



Family  
Carers  
Ireland

No one should have to care alone

# The State of Caring 2026





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## CEO FOREWORD

Family Carers Ireland is deeply grateful to every family carer who contributed to this year's State of Caring survey. Your willingness to share lived experiences - often under significant pressure - ensures that the realities of family caring in Ireland are visible and understood. I also wish to acknowledge the invaluable contribution of our Public and Patient Involvement Panel, our Research and Policy Committee, our internal research team (Dr. Nikki Dunne and Joanne Murphy), and Dr. Maeve O'Sullivan of the University of Galway for her expertise in analysing and interpreting the data.

This report captures the experiences of family carers at the most intense end of caring. Its findings are stark and consistent with our evidence since 2020 - a significant majority of those who responded to this survey continue to provide care without adequate formal support, and many are doing so without ever having access to respite. Financial strain is a persistent feature of caring, with many households struggling to make ends meet and in some cases cutting back on essentials such as food and heating. At the same time, respondents report high levels of poor physical and mental health, alongside widespread experiences of loneliness.

There are many opportunities to further develop supports for family carers - particularly through the expansion of integrated care programmes within communities and the continued development of carer supports under the Carer Guarantee. The State of Caring 2026 is both a recognition of the vital contribution family carers make and a clear call to action to ensure they receive the support they urgently need and deserve.



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Sharon Foley, CEO

# KEY FINDINGS



# SUMMARY OF RECOMMENDATIONS

**The State of Caring 2026 findings show that family carers continue to face significant financial pressure, inadequate access to services, poor health and wellbeing, loneliness, transport barriers and uncertainty about future care arrangements. These recommendations set out the key actions needed to better recognise, support and sustain family carers.**

## 1. IMPROVE INCOME AND FINANCIAL SECURITY

Abolish the means test for Carer's Allowance and establish a Family Carer Payment Implementation Group to oversee the transition to a new Family Carer Payment.

Increase Carer's Allowance and Carer's Benefit to €325 per week, make carer payments tax-exempt and introduce a Cost of Disability payment.

Extend Fuel Allowance to all Carer's Allowance recipients and introduce targeted supports for caring households with high care-related energy costs.

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## 2. IMPROVE ACCESS TO SUPPORTS AND SERVICES

Provide flexible respite options that meet the needs and preferences of both family carers and the people they support.

Introduce the statutory home support scheme and take urgent action to address the shortage of home care workers.

Reduce waiting lists for Assessments of Need, therapies and specialist services, and provide financial relief for families forced to pay privately.

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## 3. SUPPORT FAMILY CARERS' HEALTH AND WELLBEING

Fully fund the Carer Guarantee to ensure family carers have consistent access to information, training and support regardless of where they live.

Recognise family carers as a distinct at-risk group within national health and wellbeing policy.

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## 4. ADDRESS LONELINESS AND SOCIAL ISOLATION

Fund the National Loneliness Strategy and ensure family carers are explicitly included in its implementation.

Develop targeted supports for family carers experiencing loneliness, including respite, peer support, training, social connection and support to remain in employment where appropriate.

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## 5. IMPROVE TRANSPORT SUPPORTS

Progress the review of the Disabled Drivers and Disabled Passengers Scheme and introduce a replacement scheme that reflects modern disability and mobility needs.

Ensure public transport is accessible, reliable, affordable and usable in practice for disabled people and the family carers who support them.

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## 6. SUPPORT FUTURE PLANNING

Develop structured future planning pathways for family carers and care recipients, covering housing, care arrangements, financial security and decision-making supports.

Ensure future planning is underpinned by guaranteed access to appropriate community-based supports, rather than relying on informal or assumed family succession.

# STATE OF CARING 2026 CONTEXT

Each State of Caring survey is shaped by the wider context in which care is provided. Family caring is not a marginal issue in Ireland. According to Healthy Ireland 2025, 1 in 7 people aged 15 and over provide care, equivalent to an estimated 624,190 family carers when extrapolated to the population aged 15 and over. This means that family caring is a major public health, social care and economic issue, affecting a substantial proportion of households across the country.

The 2020 and 2022 surveys captured the profound impact of the COVID-19 pandemic on family carers, while the 2024 report highlighted the escalating pressures of the cost-of-living and housing crises. The State of Caring 2026 survey reflects a continuation of these challenges within a rapidly evolving national and international context.

The findings presented in this report were gathered in January to March 2026. At that point, family carers were already navigating significant financial pressures; since then, geopolitical instabilities, particularly in the Middle East, have driven further volatility in energy and fuel costs. Many of the challenges identified in this report should therefore be understood as a baseline, as it is reasonable to expect that many of the pressures described by family carers have since intensified.

Since the publication of the State of Caring 2024, Ireland has undergone a period of significant political change. A general election and the subsequent formation of a new Government resulted in a Programme for Government - Securing Ireland's Future - that includes 34 commitments relevant to family carers. These include the phased abolition of the Carer's Allowance means test, meaningful increases to the income disregard, increased funding for respite, and the expansion of alternative forms of respite. These commitments represent the most substantial policy recognition of family carers in recent years.

Yet Family Carers Ireland's Family Carer Scorecard 2025 shows that progress on the agreed commitments has been uneven. While some reforms have progressed, others remain delayed, underfunded, or incomplete. Chronic workforce shortages continue to limit access to home support, respite services remain inaccessible or irregular for thousands of children and adults,

and the Carer Guarantee, designed to provide consistent supports for family carers across Ireland, has not been fully funded.

Against this backdrop, the State of Caring 2026 centres on a number of themes that reflect the most pressing realities of family carers' lives: financial strain, access to formal supports and respite, access to transport, and loneliness and social isolation.

Formal supports and respite services are central to family carers' ability to continue caring safely. When these services are absent, delayed or inaccessible, the weight of care falls on the family, often without relief or rest. Transport is part of this picture; for many it can determine whether services can be reached, shaping access to healthcare, therapies, education and community participation for the people they care for, as well as their own ability to sustain their role. Family carers consistently describe the cumulative toll of these gaps on their health and wellbeing, and on the people they care for.

Caring can be profoundly meaningful, but it can also be profoundly isolating. The demands of caregiving often leave little room for social participation, and many family carers describe a deeper sense of being unseen, a feeling that their experiences and contributions are not fully recognised by the State and society.

The findings presented in this report illustrate the scale of these challenges and the resilience carers demonstrate in navigating them. The nearly 3,000 family carers who shared their experiences are often those carrying some of the heaviest responsibilities, managing the greatest pressures and experiencing sharp gaps in support. They need recognition, practical support and policy attention.

Family carers provide essential support that enables many people to live in their homes and communities, underpinning Ireland's health and social care system, yet they are invisible in many ways. As discussions about the future of Ireland's health and social care policy continue, the experiences shared by nearly 3,000 family carers in this report offer a clear guide for what must change and why.



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# ABOUT THE RESEARCH

This report sets out the findings of Ireland’s fourth national State of Caring survey undertaken by Family Carers Ireland between 26 January and 9 March 2026. The online survey was completed by 2,930 current family carers, making this report a substantial national account of family carers’ lived experience in Ireland in 2026. These people care for at least 4,042 care recipients and represent a range of caring situations – parents caring for a child with an illness or disability, those caring for an adult, carers of older people and those caring for multiple people. The survey was open to current family carers aged 18 years and older. A link to the questionnaire was sent to Family Carers Ireland’s membership and disseminated via our network reach, e.g. social media, website, other carer organisations, condition-specific and community organisations. Paper copies of the questionnaire were available on request via our Careline, carer groups and local support centres.

As with previous State of Caring surveys, respondents are not intended to represent a statistically representative sample of all family carers in Ireland. Rather, the survey captures the experiences of a large group of family carers who were motivated and able to respond, many of whom are likely to be at the sharper end of caring. This is important: these are often the cohort providing the most intensive or complex care, and therefore among those most in need of recognition, support and policy attention.

