while they were away, particularly where they had sole caring responsibilities or were unable to leave the person alone. Others had work or family commitments that made attending difficult. Transport and distance were also barriers for some carers.

> "Conflicting days/time! Too far away! Not long enough to be worth while!"

The circumstances of the person with dementia could also make participation difficult. For some, the person they cared for was reluctant to attend as they may not have accepted their diagnosis or did not want to attend anything *'with a dementia label'*, preferred to stay at home, or experienced anxiety, agitation or discomfort about leaving home. Health and mobility difficulties, fatigue, advanced dementia and high care needs also further limited participation.

> "Personality of the person I help care for. She does not want to attend these incredible initiatives. She attaches a stigma to Alzheimer's and doesn't believe she has it even though she is in late moderate stage."

Carers described limited range of suitable available activities in their localities or activities that did not meet the person's needs or were perceived as uninteresting or not dementia-inclusive enough. Other difficulties included a lack of awareness of available initiatives or experienced language barriers. For others, they were still on waiting lists.

> "Waiting list of over a year for extra day in Daycentre."

For those living with dementia, barriers to community participation demonstrate, however, that accessibility extends beyond simply having activities available. Transport emerged as a prominent practical barrier, with the qualitative responses illustrating how the loss of driving can leave people dependent on family members to participate ("*We have a car but if my husband isn't there I don't go. My daughter drives as well.")*. Respondents also identified limited availability of suitable or age-appropriate activities, including a perceived lack of provision for people under 65.

Cognitive and communication needs could also make participation difficult. Respondents described forgetting when activities were taking place, difficulty following conversations ("*The Men's Sheds wasn't for me. The lads were great but there were too many people talking")*, confusion in day services and finding larger or busier groups overwhelming. Language was also identified as a barrier, while online participation was preferred by some respondents.

Importantly, non-participation did not always represent an unmet need. Some respondents expressed little interest in organised groups and described preferring their own hobbies ("*I am happy enough at home. I like to read a lot and sure you are never really alone when you read. And I knit but I don't go out to do that.")*, spending time at home or participating informally with family. One respondent explained that group activities had never been part of their life before diagnosis and that attempting to join them following diagnosis added to their stress and confusion.

These findings highlight the importance of flexible and genuinely dementia-inclusive community initiatives but also the value of person-centred approaches that support people living with dementia to maintain their *own* interests and preferred forms of social connection, rather than assuming that organised group participation will be appropriate for everyone.

Training for business

There is significant value in having dementia awareness and inclusion training for staff who regularly interact with the public. There often is a greater understanding of dementia as a disease, awareness of signs and symptoms and this could improve interactions and ensure that people living with dementia are treated equally and with dignity and respect.

For carers;

If staff in a local business had training in dementia awareness and inclusion, would you be more likely to use that business?



Much more likely	**52%**
A little more likely	**30%**
No effect	**17%**

The creation of dementia-friendly public spaces was identified as a key factor in supporting inclusion and community participation. Carers reported that there is a need for environments that are accessible, easy to navigate and aware of the cognitive and sensory challenges that a person living with dementia might face. Features such as quiet spaces, softer lighting, accessible toilet facilities and clear signage were identified as practical measures that could reduce confusion, stress and enhance confidence, supporting people affected by dementia to maintain independence and continue to engage in community activities.

Growing awareness of dementia as a condition and understanding of dementia by local staff in communities, enhanced by explicit dementia awareness training was outlined as things that would further support making communities more inclusive for those affected by dementia. In educating the wider public, this may reduce stigma around the condition and person so that they can continue to live and contribute to their local community. Carers reported that this awareness would reduce stigma and any issues faced, particularly when the person with dementia may have challenging or behavioural issues in public spaces.

> "The ASI Dementia Inclusive Communities are making a difference! I see more happening locally in support of families living with dementia."

Carers also outlined how increased information around the condition and education for local communities would reduce stigma and enhance local services.

> "More awareness equals more support."

> "Public campaigns, the 2 brothers that ran all those marathons really shone a spotlight & brought attention to this."

