

The State of Caring 2024



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KEY FINDINGS

74%

reported that the individuals they support do not receive sufficient formal support

72%

have never received respite

49%

have paid privately for any product or services that, in theory, should be publicly provided to support their caring role

69%

find it difficult to make ends meet

39%

live in households with a total income less than €30,000

29%

of those struggling financially are cutting back on essentials such as food and heat

23%

missed at least one mortgage or rent payment over the past year

17%

of mortgage holders have missed a mortgage payment in the past year

48%

experience severe loneliness

34%

stated that their accommodation is not suitable to meet the needs of the person they care for

16%

report bad or very bad health

35%

in private rental and 32% in local authority housing have missed a rental payment in the past year

STATE OF CARING 2024: CONTEXT

At the start of the decade, the first State of Caring 2020 survey showed that many carers were grappling with financial hardships, on the brink of indebtedness, and lacking critical support services. The second survey highlighted that not only did these initial challenges persist, but for many, they intensified significantly during the COVID-19 pandemic. Now, the State of Caring 2024 report shows that the situation for family carers in Ireland continues to be marked by these struggles. The core issues identified at the start of the decade remain deeply entrenched, underscoring the ongoing need for a transformative approach in the support of family carers.

A key theme of the 2024 survey has been the experience of carers in Ireland's escalating housing crisis. The country's housing situation has grown increasingly dire, with skyrocketing rental prices and a severe shortage of affordable housing options placing immense pressure on carers. Many of them are facing the double-edged sword of caregiving duties and the struggle for secure, suitable housing. This crisis not only compounds the financial strain carers often experience, but also affects their ability to provide a stable and safe environment for those they care for. With waiting lists for social housing growing and private rents outpacing incomes, the ripple effects of the housing crisis are palpable in the day-to-day lives of many family carers, who find themselves missing rent or mortgage payments and struggling with unsuitable housing for the people they care for. The need for a holistic approach to carer support that includes housing security has never been more urgent, as stable housing is a keystone of both physical and mental wellbeing for carers and those in their care.

Economic fluctuations and cost-of-living increases have placed additional burdens on carers, many of whom already face financial strain due to the demands of their caregiving roles. The policy landscape, meanwhile, remains a patchwork of intentions and initiatives that have yet to coalesce into a coherent strategy capable of addressing the needs of carers and those they support. The promise of reforms, including the much-anticipated statutory home support scheme, has been tempered by delays and discrepancies in implementation, leaving carers to fill the gaps in a stretched-thin system.

This year's report not only charts the economic pressures and policy failings that define the context of care in Ireland, but also highlights the spirit of carers. Their stories illuminate the personal costs of systemic inadequacies, while also showcasing the extraordinary contributions carers make to the well-being of individuals and the fabric of society at large.

The referendum on care earlier this year, whilst rejected, has nonetheless succeeded in opening up a nationwide debate on the crucial issues surrounding care and disability. It brought to light the challenges and hardships faced by family carers and those in need of care and support at home and highlighted the need for a more inclusive and supportive care system. With a General Election to take place within the next year, it is imperative that the insights within this report are acted upon through the development of concrete, substantial and meaningful supports for family carers and the people they care for.