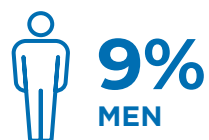
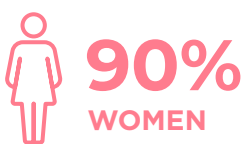
As not all respondents completed each question in the survey, a number of figures in the report are based on responses from fewer than 2,930 family carers. This, together with the variations in the numbers of different groups of family carers, should be taken into consideration when interpreting the results. It is also worth bearing in mind that some figures do not add up to 100% due to rounding. In several questions, family carers were invited to share additional comments - their responses help illustrate many of the report’s findings.

The findings presented in this report are summary headline findings from the survey. Further analysis is planned to explore key themes in greater depth. Copies of the questionnaire are available upon request.



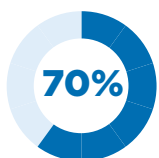
**A family carer is someone who is providing care to a child or adult with additional needs, physical or intellectual disabilities, frail older people, those with palliative care needs or those living with chronic illnesses, mental health challenges or addiction.**

## PROFILE OF RESPONDENTS



[ AVERAGE CARER AGE

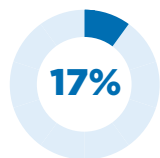
MEDIAN CARER AGE ]



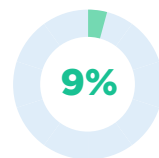
caring for one person



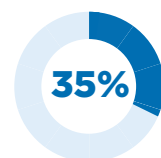
caring for two or more people



said there was a young person under 18 who helps to provide care in their household<sup>1</sup>



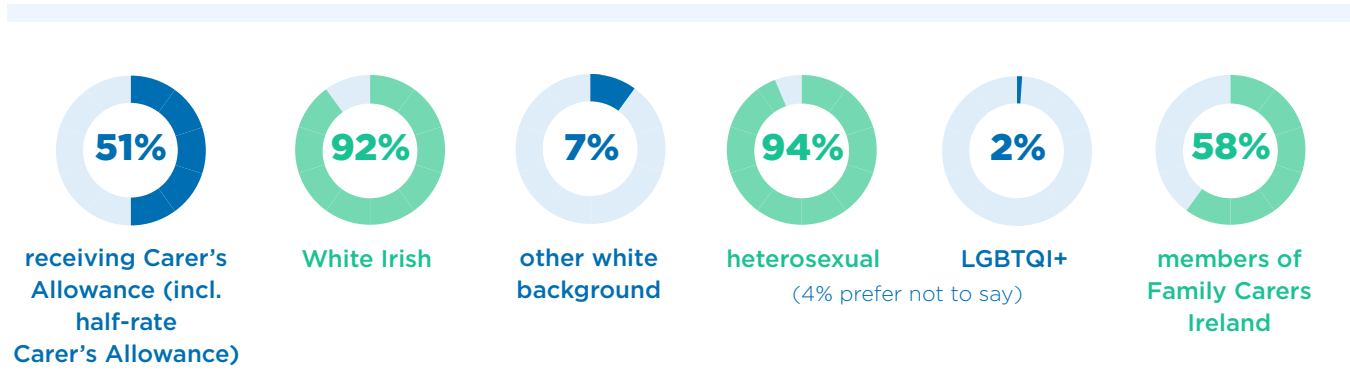
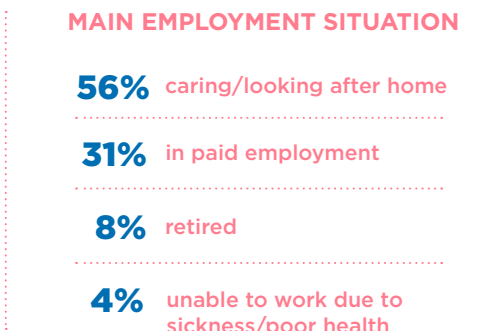
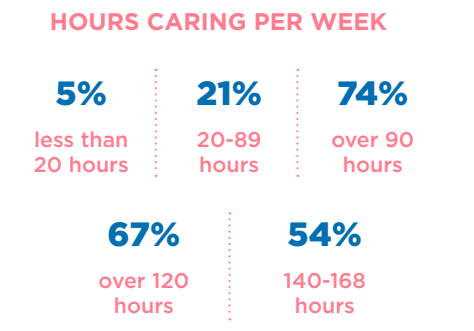
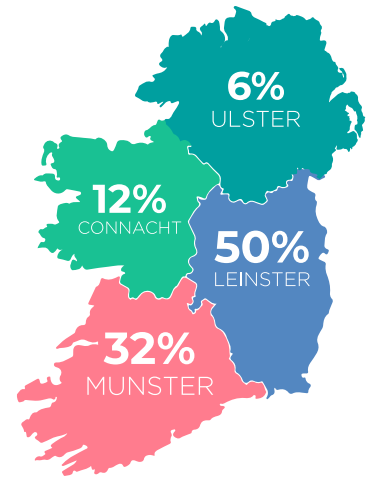
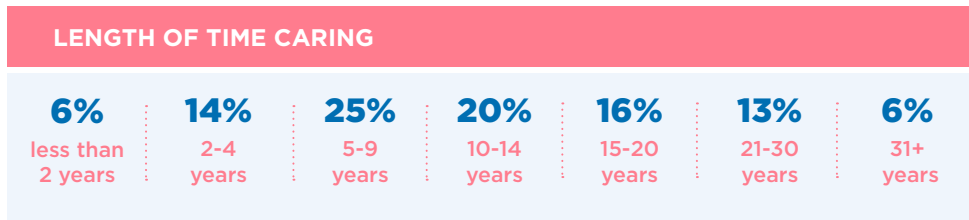
said there was a young adult (18-24) who helps to provide care in the household



have childcare responsibilities for children under 18 without additional needs

<sup>1</sup> We asked respondents 'Is there a child or young adult in your household that helps provide care on a regular basis?' Response options were 'Yes, child/children under 18 years'; 'Yes, young adult(s) under 25 years' and 'No'.

# SUMMARY OF RECOMMENDATIONS



This sample is drawn from the network reach of Family Carers Ireland and is not representative of the total population of family carers in Ireland. The Healthy Ireland Survey 2025, which is nationally representative of the general population (but not specifically of family carers), showed that 14% of people aged 15+ identify as family carers. Whilst nearly 2 in 3 (60%) family carers in that survey were women, 9 in 10 (90%) State of Caring 2026 respondents are women. Healthy Ireland indicates that almost half of all family carers (49%) are aged 45-64, compared to 60% in the State of Caring 2026 sample, while 81% of family carers rate their health as good or very good, compared to just 37% in the State of Caring 2026 survey.

There are also differences in the duration of caring. Healthy Ireland has 40% providing care for six years or more, whereas the State of Caring 2026 survey captures a higher proportion of long-term carers, with over half caring for 10 years or more.

There are also notable differences in the intensity of caring. Healthy Ireland reports a median of 10 hours of care per week with many carers providing relatively low to moderate levels of support (e.g. 37% providing 7 hours or less per week) although almost 1 in 4 (24%) provide round-the-clock support. In contrast, the State of Caring 2026 survey captures a much more intensive caring profile, with a substantial proportion of respondents providing very high levels of care, including many reporting near full-time or continuous caring responsibilities.

This suggests that, compared to the family carer profile captured in Healthy Ireland, respondents to the State of Caring 2026 survey were more likely to be women, in poorer health, and providing care over longer periods. As such, the findings are likely to reflect the experiences of family carers with more intensive and higher-need caring roles.

# CHARACTERISTICS OF CARING

No two caring experiences are the same, as the physical and emotional effects of care giving vary from one person to the next. The amount and type of care that family carers provide varies considerably - from providing a few hours a week shopping, collecting medication and taking someone to medical appointments to round-the-clock care.