Many carers stressed the value of patience and understanding, e.g. when a person living with dementia may need additional time to pay at the supermarket, slower walking on pavements. It was suggested that local services and supports could have a 'protected hour' similar to what is offered to people who are neurodivergent. During this time lights could be dimmed, quiet shopping hours and awareness. This could be supported by the use of JAM cards, inclusive community badges etc. This may help to build the confidence of the person with dementia, and the carer, helping to reduce social isolation. Dementia as an invisible disability.

> "If we are out in public, there is a lanyard that mum wears with her diagnosis and my contact number. This is in case of emergencies or if we got separated, but it acts as a visual clue to folks around us. I have found in general people are patient and understanding, and it makes me feel less like I need to constantly apologise and explain."

> "Understand that people with dementia need more time. They can't be rushed of a table in a restaurant or coffee shop."

Several carers also indicated that integrated services, rather than siloed services for people affected by dementia, would be beneficial and help to reduce social isolation.

These measures may help to build the confidence of people living with dementia and their carers, and help to reduce isolation.

They also recognise that dementia is often an invisible disability.

Respondents also emphasised that improving community awareness of dementia could reduce stigma and foster more inclusive attitudes towards all affected by dementia. When asked if they had ever felt excluded or avoided because they are supporting someone with dementia, 1 in 3 (33%) said 'Sometimes', but 57% reported 'Never' or 'Rarely'.

When asked about the general Irish attitudes towards people living with dementia, almost 1 in 3 carers thought it was generally positive (32%), 30% didn't have a positive or negative feeling and 37% had a somewhat negative attitude. This also related to carers' experience of talking about their experience of dementia in their communities. 51% said they felt comfortable talking to anyone about it, 40% said they felt comfortable but only to people they knew and only 9% felt uncomfortable talking about it. Having the ability to speak to others in your local community helps to reduce stigma and changing public awareness and attitudes, dispelling common assumptions and reduce social isolation and loneliness.

When asked about the general Irish attitudes towards people living with dementia, almost **1 in 3 carers (32%)** felt they were generally positive, **30%** didn't have a positive or negative feeling and **37%** had a somewhat negative attitude.



Person living with dementia

If staff in a local business had training in dementia awareness and inclusion, would you be more likely to use that business?



Much more likely	**32%**
A little more likely	**45%**
No effect	**23%**

The importance people living with dementia placed on dementia awareness and inclusion should be read alongside their experiences of wider societal attitudes. Almost half (45%) of respondents reported that they had sometimes or often felt avoided or excluded by others because they were living with dementia, while a further 11% had experienced this rarely. Conversely, 44% reported never having experienced such exclusion.

Perceptions of attitudes towards people living with dementia in Ireland were mixed. While 39% of respondents described attitudes as somewhat or extremely negative, 36% considered them somewhat or extremely positive. A further 25% viewed attitudes as neither positive nor negative. These findings suggest considerable variation in how people living with dementia experience and perceive attitudes within wider society.

Respondents also differed in how comfortable they felt discussing their experience of dementia within their community. While 40% felt comfortable talking to anyone about it, a further 40% were comfortable only when speaking with people they knew well, and 20% did not feel comfortable talking about their experience. Although the survey cannot establish whether experiences of exclusion or perceptions of public attitudes influence willingness to talk openly about dementia, the findings collectively reinforce the importance of creating communities in which people living with dementia feel understood, respected and included.

This complements earlier findings on dementia awareness within local communities. More than three-quarters (77%,) of respondents indicated that dementia awareness and inclusion training among local business staff would make them at least somewhat more likely to use same. Respondents described supportive communities as those characterised not simply by knowledge of dementia, but by patience, understanding, dignity and appropriate communication. "*There are a few people in the community with family and they get it. But its not enough. Theres not enough understanding.*" Taken together, the findings suggest that improving dementia inclusion requires both greater public *"awareness, understanding what it [dementia] is"* and *"more general awareness of hidden disabilities,"* and translating that awareness into everyday interactions that enable people living with dementia to participate in community life without feeling judged or excluded. As one respondent explained, *"Slower pace is good but infantilising is not – patience and presence is all I need from people around me."*

Practical suggestions included dementia-friendly signage or badges identifying trained staff in frequently used community settings such as shops, pharmacies, libraries, hairdressers, GP surgeries and cafés. Respondents also highlighted the value of proactive outreach from the likes of County Councils and Age Action for people who may have difficulty finding information or navigating online resources, alongside continued investment in community initiatives and the volunteers who support them. Ultimately, the responses to what would make communities more supportive of people affected by dementia suggest that a dementia-inclusive community is not defined solely by the availability of dementia-specific services, but by greater understanding, patience and inclusion within the everyday places and interactions that make up community life.