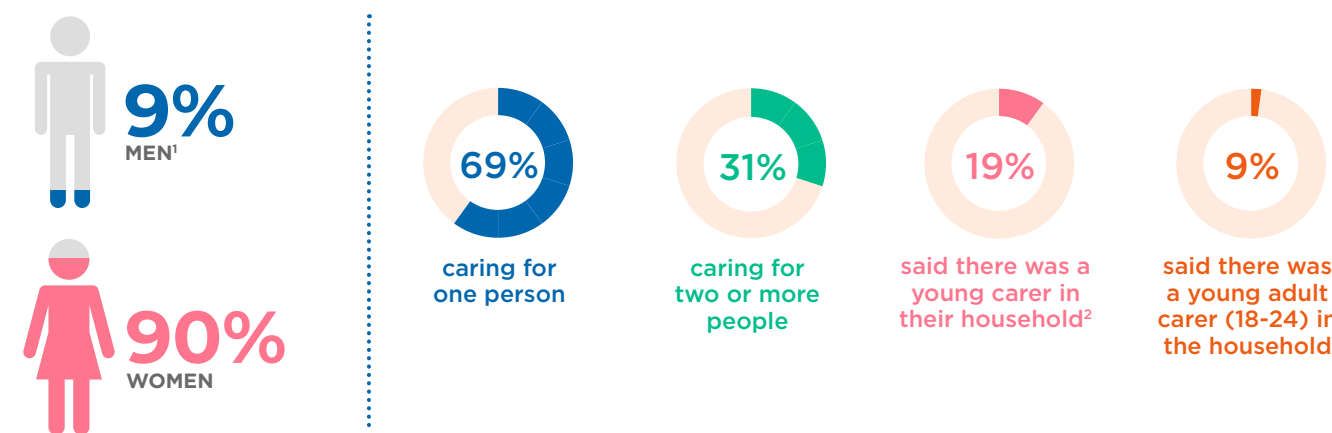
ABOUT THE RESEARCH

This report sets out the findings of Ireland's third national State of Caring survey undertaken by Family Carers Ireland between 21st January and 5th March 2024. The online survey was completed by 2,127 current family carers who shared their views and experiences of what life is like for family carers in Ireland in 2024. These carers care for approximately 3,000 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 respondents 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 community support centres. As not all respondents completed each question in the survey, a number of figures in the report are based on responses from fewer than 2,127 carers. This, together with the variations in the sample sizes of different groups of 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.



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 or mental health challenges.

PROFILE OF RESPONDENTS



¹Note: the percentages do not add up to 100% because <1% prefer to self-identify and <1% prefer not to say

²Note: 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'.

LENGTH OF TIME CARING

6% LESS THAN 2 YEARS

13% 2-4 YEARS

16% 15-20 YEARS

25% 5-9 YEARS

13% 21-30 YEARS

22% 10-14 YEARS

4% 31-50 YEARS

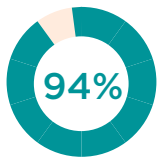
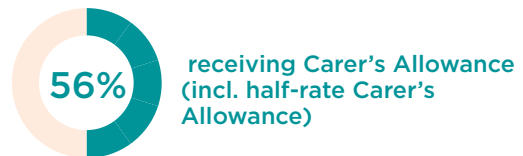
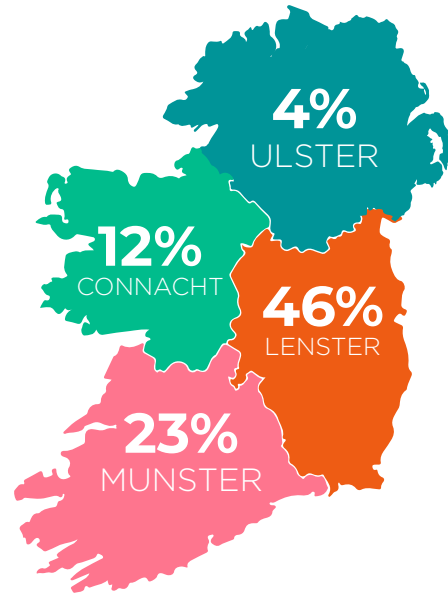
HOURS CARING PER WEEK³

4% LESS THAN 20 HOURS PER WEEK

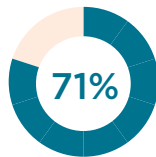
78% OVER 90 HOURS PER WEEK

71% OVER 120 HOURS PER WEEK

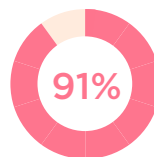
58% BETWEEN 140-168 HOURS



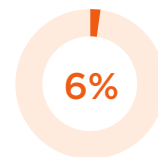
heterosexual⁴



members of Family Carers Ireland



white Irish



other white background

This sample is not representative of the wider Irish family carer population⁵. The 2022 census showed that the majority of carers are women (61%). The majority of respondents to the State of Caring 2024 survey are also women but in much higher proportion (90%). The census shows that half of all carers (46%) are between the ages of 40 and 59, with the age group 50-54 accounting for almost 14% of carers. In comparison, 65% of respondents to the State of Caring 2024 are aged between 40 and 59, and the age group 50-54 account for just over 19% of respondents. This suggests that, compared to the average carer in Ireland reported in Census 2022, respondents to the State of Caring 2024 survey were more likely to be women and younger.

³ Note: the percentages do not add up to 100% because some categories includes those from the previous categories. For example, those caring over 120 hours per week (71%) are also included in the 78% caring over 90 hours per week."