Figures from the State of Caring 2026 survey show:

**78%** help with aspects of personal care

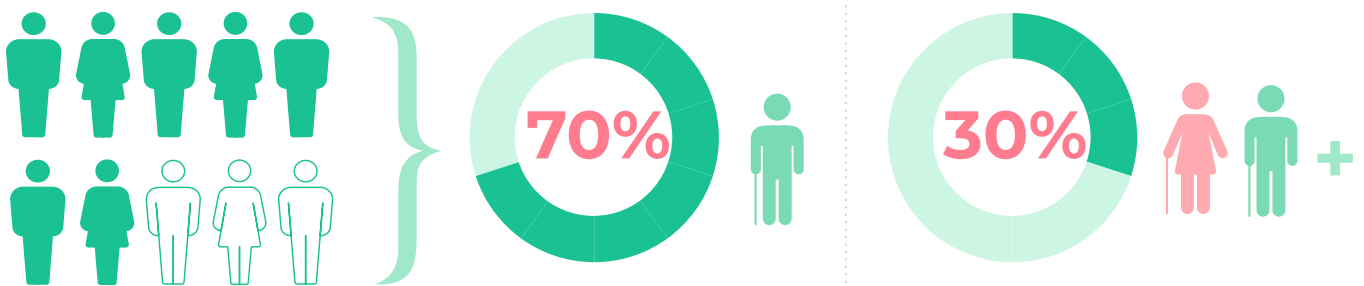
**85%** provide practical help such as preparing meals

**92%** arranged/coordinated care and support, medical appointments and other forms of support

**77%** help with medication

**89%** provide emotional support

**83%** provide transport for the person(s) they care for



Seven in ten (**70%**) care for one person

**30%** are caring for two or more people.



**61%** care for a son or daughter



**26%** care for their parents or parents-in-law



**14%** care for their spouse or partner



**4%** care for siblings



**36%** care for someone with an intellectual disability



**35%** care for someone with a physical disability



**43%** care for someone with autism



**20%** care for someone with frailty



**13%** care for someone with dementia



**20%** care for someone with mental health challenges<sup>2</sup>

<sup>2</sup> These figures do not add up to 100% due to co-morbidities amongst those receiving care.



# CHANGES OVER TIME:

## COMPARING STATE OF CARING SURVEYS

**The 2026 State of Caring survey suggests that many of the challenges identified in earlier waves have not eased but have rather persisted. By comparing headline findings over time, it is possible to identify patterns in family carers' circumstances, areas where challenges persist or where conditions may be changing. The basic survey method used in the State of Caring has been the same, so results can be compared over time.<sup>3</sup>**

Participation in the study has increased steadily since 2020. The 2026 survey is the largest State of Caring survey undertaken in Ireland to date, capturing the experiences of nearly 3,000 family carers. This growing participation reflects the expanding reach of the survey, increasing awareness among family carers and the continued need for them to have their experiences recognised and documented. As in previous years, respondents reflect a wide range of caring situations, including parents of children with additional needs, those supporting adults with chronic conditions or disabilities, and those caring for older people.

The demographic profile of respondents has remained broadly stable across all waves. The majority are women and are typically in mid-life. However, men, younger carers, migrant carers and those outside established support networks remain underrepresented. This is a methodological limitation that persists across the survey series and continues to require more targeted recruitment approaches.

The intensity of caring roles continues to be a defining feature across all four surveys. A substantial proportion of respondents report providing very high levels of care each week, often alongside employment and/or parenting responsibilities. There is also a substantial minority providing care to more than one person.

Financial strain is one of the few areas where the data show both change and continuity. On the one hand, the proportion of family carers in households earning less than €30,000 has decreased over time (from 53% in 2020 to 35% in 2026). However, this should not be read as a straightforward reduction in financial hardship. The period was marked by significant cost-of-living pressures, including high inflation in 2022 and continuing price increases in subsequent years, while the proportion of those reporting difficulty making ends meet has remained persistently high. In 2026, 71% reported financial difficulty which is broadly in line with previous waves.

Health and wellbeing outcomes show little sign of improvement. Across all survey waves, family carers consistently report poorer health than the general population, with a gradual increase in the proportion reporting bad or very bad health. Earlier surveys established that many experienced very high levels of loneliness and the 2026 findings suggest little change on that front.

Access to respite and formal supports also shows little improvement. The proportion of those who have never received respite has increased across survey waves, reaching 75% in 2026. However, awareness of the Assisted Decision-Making (Capacity) Act 2015 has increased significantly since 2020, indicating increased awareness of the act, although recognition does not necessarily translate to understanding.

Overall, the survey series provides an uncomfortably persistent picture of hardship experienced by family carers in Ireland over time. The broad underlying challenges in terms of financial strain, access to supports and services and loneliness appear very similar.

<sup>3</sup> These four surveys are not directly comparable because they are based on convenience samples which means that different carers could have responded to each survey. Nonetheless, the sampling process was the same in all surveys, so we assume the same biases are present. While the surveys may be not representative of the whole carer population, the biases are consistent, so that results can be meaningfully compared.

## Comparisons of key findings over time

<b>FAMILY CARERS PARTICIPATING IN STATE OF CARING</b>	<b>2020</b>	<b>2022</b>	<b>2024</b>	<b>2026</b>
<b>NUMBER OF PARTICIPANTS</b>	<b>1,250</b>	<b>1,484</b>	<b>2,127</b>	<b>2,930</b>
Gender Breakdown	<b>88% women, 11% men</b>	<b>88% women, 10% men</b>	<b>90% women, 9% men</b>	<b>90% women, 9% men</b>
Average age	<b>48</b>	<b>49</b>	<b>49</b>	<b>51</b>
Median age	<b>-</b>	<b>49</b>	<b>49</b>	<b>45</b>
Caring for a son/daughter	<b>63%</b>	<b>61%</b>	<b>68%</b>	<b>61%</b>
Caring 90 hours or more per week	<b>82%</b>	<b>79%</b>	<b>78%</b>	<b>74%</b>
Caring for two or more people	<b>26%</b>	<b>27%</b>	<b>31%</b>	<b>30%</b>
Have never received respite	<b>65%</b>	<b>66%</b>	<b>72%</b>	<b>75%</b>
Living in households with a total income of less than €30,000 per year	<b>52%</b>	<b>47%</b>	<b>39%</b>	<b>35%</b>
Finding it hard to make ends meet	<b>70%</b>	<b>67%</b>	<b>69%</b>	<b>71%</b>
Bad or very bad self-reported health	<b>14%</b>	<b>15%</b>	<b>16%</b>	<b>18%</b>
Moderate self-reported health	<b>48%</b>	<b>43%</b>	<b>44%</b>	<b>45%</b>
No awareness of the Assisted Decision-Making (Capacity) Act 2015	<b>73%</b>	<b>68%</b>	<b>37%</b>	<b>39%</b>

# FINANCIAL IMPACT OF CARING:

'CAUGHT IN A POVERTY TRAP NOT OF MY OWN MAKING'

Family caring continues to place significant financial strain on households. Some family carers leave or reduce employment to care, so they experience a loss of income alongside the costs associated with caring. Evidence has long shown that these costs are substantial. Even prior to the cost-of-living crisis, households caring for a child with a profound disability incurred an additional €244 per week in direct care-related expenses (Mac Mahon et al., 2022). The State of Caring 2026 findings show that many experience financial hardship whilst facing barriers to income supports.

Asking about difficulties in making ends meet is a useful way of capturing financial hardship, as many factors that affect a person's situation may not be reflected in the usual statistics on income or relative measures of poverty (Eurofound, 2017). When asked about their ability to cope financially, more than 2 in 3 (71%) reported finding it difficult to make ends meet, 18% with great difficulty. In comparison, nearly half (45%) of households in the general population report at least some difficulty making ends meet, with around 6% experiencing great difficulty (CSO SILC, 2025). There is a substantially higher level of financial strain among family carers.

**38%** said housing costs were a heavy financial burden to their household

**Financial strain is high across all groups of family carers but is higher among those caring for children (74% reporting difficulty making ends meet). This compares with 67% of those caring for a parent or parent-in-law and 57% of those caring for a spouse or partner.**

I'm currently living down to the last cent every week.