Theme 6:
Assisted Decision Making (Capacity) Act 2015

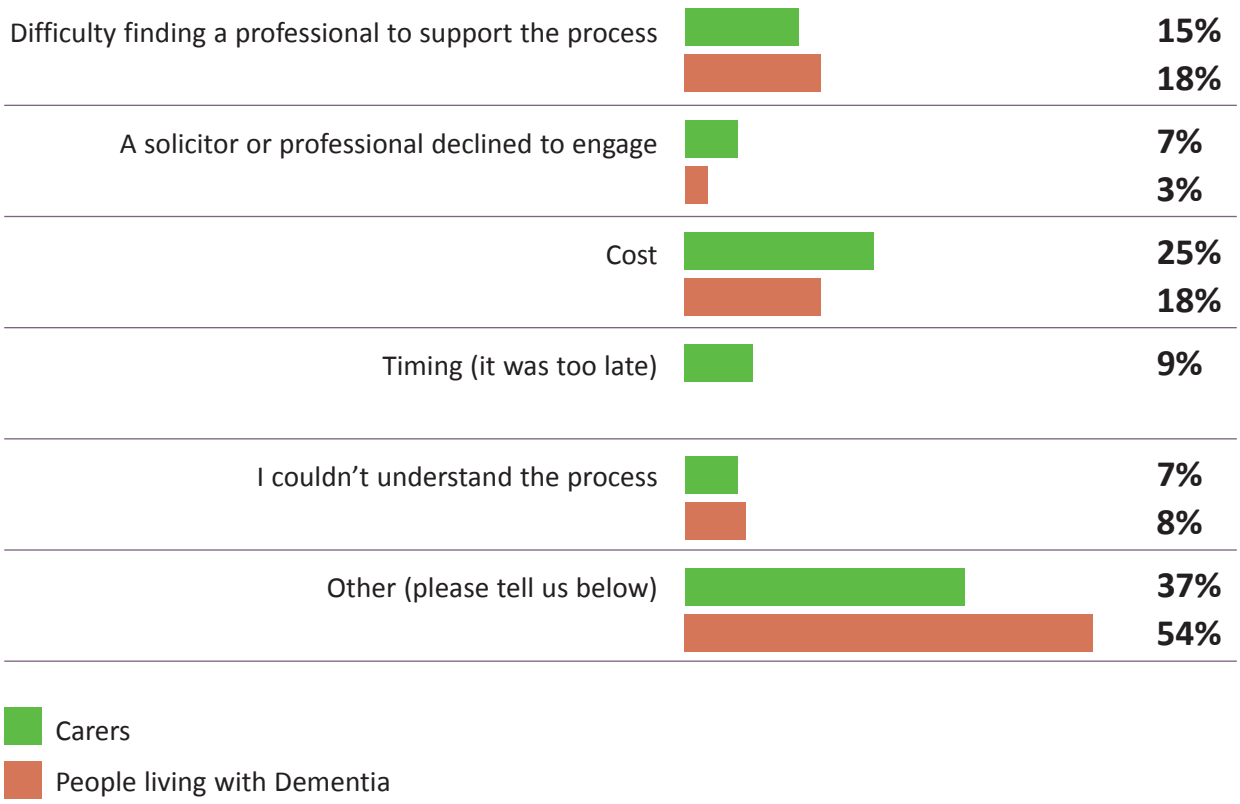
The Assisted Decision Making (Capacity) Act 2015 is a law that allows for supported decision making in Ireland. This is particularly relevant for people who don't have the capacity to make decisions either now or in the future without support. This Act came into effect in April 2023 in Ireland.