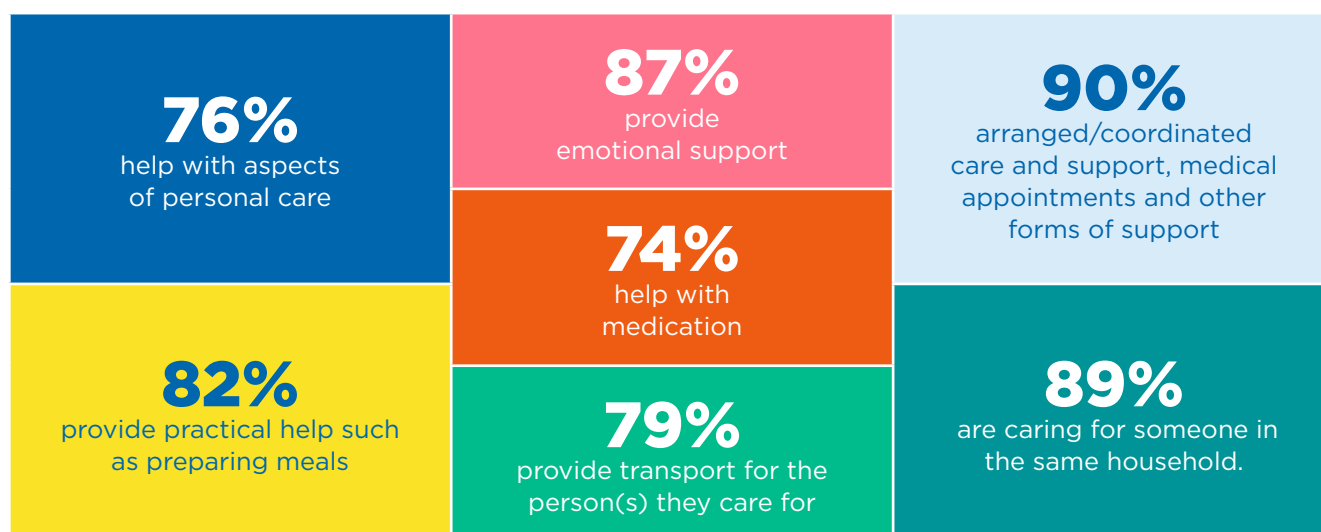
⁴ The remaining 6% is made up of <1% lesbian, gay or homosexual, 1% bisexual, 1% prefer to self-describe and 3.5% prefer not to say.

⁵ We draw on the CSO's Census of Population 2022 for carer statistics. However, the carer prevalence rate identified through the census has been consistently low and at variance with prevalence rates in other countries and other Irish research, e.g. the Irish Health Survey. The question relating to unpaid care in the Irish census is fraught with a number of practical challenges which typically contribute to inconsistencies and under-reporting in carer prevalence rates. See Family Carers Ireland paper 'Counting Carers: Carer prevalence in Ireland' for more detail on the problems enumerating carers in Ireland <https://familycarers.ie/media/2381/counting-carers-carer-prevalence-in-ireland.pdf>

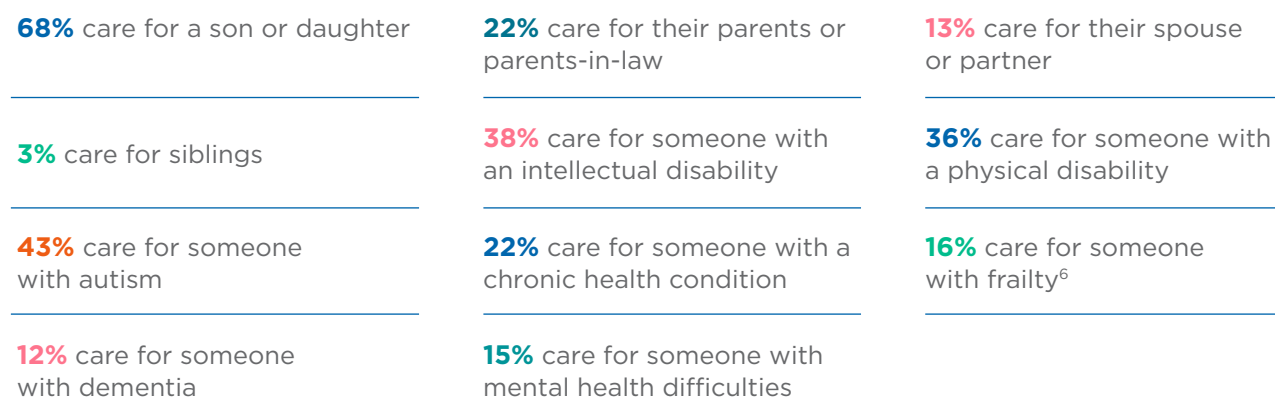
CHARACTERISTICS OF CARING

Caring is not a one-size-fits-all concept, and the experience and effects of caring are not the same for each group of carers. The amount and type of care that 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 2024 SURVEY SHOW:



ALMOST 3 IN 4 (73%) CARE FOR ONE PERSON BUT 1 IN 4 (27%) ARE CARING FOR TWO OR MORE PEOPLE



⁶ These figures do not add up to 100% due to co-morbidities amongst those receiving care.