## FINANCIAL STRAIN AND EVERYDAY CUTBACKS

Given the financial difficulties many family carers face, it is not surprising that many describe struggling to meet bills, cutting back on essentials and socialising. Whilst this is increasingly common across the population given the cost-of-living crisis, it is especially concerning for the family carer population given their increased risk of loneliness and the implications of not being able to keep their home warm. Amongst those experiencing acute financial distress (n=960 who said they were experiencing difficulty or great difficulty making ends meet):

**49%** are cutting back on essentials such as food and heat

**76%** are cutting back on non-essentials

**66%** are cutting back on seeing friends and family

**77%** are cutting back on hobbies and leisure activities

**29%** have struggled to pay utility bills

**36%** are borrowing money from family or friends

**15%** are falling into arrears with rent or mortgage payments

**16%** are cutting back on support services which help with caring

I haven't made a bin or electricity payment since early December.

These stark figures suggest that significant numbers of family carers are experiencing fuel and food poverty, with a small number of those struggling financially reporting reliance on food banks (8%) and charities such as St. Vincent de Paul (15%) to get by.

Whilst many people across Ireland are feeling the pinch of the cost-of-living crisis, 46% of respondents report that their caring role contributed to the financial pressure their household has faced in the last year.



**With the cost of living gone up... I've cut back on anything outside the house... I don't see anyone or hear from anyone on a day-to-day or week-to-week basis.**



## INCOME SUPPORTS: COVERAGE AND GAPS

We asked family carers about the social welfare payments and financial supports they receive. Over half (51%) receive Carer's Allowance (incl. half-rate Carer's Allowance) and 7% receive Carer's Benefit. Almost half (46%) receive the Carer's Support Grant and 33% reported that their child received Domiciliary Care Allowance. Only 18% receive Fuel Allowance.

Carers who were not in receipt of any of these supports (19%) provided short explanations about why they were not accessing them. Analysis of these responses shows a set of persistent barriers that were also present in 2024.

### 1. Restrictive Means Testing:

A recurring theme in 2024 and 2026 is the ongoing challenge posed by the means testing of Carer's Allowance. Carers reported being excluded due to household income, partner earnings, savings and pensions, despite many experiencing significant costs and financial strain associated with caring. Many responses suggest a perceived mismatch between how means are assessed and the actual costs of care and living alongside reduced income.



Our household income has been significantly reduced, and our costs hugely increased, due to my wife's disability rendering her unable to work. The sole focus is on our income, which I can only maintain because I'm self-employed. We are also penalised for my wife's good judgement in securing income protection.



My pension is slightly above the current cap.



## 2. Eligibility and Paid Employment:

A large number of family carers described being unable to access some supports because they are in paid employment and therefore exceed the income or hourly thresholds. At the same time, many emphasised that they cannot afford to reduce or give up work due to financial pressures. This highlights a tension between eligibility rules and the realities of combining paid work with caring responsibilities.

**I work full time as have no more Carer's Leave left... My health is affected with burnout, exhaustion, weight loss, am now under the care of psychiatry myself.**

## 3. Definition of Caring Roles:

Some reported being ineligible as they are not recognised as a 'primary' carer or because care is shared across family members or households.

## 4. Care Recipient Needs:

Some family carers reported being refused supports on the basis that care needs were not considered severe enough, that required hours were not met, or that medical or administrative evidence did not support their application. Others highlighted challenges linked to life-course transitions, such as children ageing out of supports.



**My mother is deemed primary carer for my brother. But I'm caring for both of them. I also work full time.**



## 5. Administrative Burden and System Complexity:

Some described the application process as complex, time-consuming and emotionally demanding. Long forms, repeated requests for documentation, refusals, appeals and delays in decision-making were cited as deterrents. Several respondents indicated that they had abandoned applications due to stress or lack of capacity to engage with the process.



**Though I'm well educated, I find filling the forms out difficult.**



**The 28-page form and all the bureaucracy... We just gave up. It's designed to be inaccessible.**



# GAPS IN FORMAL SUPPORTS:

'CARING FOR MY DAUGHTER IS THE EASY PART'

**Family carers continue to experience significant challenges in accessing adequate formal supports for the people they care for. When asked whether the person they support receives enough formal support in their everyday life, 69% reported that they do not, while 21% felt that needs were being met, and 10% indicated that formal support was not required.**

**69%** report that the person they care for does not receive enough formal support

The reasons underpinning this lack of support point to systemic gaps in service provision. The most commonly cited issue was inadequate staffing, reported by 42% of carers, which directly limits service availability. **Over one-third (37%) had actively sought services but had not received them, while 25% reported that available services were not appropriate to the needs of the person they care for.** Financial and administrative barriers also persist, with 16% identifying cost as a barrier and 12% describing the process of accessing supports as too complex.



I'm sometimes sad that I may be spending what may be the little time we have left together running around stressed out.



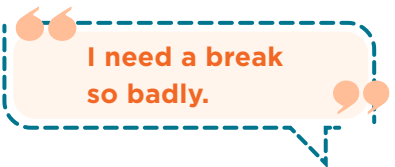
I don't have a minute to myself to just be me. My life is for everyone else. I'm advocating so much for my mother and fighting for services, but I'm just faced with obstacles.



These access challenges are further reflected in prolonged waiting times. Almost two-thirds (65%) reported being on a waiting list for publicly funded services such as therapies, wheelchairs and Assessments of Need, with 66% of these waiting over a year. In response to these gaps, **more than half (55%) reported paying privately for services or supports that should, in principle, be publicly provided.** These findings suggest there is significant and widespread unmet need and that families are filling these gaps themselves.

## RESPITE CARE: HIGH DEMAND, LIMITED ACCESS

Respite care remains a critical but largely unmet need within this broader context. Three-quarters of carers (75%) reported that they have never received respite, with a further 5% indicating that it has been more than two years since they last accessed it. Despite this, a clear majority (64%) expressed a desire to receive respite, provided it is available and appropriate to the needs of the person they care for.



**75%** have never received respite

**64%** would like to receive respite if available and suitable to the needs of person they care for



I need respite where my son is safe, stimulated and having fun. So I can spend time with my other child and just focus on her. So I can sleep. So I can just switch off being hypervigilant all the time. I adore my son, I am blessed to be his mam. But I am not a robot. I can't keep going at this pace without some quality of life for myself. I'm a person too.



Among those who would like respite (n=1,842), **the majority (91%) reported that their needs for respite are not currently being met, highlighting a massive gap between demand and provision.** Preferences for respite are varied, but indicate a need for regular and flexible support: 21% would prefer monthly respite, 17% as needed, 15% weekly, and 15% every 1-3 months. This distribution suggests that respite is not viewed as an occasional intervention, but as an ongoing support necessary to sustain caring roles.

However, this gap cannot be understood solely in terms of service availability. While structural barriers are important - including availability, cost, and accessibility - relational factors also play a significant role.

**The person I am caring for does not wish to avail of respite care.**

### RESPIRE NOT PERCEIVED AS A VIABLE OPTION BY SOME

Over one third of respondents (36%) indicated that they would not like to receive respite care. However, responses suggest this should not be interpreted as a straightforward lack of demand. In many cases, family carers described significant constraints that make respite feel unrealistic or unworkable in practice.

The most common reason given was that the person being cared for would not accept respite. This was often linked to concerns about the quality, suitability or safety of alternative care, as well as the potential distress caused by disruption to established routines. In this sense, reluctance is not necessarily a rejection of respite itself by the family carer but reservations about the willingness of the care recipient and a lack of confidence in the available options.

Other respondents noted that they did not currently need respite but might in the future, while some reported having sufficient support through family or community networks. A smaller number highlighted that the person they care for is too young for existing respite services.