Almost half of carers (46%) reported having a basic understanding of the Assisted Decision Making (Capacity) Act 2015. A further 13% had heard of it but did not understand it, while 17% had not heard of it. Only 24% reported having a comprehensive understanding. For those living with dementia, 45% reported never having heard of the Act, 22% had a basic understanding, 22% had a familiarity but no understanding of the Act and 12% had a comprehensive understanding.

Challenges

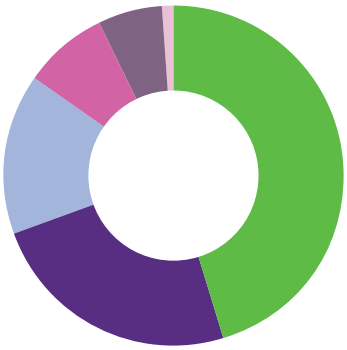
Carers / People living with Dementia

Did you encounter any challenges in putting legal decision-making arrangements in place? (Please tick all that apply)



Challenges: Carers

Have you tried to put legal decision-making arrangements in place? (for example, an Enduring Power of Attorney with a solicitor)



Yes, completed	**45%**
Yes, in progress	**24%**
Unsure	**15%**
No, but I plan to in the future	**8%**
No, and I do not plan to	**6%**
Prefer not to say	**1%**

Among carers who tried to put legal decision-making arrangements in place, 45% reported having been successful with" *no difficulties encountered" and "no problems whatsoever".* However, a number of carers encountered several barriers which included difficulty finding a solicitor who was willing to engage, the varying and sometimes high costs involved – mainly solicitor fees, difficulty understanding the process or finding a professional to support *describing the experience as "traumatic and expensive".*

Some carers found the process complicated, with unclear guidance and an online system that was difficult to navigate, particularly for older adults.*"The online process is quite complicated. If I wasn't fairly proficient in technology, it would be very difficult".* Other respondents described having limited support available in navigating the process and encountered uncertainties around requirements. They also identified a need for more information and guidance documents from the Decision Support Service.

> "takes way too long for application to be processed."

> "I am a solicitor so I assisted my mother with the procedure for putting an EPOA in place but I couldn't believe how user-unfriendly the system is i.e. it is mostly completed online when many elderly people simply would not be computer literate enough to manage this and anyone even in the early stages of dementia would really struggle to follow the steps, make the appointment with the solicitor etc. It was challenging for us to complete the process and I wonder how people who do not have supportive caring people around them manage to do this. The system needs to be made much more user friendly."

A significant hurdle for carers was finding a solicitor who was willing to engage, and when they did, the costs were often variable and sometimes prohibitively high. Some described experiencing lengthy application processing times due to court delays and found the paperwork to be time-consuming.

Suggested improvements

Carers recommended a simpler, streamlined process, with plain English guidance at each step and a more age-friendly design. They recommended better involvement by the Decision Support Service with solicitors to ascertain why some were unwilling to engage. Training health and legal professionals on the process would help them better support people who need the service.

Some carers recommended faster processing, streamlining paperwork and having fast-track options for emergency cases. They also recommended education during or at diagnosis – as some found out about the process too late, and extending support for people with dementia and their families during planning.

> "Difficult process to follow, website isn't straightforward. Quite time consuming for the average person and we only tried to get it in place and it was already too late as mum wouldn't sign the forms."

Carers also highlighted the value of media information and campaigns about the process. Increasing the reach of these could improve public awareness and encourage more people to put arrangements in place. It was noted that the current advertisement campaign, particularly on the television were very good initiatives that could be scaled up in local communities to reach more people.



Challenges: People living with dementia

Respondents demonstrated varying levels of awareness and understanding of the Assisted Decision-Making (Capacity) Act 2015. Almost half had never heard of the legislation, while a further 22% had heard of it but did not understand it. Only 32% reported having either a basic or comprehensive understanding.

Despite these findings, 45% reported having completed legal decision-making arrangements, with a further 24% indicating that arrangements were in progress. While these questions measure different aspects of legal decision-making, the findings highlight the importance of ensuring that individuals understand the arrangements available to them and can access appropriate guidance throughout the process.

Respondents identified several challenges associated with establishing legal arrangements, including cost, administrative complexity, delays and difficulties navigating the process independently. Some described lengthy procedures and difficulties accessing appropriate forms or professional assistance. Conversely, others reported positive experiences where solicitors or family members provided practical support.