CHANGES OVER TIME: COMPARING 2020, 2022 AND 2024 SURVEYS

The State of Caring 2024 survey shows that the challenges identified in the previous surveys have not abated and, in some instances, have deepened amidst a cost of living and housing crisis. The most notable findings from the State of Caring 2020, 2022 and 2024 surveys are compared and summarised below⁷.

Since 2020, the number of respondents to the State of Caring survey has risen sharply, from 1,250 in 2020 and 1,484 in 2022, to 2,127 in 2024, an increase of almost 1,000 carers since 2020. Despite the increased numbers, demographically, the carer population has remained relatively stable with a majority being women between the ages of 36 to 64. As outlined above, compared to the average carer in Ireland reported in Census 2022, respondents to the State of Caring 2024 survey were more likely to be women and younger. There has been no notable influx of new carers (those caring less than two years) since the pandemic, possibly reflecting the method of data collection amongst Family Carers Ireland membership and networks. However, the increase in the proportion of carers tending to multiple people or children with additional needs suggests a shift in the caregiving landscape, with the potential for increased stress and demand on resources. The continued underrepresentation of male, young adult, LGBTQI+, migrant, and newer carers indicates groups that may require more focused outreach and advocacy to ensure they receive necessary support and recognition.

Notably, there is a shift in the financial landscape; fewer carers report household incomes below €30,000, indicating an increase in those earning above this threshold. However, this rise in household income does not seem to alleviate the financial distress experienced by carers. The proportions of carers struggling to make ends meet have remained high and relatively stable over the years, with approximately 70% still finding it

difficult to manage financially in 2024. This paradox suggests that while overall income may be on the rise for some, the costs associated with caring—potentially exacerbated by the current cost-of-living crisis—are likely also increasing, nullifying any nominal financial gains. The near-constant rate of carers who must cut back on essentials, including food and heat, remains alarmingly high, signalling that financial distress persists unabated despite higher earnings.

Healthwise, there's a small but steady increase in carers reporting poor health, rising from 14% in 2020 to 16% in 2024. Severe loneliness, a major concern affecting nearly half of the carers, has seen a slight decrease since 2022 (51% in 2022, 48% in 2024). However, the high prevalence continues to signal a profound sense of isolation that persists beyond the immediate impacts of the pandemic. The link between this isolation and the lack of respite care is impossible to overlook. Respite care is not just a service, it is a chance for carers to recharge and to maintain their own health and social connections. However, the surveys reveal a distressing trend: the percentage of carers who have never accessed respite care has risen from 66% in 2022 to a stark 72% in 2024, possibly reflecting that respite and day care services are still not back to pre-Covid levels in many parts of the country.

In terms of policy, the dramatic increase in awareness of the Assisted Decision-Making (Capacity) Act from 2020 to 2024 suggests growing engagement with legislative reforms. Yet, with over a third still unaware, it is evident there is a significant gap in knowledge dissemination that needs to be bridged for carers to fully understand the magnitude of this legislative change for both them and the people they care for.

⁷ Note that these two surveys are not directly comparable because they are both based on convenience samples which means that different carers could have responded to each survey. Nonetheless, the sampling process was the same in both surveys so we assume the same biases are present. While the surveys may not be representative of the carer population, they can be meaningfully compared.

In summary, the data across these three State of Caring surveys paints a sobering narrative of increased complexity in carer responsibilities, persistent financial and emotional burdens, and a lag in the support system’s responsiveness to their evolving needs. It suggests there remains a critical need for both policy action and societal change to recognise and support the vital role of family carers. The trajectory of these data points underscores the urgency for a comprehensive approach to supporting carers, integrating financial, health, and social support to empower carers to provide care, where willing, in a manner that is both secure and sustainable.