**I wouldn't be able to go anywhere. I would be afraid to look for respite to leave my husband - he would go mad. It would be upsetting for him, then that would be my fault.**

### WHAT FAMILY CARERS NEED FROM RESPIRE CARE

When asked to identify the most important factors in seeking respite care, respondents prioritised quality and safety, with 49% selecting care delivered by well-trained staff as their top concern. This was followed by accessibility and availability when needed (38%).

Affordability was ranked lowest (37%). However, this should not be interpreted as cost being unimportant. Rather, it suggests that family carers see trust, reliability and ease of access as more immediate barriers to using respite services. Cost may still act as a constraint, but only once these other conditions are met.

Preferences for respite models reinforce this emphasis on trust and continuity. Family carers were asked to select their top three most valued settings for respite: the most valued option was in-home respite (31%), followed by residential or overnight care (24%) and self-catering or holiday-style breaks (19%). While in-home respite was the most selected option, the fact that almost 1 in 5 carers prioritised self-catering or holiday-style breaks indicates a significant demand for alternative respite models. These findings point to the need for a broader mix of respite options, including models that minimise disruption and maintain continuity of care, while also offering opportunities for a meaningful break in a setting that feels appropriate and manageable.

These challenges are occurring in the context of already high and, for many, increasing caring demands, with a majority of respondents (74%) providing more than 90 hours of care per week. Over one-third (36%) of all respondents indicated that their caring hours have increased in the past year. Against this backdrop, limited access to formal supports and respite raises serious concerns about the long-term sustainability of care.

## TRANSPORT AND CARING:

'BUS SERVICES CAN BE LATE OR NOT TURN UP SO AREN'T DEPENDABLE'

Transport is a fundamental, yet often overlooked, component of the caring role. For many family carers, the ability to access reliable and affordable transport is essential to carrying out daily care activities such as attending medical appointments, collecting prescriptions and accessing services.

**95%**

use their own car or take taxis to travel with the person they care for

The survey highlighted the extent to which family carers provide transport as part of their role, with a significant majority involved in facilitating travel for the person they care for.

Transport also intersects with other dimensions of the caring experience, including loneliness and social participation. Family carers and those they support can become increasingly isolated, with fewer opportunities to engage with their communities when transport options are limited or unaffordable.

**64%**

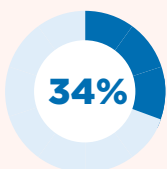
found it difficult to meet the transport costs of running a car or taking taxis

**45%**

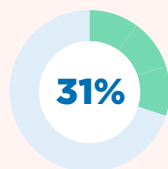
don't use public transport with the person they care for

Family carers who feel lonely are more likely to struggle to afford transport, with nearly three-quarters (74%) of those who often feel lonely reporting difficulty meeting transport costs, compared to 61% of those who feel lonely some of the time and 41% of those who hardly ever or never feel lonely.

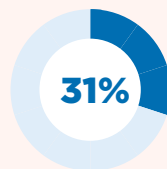
### When asked about why they found it difficult or did not use public transport:



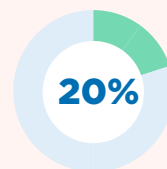
Timetable does not suit or provides poor connections



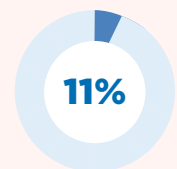
Service is not accessible



Service is too infrequent



No service



Cost



Public transport bus services can be late or not turn up so aren't dependable.





We live in rural Ireland and the nearest bus service is almost five miles away.



The person I am caring for with mental health needs finds it very difficult to use public transport due to their anxiety levels around others. However, I can't always afford petrol and parking.



The qualitative responses to this question provide further insights into the barriers carers face in accessing transport, highlighting issues of accessibility, reliability and suitability.

**1. For some, particularly those living in rural areas, the absence of local services or poor connectivity between routes makes public transport effectively unavailable.** Although public transport services exist in many parts of rural Ireland, infrequent timetables and unreliable scheduling can make it difficult to attend time-sensitive appointments or access supports located outside of local areas.

**2. Accessibility also remains a significant concern.** Family carers described difficulties related to limited wheelchair space, long distances between connections and station infrastructure that does not adequately support those with mobility challenges. These barriers can make journeys physically demanding or completely unmanageable.

**3. Many also highlighted that public transport is not always suitable for the needs of the person they care for.** Sensory overload, anxiety, behavioural challenges and a lack of awareness of invisible disabilities were frequently cited as factors that make using public transport difficult or distressing. In these situations, family carers often rely on private cars or taxis, although some emphasised that this placed additional financial strain on already limited resources.



There's no awareness of invisible disability.



On buses there may not be enough space for a wheelchair if someone else is already using the space.



I popped my elbow out of its joint in a fall last summer and had zero means of transport as a result. I couldn't drive and received zero support as the people I care for were not injured.



# FAMILY CARER HEALTH AND WELLBEING:

'I AM NOT A ROBOT. I CAN'T KEEP GOING AT THIS PACE'

While caring brings a sense of personal growth and confidence for some (Pysklywec et al., 2020), research also shows the toll that caring can take on health and wellbeing, including an increased risk of issues such as depression (del Pino-Casado et al., 2019). As noted earlier, the State of Caring survey is likely to give particular visibility to those at the more intensive end of caring, many of whom are managing sustained, complex or high-pressure caring responsibilities. The 2026 survey data support this pattern - family carers report poorer overall health than the general population in Ireland with many reporting poor mental and physical health, and a small proportion describing acute distress. Almost three quarters (71%) reported that their health has been negatively affected by their caring role.

Self-reported health status	Family Carers in 2026	General Population Aged 15+ <sup>4</sup>
Very good or good	37%	83%
Fair	45%	9%
Bad or very bad	18%	2%

Respondents were asked to rate their physical health and mental wellbeing. Although these are not comparable with the general population, they indicate that many feel that their mental wellbeing is particularly poor, with almost 1 in 3 (32%) reporting bad or very bad mental wellbeing.

Self-reported health status	Physical Health	Mental/Emotional Wellbeing
Very good or good	35%	20%
Fair	46%	48%
Bad or very bad	19%	32%



I am 78 years old... I rarely go outside or meet friends any longer. Even visiting my other children and grandchildren is rare for me. I'm not living. I have recently been prescribed anti-depressants to help with my low mood. My GP tells me to go for walks in the daylight, but I cannot find the time.



I am constantly scrimping by every week, worried sick about bills, petrol costs, cost of living etc., socially isolated by not having the money to engage in normal social activities, exhausted from no respite, can't afford holidays, etc., all detrimental to my physical and mental health.



<sup>4</sup> Census of Population 2022 'Health, Disability, Caring and Volunteering'.

## WHEN CARING BECOMES UNSUSTAINABLE: SEVERE DISTRESS AND CRISIS

Respondents were offered the opportunity to explain how loneliness or isolation has, or has not, affected them as a family carer. In total, 789 left free-text comments. Within these comments, 110 responses reflected very high levels of distress. A much smaller number of responses explicitly referred to suicidal thoughts, wishing their situation would end or feeling unable to continue.

**It's 24/7. I've no one... I'm exhausted, mentally broken... I have to be everything for everyone.**

These accounts went beyond loneliness and social isolation. Family carers described emotional exhaustion, feeling trapped, hopelessness, loss of identity and high levels of psychological strain, pointing to the potential consequences of intensive caring without adequate support.

Those with high levels of distress described their role as unrelenting with little or no opportunity for rest or relief. The intensity of care, combined with limited support, contributed to a sense of being overwhelmed and unable to step away:

For some, this level of pressure was accompanied by a loss of identity and a withdrawal from social relationships. Several described no longer sharing their experiences with others, either because of a lack of understanding or a desire to avoid burdening those around them:

**I've stopped talking about how hard it is... even to my closest family. That's how lonely it is.**

In these accounts, loneliness was often intertwined with a deeper sense of disconnection and invisibility, where carers felt unsupported by the systems and networks around them:

**We as carers are invisible.**

A small number of responses included direct references to suicidal thoughts or a desire for the situation to end, reflecting wider research that identifies family carers as a group at increased risk of suicide and self-harm (O'Dwyer et al., 2021).