Respondents emphasised the importance of earlier awareness, accessible information and personalised assistance. Suggestions included plain-English information campaigns, community workshops, practical guidance at diagnosis and opportunities to speak directly with knowledgeable professionals. The importance of human assistance was particularly evident, with one respondent identifying the need for *"access to a human being"*, while another suggested involving trusted healthcare professionals who could explain the process and provide practical support.

Responses suggest that improving access to legal decision-making arrangements requires more than raising awareness of the legislation. Respondents identified a need for timely, understandable information, simplified processes and appropriate individualised assistance to help people living with dementia understand their options and participate in decisions about their future.

"I filled in one application for Power of Attorney which I took from the Web but it was already out of date even though still available on line. Now having to fill in more forms for the same thing."

"I get so far, but then it gets too complicated for me."

"The government have changed the way this is supported so it's difficult to get a solicitor to sign off."

"My daughter helped me to arrange this, but the legal cost was very expensive."

Section 4:

Needs of people with dementia and carers



Respondents were asked to list the services they felt would be most helpful to them.



Homecare

This was the most reported response from people living with dementia and carers. Carers spoke about their need for additional home care hours to best support their loved one to remain at home. Challenges include receiving the appropriate number of hours allocated by care providers, ensuring staff have dementia specific training and scheduling of visits. For those living with dementia, this was important for (instead of viewed in terms of) maintaining independence and quality of life.



Transport

Issues around transport were reported by people living with dementia and carers. Accessibility to services is often determined by a person's ability to get to a day centre, appointments or local community services and activities. This is unfortunately a challenge that remains in both urban and rural areas. Transport can also be linked with independence and social participation, both of which are negatively impacted by changes in an individual's ability to drive or indeed loss of their license entirely.



Day services

Day centres were highlighted as a key support for people living with dementia and carers. Those living with the condition enjoyed the opportunities to socialise and meet others in a community setting, while carers receive respite. Access to these services can improve overall health and wellbeing for people affected by dementia.



Services that support social connection, companionship and meaningful activity

Activity clubs, Alzheimer cafes, and other services that support social connection and interaction are critical to those living with dementia. For people living with YOD, these activities must be age and stage appropriate. By fostering companionship and meaningful engagement with peers, this allows respite for carers and contributes to the wellbeing of all affected by dementia.



Respite

For many carers, respite was described as invaluable to their ability to support their loved one, but they often faced challenges in accessing public respite. This results in carers having to self-fund private respite, seek support from their family members, friends and communities "*just to have a break*".

Section 5:

Recommendations



This research highlights the persistent and significant challenges faced by people living with dementia and carers in Ireland. Many continue to experience difficulties in accessing the supports and services they need, whilst also coping with financial strain, physical and mental health issues and loneliness. A diagnosis of dementia can profoundly change lives, however with the right supports in place, people living with dementia and carers can be better supported to maintain their wellbeing, independence and overall quality of life.

1.
Incremental, sustained funding for services and support for the implementation of the Model of Care for Dementia in Ireland

Over the last number of years, we have seen investment in dementia specific services and supports by successive governments. In comparing findings from our Experience of Dementia survey in 2023 to this report, we can see what improvements these investments have brought. However, this investment needs to be incremental and sustained to meet the demands of an ageing population and increasing prevalence rates of dementia. The full implementation of the Model of Care for Dementia in Ireland represents a key opportunity to improve outcomes for people living with dementia and carers by addressing longstanding challenges in care, support and service delivery.

Action:

- Incremental, sustained investment from government for the implementation of the Model of Care for Dementia will positively improve the lives of all affected by dementia in Ireland.
- Increase investment in services that provide cognitive and physical stimulation and companionship, with the dual effect of offering respite for carers.

2.
Improve access to home care support hours

To ensure that people living with dementia preference to remain living at home in their local communities is met, there needs to be continued investment and funding allocated for home support hours across Ireland. Challenges in allocation of hours was highlighted as part of this research, as well as time allocated to each client and the demands on home care staff. Increased access to home care hours supports improved carer mental health and wellbeing, as well as allowing the person receiving care the ability to live more independently.