**In the last nine months I have become suicidal. The loneliness is unbearable at times.**

At the same time, many described continuing in their role despite this level of distress, often motivated by a strong sense of responsibility towards the person they care for:

**The only reason I haven't given into my darkest thoughts is that... he deserves to be loved and protected.**

These responses point to a group of family carers experiencing very high levels of distress, including a small number whose accounts suggest crisis-level psychological strain. While these accounts do not represent all family carers, they highlight the serious potential consequences of intensive caring without adequate support. They also point to the need for earlier identification of crises, accessible mental health supports, and interventions that address the pressures associated with caring.

# LONELINESS AND CARING:

'YOUR WORLD SHRINKS'

Loneliness is increasingly recognised as a serious public health issue, with research linking it to poorer physical and mental health, reduced quality of life, and risks to life expectancy. Research consistently shows that family carers experience higher levels of loneliness than the general population (Hajek et al., 2021). The reasons for this are interconnected: caring limits time for social contact and leisure, can bring feelings of guilt, burden or resentment, and the physical and emotional demands of the role can erode motivation to maintain relationships. Loneliness matters not only for family carers' health and wellbeing but for the sustainability of care itself as higher levels of loneliness have been linked to poorer outcomes for both those caring and the people they support, including earlier moves to formal care settings (Hajek et al., 2021).

**42%** feel lonely most of the time

**50%** feel left out most of the time

**49%** feel isolated from others most of the time

Finding places to go that are fully disability friendly... with proper changing facilities is nigh on impossible... Limited venues mean I have to constantly say no. Then people stop asking and your world shrinks.

## SEVERITY OF LONELINESS AMONG CARERS

People experience loneliness in different ways; some people may feel lonely even if they have regular contact with people around them whilst others may have few contacts but not feel lonely at all. In the State of Caring 2026 survey, we measured emotional loneliness by asking carers about their satisfaction with the quality of their social relationships<sup>5</sup>. Nearly half of family carers were noted as experiencing severe loneliness.

Level of loneliness	
None/low loneliness	20%
Moderate loneliness	32%
Severe loneliness	48%

Loneliness is more common among those who are not in paid employment. Nearly half (47%) of respondents who are not employed say they feel lonely often. Almost 4 in 10 (39%) of those in employment say they feel lonely often, although family carers in employment are also more likely to say they hardly ever feel lonely.

While loneliness was reported across all age groups, those aged between 36 and 65 appeared somewhat more likely to report frequent loneliness than older family carers. This suggests that loneliness is shaped by a range of interconnected factors including employment, age, caring responsibilities, health and level of support. Future analysis will help build a clearer understanding of how these factors interact in family carers' experiences of loneliness.

<sup>5</sup> The level of emotion (subjective) loneliness was measured with the modified 5-item UCLA Loneliness Scale. The questions were measured on a 3-point Likert scale, where 1 meant hardly ever or never, 2 stood for some of the time, and 3 was defined as often. These responses provided scores between 0 and 10 with higher scores indicating more severe loneliness. The scores were categorised and responses ranging from 0 to 4 were defined as no/low loneliness, 5 to 6 as moderate loneliness, and 7+ as severe loneliness.

**82%** feel that society has left them alone to manage caregiving responsibilities

**8%** feel their experiences and struggles as a family carer are genuinely heard and understood by policymakers or government officials

**6%** feel their contributions as a family carer are recognised and valued by society

## THE CONTRACTION OF SOCIAL AND PERSONAL LIFE

For many, loneliness was described as a gradual narrowing of life around their caring responsibilities. Responses pointed to a combination of loss of friendships, constrained time, reduced opportunities for work and social participation and a sense of disconnection from the lives of others.

Changes in relationships and social participation were a consistent theme. Many described friendships fading over time as they became less able to take part in ordinary social life. The constant and unpredictable demands of caring also limited their ability to make plans or engage in social activities.

For others, loneliness was closely tied to a loss of identity and independence as caring became all-consuming and left little space for other aspects of life:

Several respondents explicitly linked their experiences of isolation to wider structural and societal factors, rather than to the caring role alone:

“Our world has got smaller and smaller. No options for respite. No friends left.”

“I feel like I don't have a life of my own, I feel as [if] I've lost my identity, I don't have any time for myself, nobody offers to help me or let me have a break.”

“I feel like a ghost, very unseen in life.”

These responses suggest that loneliness is shaped by the demands of caregiving alongside the wider conditions in which care is provided, including limited support, restricted participation in paid employment and community life, and a lack of recognition.

“I feel that a carer is isolated not because they are in a caring role but because society has placed financial, attitudinal, social and cultural barriers in place that isolate carers and keep them marginalised.”

**90%** feel as though their role as a family carer is dismissed as a private, personal matter rather than a crucial service to society that deserves support

**88%** feel that outside their family, they often feel alone in their journey as a family carer, as if no one truly understands the challenges they face

**84%** report that even within their family they sometimes feel that their caring role is not adequately understood or valued

## THE ROLE OF SUPPORT IN MITIGATING LONELINESS

**Not all family carers reported experiencing loneliness; strong and reliable support networks, particularly from partners and family members, and the ability to share caring responsibilities appeared critical to reducing or avoiding loneliness and isolation. Access to peer support was also important. Respondents described connecting with others in similar situations through groups and organisations such as Family Carers Ireland.**



I'm very lucky to have my wife and family fully supporting my role... that makes life easier.



I've never felt alone in caring for our son because myself and my husband do it together. I'm very grateful how supportive he is.



However, even where family carers did not report loneliness, their accounts often reflected ongoing constraints on their lives:



I don't feel lonely as I have a supportive husband and friends that are going through the same. But I feel I gave up a lot to care for my parents and mother-in-law...



We support each other because we understand - we "get it" - unlike most of society who have regular "normal" lives without the extra role of caregiving.



Until I found Family Carers Ireland, I really was alone and plodding along with no thought for myself. Everything was focused on looking after and minding my loved one from day to day, walking the tightrope, trying to keep it all balanced.



Access to support makes a clear difference to family carers' experience of loneliness.

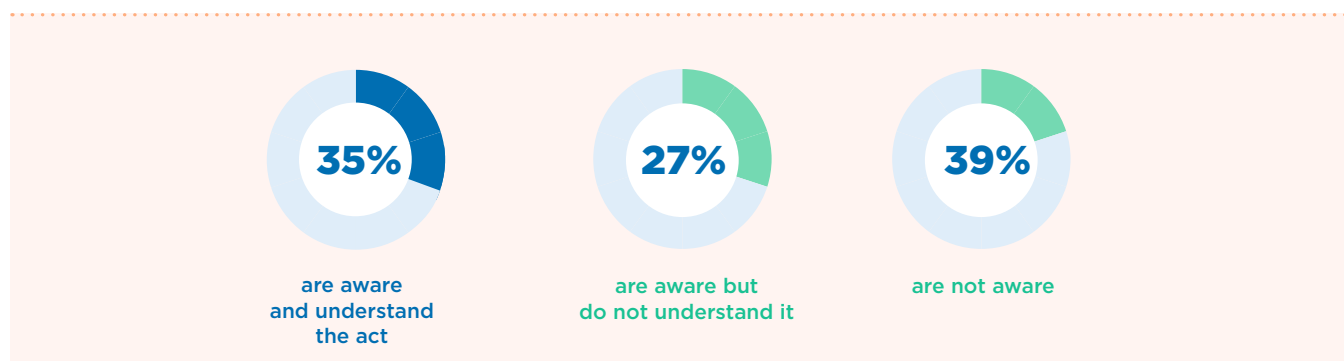
- Among those who do not receive help from others, nearly half (47%) say they feel lonely often.
- This drops to around one-third (34%) among those who do receive support.

Although not necessarily removing the wider constraints associated with caring, these responses suggest the important role that support in different forms can play in reducing or buffering loneliness.

# CHANGING LEGAL LANDSCAPE:

## ASSISTED DECISION-MAKING (CAPACITY) ACT 2015

The Assisted Decision-Making (Capacity) Act 2015 was signed into law in December 2015 and was fully commenced in April 2023. The act recognises that, as far as possible, all adults have the right to play an active role in decisions that affect them such as their personal welfare, healthcare or finances. Where this is not possible, a representative (likely a family carer) is appointed as a decision support. Whilst awareness of the act has increased since its commencement, many report not understanding it.



Awareness of the act varies depending on the age of the person being cared for. Family carers of working-age adults (18-64 years) report the highest levels of awareness, with 44% indicating they are aware of the act, compared with 37% of those caring for someone aged over 65, and just 25% of those caring for someone under 18.

Nearly half (49%) of family carers of those under 18 report no awareness, compared with 29% of those caring for working-age adults, and 39% of those caring for older people.

Importantly, across all age groups, a substantial proportion of family carers report being aware of the act but not understanding it (24-28%), indicating that awareness does not necessarily translate into meaningful understanding.

Given that family carers are central to the operation of this legislation, these findings point to gaps in both awareness and understanding, which will limit family carers' ability to effectively engage in supported decision-making processes.



# FAMILY CARERS' REFLECTIONS:

## WHAT WOULD HELP

We asked family carers what is the one thing that would help them. Across 2,405 responses, the answers were grouped into seven broad areas:

### Financial Security

The call for abolition of the means test was among the most common. Family carers also called for the payment to be reframed as a form of income that reflects the intensity and continuity of caring, rather than a welfare support. This included requests for adequate rates, access to PRSI credits and pension entitlements.

“Payment should not be based on my husband’s income. I gave up my career to care for my children with additional needs. I should not have to ask for money to buy something. I deserve better.”

### Access to Services and Supports

Many responses highlighted the time and effort required to navigate systems in order to access supports. Family carers described a significant burden associated with applying for income supports, coordinating services and advocating on behalf of those they care for. Simplifying access processes and improving coordination across services were identified as key areas for improvement.

“Sometimes I think caring for the person is easier than trying to get the supports they are entitled to. It is all one big battle.”

“Access to the appropriate therapies... would make a huge difference... I feel I am constantly fighting a battle to gain access to services for my child.”

### Recognition

A recurring theme across responses was a perceived lack of recognition. Family carers described feeling undervalued by policy, services, and wider society. This was linked not only to financial supports but also to how caring is understood and acknowledged.

“Being seen and recognised as a vital part of society...”

“To be seen and recognised as a carer. I’m sick of being told by family I don’t work and don’t contribute to the household. People don’t understand what we do and how our health is impacted.”

### Respite

Access to respite was identified as a critical issue, with many reporting limited or inconsistent provision. Some described going extended periods without a meaningful break while others noted that existing respite services were inflexible or difficult to access.

“More respite on a regular basis. I am doing things like this survey - advocating for my child and myself as a carer late at night because there is no other time to do it. There are no breaks. This is a 24/7 role with constant burnout.”

“We have not had a break since 2006. That’s 20 years, 20 years! Ireland is lucky to have families like us who survive on the love we have for our family members.”

## Housing and Accessibility

A group of family carers identified housing as a central concern, particularly where accommodation was unsuitable for care needs or insecure. Issues included poor housing conditions, lack of accessible housing and barriers within the rental system.



**Without stable housing, it is impossible to feel settled or safe while providing full time care... A secure home would not solve everything, but it would remove the constant fear and instability that hangs over us. It would allow us to focus on health, care, and living, rather than surviving.**



## Work and Study

Some family carers described leaving employment due to caring responsibilities, with ongoing impacts on income, identity and future opportunities. The 18.5 hour weekly work limit associated with Carer's Allowance and Carer's Benefit was frequently identified as restrictive. Access to flexible employment, education and retraining opportunities was also raised.



**To have the choice to work or care and not be financially penalised by either choice. I want to work, I loved working as a physiotherapist but now I can't... I would like to live some version of the life I envisioned for my family instead of the hand to mouth financially crippling, physically and mentally exhausting situation I find myself forced into as a parent of a child with physical and intellectual disabilities.**



## Future Planning

Concerns about the future were particularly prominent among those caring for people with long-term or lifelong care needs. This included worry about care arrangements when the family carer is no longer able to provide support, as well as uncertainty about their own financial and social situation after caring ends. Respondents highlighted the need for clearer, accessible mechanisms to support future planning.



**To have a plan in place for when I die, I have no one to take over care for my son. I live my entire life wondering where he will go when I die and it eats me up every single day.**



**Being able to study online. One of the worst things about being a carer is not being able to make any provision or plans for your future when caring ends. The longer it goes on for, the bleaker life becomes and you start to think that even if it does end you won't be able to rebuild your life afterwards.**



What stands out across responses is that family carers identify practical changes that would improve their day-to-day lives, ranging from adequate income supports and accessible services to flexible employment options, respite provision and clearer pathways for future planning. Individual circumstances may vary but the priorities identified point to identifiable gaps in policy and service provision. The following recommendations are directly informed by these reported needs and the findings of the survey.

# STATE OF CARING 2026 RECOMMENDATIONS

**The State of Caring 2026 recommendations reflect the continued relevance of priorities identified in earlier surveys. This includes a clear and ongoing call for the abolition of the means test for Carer's Allowance. Several recommendations from the 2022 and 2024 reports have also been retained where they remain applicable. Many of these priorities align with those set out in Family Carers Ireland's Family Carer Scorecard 2025.**

## INCOME AND FINANCIAL SECURITY

Family carers are facing persistent levels of financial stress and worry. It is essential that the Government takes immediate action to provide additional and targeted financial support for family carers, particularly for those on low incomes.

### Abolish the means test for Carer's Allowance

Abolishing the Carer's Allowance means test would ensure all family carers are recognised and supported for the essential work they do, regardless of their own or their partner's income. It would reduce financial stress and administrative complexity, prevent family carers from losing support as household income changes, and promote fairness by recognising caring responsibilities rather than assessing financial circumstances.

Family Carers Ireland acknowledges the significant progress made in increasing the income disregards for Carer's Allowance, with 68% of Irish households now falling within the financial eligibility criteria. Department figures showing that the scheme has not been overwhelmed as a result, and we encourage the department to use Budget 2027 to announce the full abolition of the means test. In the interim, we call on Government to establish a Family Carer Payment Implementation Group to oversee the transition from Carer's Allowance to a new Family Carer Payment.

### Provide family carers with an adequate income

Taking on full-time caring responsibilities can result in long-term financial hardship, with the loss of income from employment exacerbated by higher household costs. Increasing social welfare rates to mitigate the rising costs of living, as well as valuing the immense contribution of family carers, is critical to ensuring they are protected from financial hardship and have a decent standard of living.

Family Carers Ireland believes the Government should increase Carer's Allowance and Carer's Benefit to €325 per week, in line with the Basic Income for the Arts and to reflect the additional costs of caring, while also making carer payments tax-exempt and introducing a Cost of Disability payment.

### Address additional household cost pressures

Caring households often face higher energy costs due to spending extended periods at home, increased heating requirements, and the use of medical or assistive equipment, while also experiencing limited household incomes.

To address this, Family Carers Ireland is calling on Government to:

- Extend Fuel Allowance eligibility to all recipients of Carer's Allowance, recognising that many family carers face sustained financial pressure.
- Introduce targeted, needs-based supports for households with high energy use due to caring responsibilities (e.g. use of medical equipment or limited ability to reduce energy consumption), ensuring that those with the greatest need are not disadvantaged by flat-rate supports.

## IMPROVE ACCESS TO SUPPORTS AND SERVICES

### Provide flexible and appropriate respite options that meet the needs and preferences of both the family carer and care recipient

Regular and appropriate respite is a crucial component of sustainable caregiving. It offers family carers essential, temporary relief from the demands of caring, helping prevent burnout and safeguarding their long-term physical and mental health. Respite is not a luxury, but a critical support that sustains both the family carer and the person receiving care. Providing a flexible array of respite options, such as in-home support, short-term residential placements, or day programmes, ensures that respite can be tailored to individual schedules and preferences.