Action:

- Increase ring-fenced funding for home support hours across Ireland to ensure equity of access.
- It is important for those in receipt of home support, that they are provided with allocated hours and with staff who have sufficient time.
- Staffing and workforce management issues must be addressed by those who provide home care staff to clients.

3
Tackle loneliness and social isolation as a growing public health concern and brain health priority

Ireland, as a nation, has been cited as the loneliest country in Europe, a sentiment largely reflected / reiterated in our findings. As outlined by The Lancet Commission[14], maintaining social connections is incredibly important for our brain health, and has the potential to be a modifiable risk factor for dementia. Since our Experience of Dementia 2023 report, overall awareness of existing community supports and services available for people living with dementia has increased, following significant resourcing of community engagement initiatives. We must continue to ensure that new and existing initiatives and services remain diverse and accessible to all and that the needs of people at different ages / stages of dementia are suitably supported. Staff turnover creates gaps in awareness regarding available services and supports. To address this, it is vital to continuously build that awareness and provide clear connections for people affected by dementia to reduce loneliness, lower stigma, and support ageing in place.

Loneliness is a growing public health concern and we need commitment and funding from government. We need continued investment in this area to avoid falling short for this generation and future generations to come.

Action:

- Government to deliver on the commitment to fund the development of a coordinated plan to address loneliness, as included in the 2020 Programme for Government, Roadmap for Social Inclusion 2020–2025, Healthy Ireland Strategic Action Plan 2021–2025 and Sláintecare Strategy and Action Plan 2021–2023.[15]
- Continue investment in Dementia-friendly communities initiatives. The ASI and the HSE's Dementia Campaign *Understand Together* are critical in these roles.
- Provide funding for transport options for those across Ireland to support them to attend in person support groups, social activities and services to tackle social isolation.

14 The Lancet Commission. Dementia prevention, intervention, and care 2024. The Lancet [internet]. 2024. Available: **Dementia prevention, intervention, and care 2024** [Accessed 2026 Oct 10]
15 The Alliance of Age Sector NGOs. Taking Stock 2026[Internet]. 2026 [cited 2026 Oct 16]] Available: **https://ageandopportunity.ie/wp-content/uploads/2024/02/Taking-Stock-Full-Report.pdf**

4
Young onset dementia (YOD) supports

As the number of people living with YOD in Ireland grows, it is essential to recognize their specific needs and adapt services accordingly. Over the last three years The ASI has developed a number of Activity Clubs to cater for those in early stages of dementia / living with YOD. These clubs are important as they provide families with the opportunities to socialise, offer informal peer to peer support and cater to the interests of those in the early stages of diagnosis.

Family support groups and counselling play an important role for those diagnosed with YOD as they navigate social and financial challenges typical of people of their age. It can often be challenging for family members to see a loved one's condition progress over a short period of time, resulting in ambiguous grief. A diagnosis of YOD can remove a certain level of independence, which can cause profound changing dynamics within the family. When a person living with dementia has access to adequate services, our findings show that there can be an improvement in mental health and overall wellbeing.

Action:

- Develop wrap-around psychological support that encompasses the family unit, rather than just the person living with young onset dementia or their spouse.

5.
Expansion of post-diagnostic education and support for people with dementia and their carers

The Model of Care identifies timely and equitable access to post-diagnostic support as a key priority. While a range of services and initiatives are already making a positive difference for people with dementia and carers, survey findings highlight ongoing gaps in access to practical guidance and support. Some carers described uncertainty about how best to meet the needs of the person they care for, including day-to-day activities such as supporting with mealtime and personal care challenges, as well as how to respond to emotional and psychological symptoms.

The ASI contributes to this area through initiatives such as Family Carer Training and our Dementia Adviser service. These supports provide practical education, guidance and signposting to relevant services and resources. The Dementia Advisor service is particularly valuable in helping carers navigate available supports in a way that reflects their individual circumstances and time constraints. However, the continued need for this support, alongside increasing numbers of people receiving a dementia diagnosis, highlights the importance of further investment.

Action:

- Sustained investment in post-diagnostic education and information-sharing initiatives in anticipation of increased prevalence rates over the coming years.

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.

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

Monday to Friday 10AM – 5PM
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