Family Carers Ireland acknowledges recent Government efforts to expand respite services and fund emergency respite. However, for the majority of caring families, access to regular and appropriate respite remains a dream. Respite should be understood as a core entitlement for family carers, not a discretionary add-on. It should be embedded as a central component of carer support policy and adequately funded on a sustainable basis.

### **Introduce the statutory home support scheme and address the shortage of home care workers**

A statutory scheme for the financing and regulation of home support services is a key Sláintecare proposal and a long-standing Government priority. The scheme aims to ensure that all users of home support services are provided with a standard, high-quality level of care which is safe, effective and person-centred. This should go some way towards helping the 69% of respondents who reported that the individuals they care for do not receive sufficient formal support. However, the delivery of the scheme is dependent on having access to a skilled pool of home care workers available across the country. Even before the statutory home support scheme is launched, the acute shortage of home care workers is having a detrimental effect on the sector, with home care providers frequently unable to deliver funded home support services due to a lack of staff. The urgent implementation of the recommendations made by the Strategic Workforce Advisory Group is needed to promote employment and attract and retain workers in the home care sector.

### **Address waiting lists for essential therapies and Assessments of Need**

Over half of respondents (55%) have paid privately for some product or services that should be publicly provided to support their caring role, including Assessments of Need (AON) and therapies. Qualitative responses highlighted the lengthy waiting lists for appointments with consultants, procedures and essential therapies such as psychology, speech and language, occupational therapy and physiotherapy. Denying children early intervention is denying them the right to develop to their full potential.

While Family Carers Ireland recognises ongoing efforts to reduce waiting lists, there is a need for targeted emergency measures to ensure timely access to assessment and intervention while waiting list backlogs persist. In addition, immediate financial relief is required for families who have had to pay privately due to lack of access within the public system. This could include reimbursement or direct coverage of costs for necessary assessments and therapies, recognising that current arrangements are placing an unfair financial burden on caring households.



## SUPPORTING FAMILY CARER HEALTH AND WELLBEING

### Fully fund the Carer Guarantee

Years of inconsistent and inadequate funding for the caring sector created a postcode lottery, where access to essential supports such as respite, training, and advice depended on where a family carer lives rather than their actual needs. The Carer Guarantee is a Government commitment to fund carer organisations to eliminate this postcode lottery, ensuring the consistent delivery of a core set of services to all family carers, regardless of where they live.

Family Carers Ireland is calling on the Government to commit the additional €3 million in annual funding needed to complete the roll out of the Carer Guarantee and to fulfil its ambition of providing family carers with uniform access to information, training and support, regardless of where they live. In September 2025, Family Carers Ireland met with the Minister for Health and agreed to co-develop a three-year implementation plan for the Carer Guarantee. This collaborative roadmap, created in partnership with the Department of Health and the HSE, will form the basis of Family Carers Ireland's funding submission for Budget 2027 and future years.

### Recognise and respond to family carers as an at-risk group within health and wellbeing policy

Findings from the State of Caring surveys consistently show that family carers report poorer physical and mental health than the general population. These outcomes reflect the cumulative impact of sustained and high-intensity caring roles, often carried out with limited formal support, inadequate respite and significant financial and social pressures.

Family carers should be recognised as a distinct cohort within national health and wellbeing policy, rather than considered only in relation to the needs of the person they care for. As Ireland continues to invest in integrated care, chronic disease management, healthy ageing, and mental health promotion and prevention, family carers must be explicitly included in the development and implementation of these strategies. Supporting family carers' health and wellbeing is essential both in its own right and to the sustainability of care in the home and community.



## ADDRESSING LONELINESS

The findings from the State of Caring 2026 survey highlight that loneliness is a significant feature of the caring experience; these experiences are influenced by the intensity of care and limited access to supports. Addressing loneliness among family carers requires targeted, practical interventions that are embedded within wider support systems.

### Fund a National Loneliness Strategy

Family Carers Ireland is a member of the Loneliness Taskforce. We urge Government to fund a national Loneliness Strategy and its associated recommendations.

### Targeted support for family carers through interventions designed to tackle loneliness

There is no one-size-fits-all approach to addressing loneliness or social isolation, so it is necessary to tailor interventions to meet the needs of family carers. Understanding the challenges they face is crucial for designing appropriate supports. The Programme for Government committed to deliver a 'Carers' Guarantee' to provide a uniform basket of services to family carers regardless of where they live, including access to respite, training and peer support. The guarantee is an important mechanism to helping address loneliness and social isolation amongst family carers, by giving them respite cover to pursue hobbies, meet friends, or participate in training. It also aims to provide peer support for family carers through support groups where they can meet and form friendships with other family carers in a similar situation. To begin to address the loneliness and isolation experienced by so many family carers, it is imperative that basic supports, including respite, are in place that allow them to have a break from their caring role.

### Supporting family carers to remain in employment

Where the caring situation allows, engagement in employment remains one of the most important ways to support family carers, providing some protection from the risks of loneliness as well as providing financial security. To reduce the negative impact of loneliness and isolation and to support family carers to remain in paid employment, where appropriate, employers should foster a workplace culture where caring responsibilities are supported with carer-friendly policies. This will not only support family carers but also help employers retain staff. Peer to peer support, for example through the establishment of staff carer network groups, can give employees with caring responsibilities the opportunity to talk to each other, be supported and share advice. Whilst employers need to have better carer-friendly initiatives and supports, it is critical that national welfare and taxation policies also support family carers to remain engaged in the workforce.

## TRANSPORT AND CARING

The findings illustrate that transport is an enabler of care, yet many family carers face significant barriers related to availability, accessibility, suitability and cost. Addressing these challenges requires coordinated action across transport, health and social care systems.

### Progress the review of the Disabled Drivers and Disabled Passengers Scheme

Reviewing the Disabled Drivers and Disabled Passengers Scheme is essential because the current system is accepted by Government and people with disabilities and their families as outdated, overly restrictive, and no longer 'fit-for-purpose' for modern disability needs. Government recognises that the scheme must be updated. It is therefore important that it takes urgent action to introduce a replacement scheme - including revising eligibility criteria to reflect the needs of all people with disabilities, expanding the range of supports available and simplifying the application process to improve accessibility. The scheme should also be aligned with modern standards of mobility and independence, ensuring it effectively enables people with disabilities to participate fully in work, education, and community life.

### Ensure public transport is accessible, reliable and usable for family carers and those they support

Under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006, ratified in 2018), equal access to transport and public facilities is a legal obligation. Yet many family carers described the barriers the people they care for face when trying to access public transport. Improving physical accessibility of public transport is key. Accessibility must also extend beyond infrastructure to ensure services are usable in practice: this includes ensuring staff can offer appropriate assistance and having dependable services. Without this, family carers and the people they care for have little choice but to use private transport such as cars and taxis, creating additional costs that not all households can absorb.



## FUTURE PLANNING

Family Carers Ireland calls on the Government to prioritise the development of structured future planning supports for family carers and the people they care for, grounded in the right to independent living as set out in Article 19 of the UNCRPD. This should include the establishment of clear pathways for long-term care planning, covering housing, care arrangements, financial security and decision-making supports, particularly for those with lifelong or complex needs. Planning must be proactive rather than crisis-driven, and available early in the caring journey.

Critically, future planning cannot rely on informal or assumed family succession. It must be underpinned by guaranteed access to appropriate community-based supports and services, ensuring that individuals can continue to live with dignity, regardless of changes in family circumstances.



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Family Carers Ireland is the national charity supporting the 624,190 family carers across the country who care for loved ones such as children or adults with additional needs, physical or intellectual disabilities, frail older people, those with palliative care needs or those living with chronic illnesses, mental health challenges or addiction.

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