COMPARISONS OF KEY FINDINGS OVER TIME

FAMILY CARERS PARTICIPATING IN STATE OF CARING	2020	2022	2024
Gender Breakdown	88% women, 11% men	88% women, 10% men	90% women, 9% men
Average Age	48	49	49
Caring for a son/daughter	63%	61%	68%
Caring 90 hours or more per week	82%	79%	78%
Caring for two or more people	26%	27%	31%
Carers who have never received respite	65%	66%	72%
Carers living in households with a total income of less than €30,000 per year	52%	47%	39%
Finding it hard to make ends meet	70%	67%	69%
Carers cutting back on essentials such as food and heat to make ends meet	21%	24%	20%
Bad or very bad self-reported health	14%	15%	16%
Moderate self-reported health	48%	43%	44%
No awareness of the Assisted Decision-Making (Capacity) Act 2015	73%	68%	37%

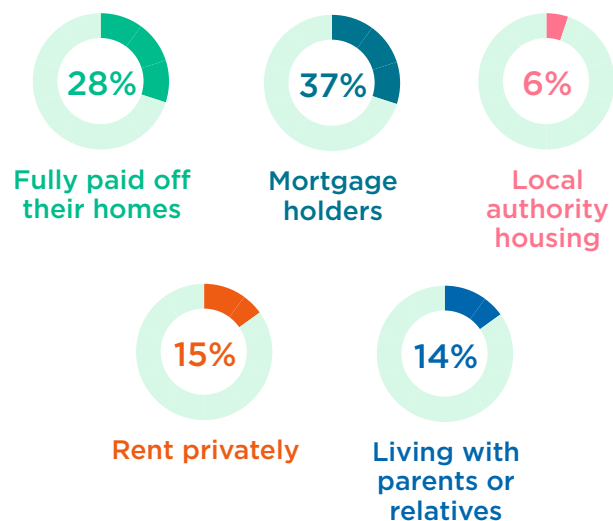
HOUSING AND CARING IN 2024

Family care predominantly takes place in the home environment and, as such, care is deeply influenced by its physical surroundings. The layout and condition of the home—its space, the comfort and protection it offers—plays a pivotal role in facilitating or hindering the care provided (Bowlby et al, 2019). This extends beyond the walls of the home to encompass the broader neighbourhood, where accessible services and a supportive community can significantly influence caregiving activities. Stable and appropriate housing is foundational to providing effective care, as it influences daily caregiving routines, access to care services, and the overall quality of life. Furthermore, the financial strain of housing costs can exacerbate the already considerable economic pressures on carers, many of whom face reduced earning capacity due to their caregiving responsibilities.

Against this backdrop, the State of Caring 2024 survey findings reveal the nuanced realities of housing for family carers in Ireland today, highlighting the challenges carers face in making their homes suitable for caring, the financial burdens encountered, and the pressing concerns over housing instability. Through this lens, we shed light on the crucial role that housing plays in the caregiving experience, framing our discussion within the broader context of social support systems and the need for targeted policy interventions.

HOUSING TENURE AND ARREARS

The dynamics of home ownership and living situations amongst respondents paint a complex picture, essential to understanding the broader context of caregiving challenges and experiences. Notably, over a quarter (28%) have the security of owning their home outright.



Carers were asked if they had mortgage or rent arrears i.e. failed to make a payment in time during the previous year, due to financial difficulties. **Almost one in four (23%) making mortgage or rental payments—1,220 carers—reported an inability to make timely mortgage or rent payments over the past year due to financial difficulties.**

17% of mortgage holders have missed a mortgage payment in the past year

The burden of rising mortgage payments adds a layer of uncertainty and stress, compounding the complexities of caregiving duties.

35% of those renting privately have missed a payment in the past year

32% of those in local authority housing have missed a payment in the past year

This suggests that, amongst carers who responded to this survey, those in rented accommodation are twice as likely to miss a payment as those with a mortgage. This is especially worrying given the precarity of the private rental market, known for its high turnover and rising rental prices. The lack of long-term security, coupled with the ever-increasing financial demands of rental commitments, exacerbates the challenges faced by carers, making it increasingly difficult to provide a stable and consistent care environment.

These statistics contrast starkly with findings from the general population. **In 2023, the Central Statistics Office's Survey on Income and Living Conditions (SILC) reported that 7% of households making mortgage or rent payments failed at least once to make a payment in time in the past 12 months. 12% of those making rental payments and 3% of those with mortgages failed to make at least one payment.** This discrepancy highlights the heightened vulnerability faced by carers who are confronting serious financial challenges that directly threaten their housing stability.

The precarious nature of their living situations is further highlighted by the 5% of carers who expressed that it is likely they will need to leave their current accommodations within the next six months due to financial untenability. Whilst a small proportion, this statistic not only reflects the immediate stress experienced by these individuals but also the looming uncertainty about their housing security.

These findings point to a critical need for tailored financial support systems that can alleviate the burden of housing costs on carers, ensuring that they can maintain stable and secure homes as they continue to provide essential care. This support is not just crucial for their financial health but also for their overall well-being and ability to sustain caregiving responsibilities without the added stress of unstable housing conditions.

INADEQUACY OF HOUSING FOR MANY FAMILY CARERS

The adequacy of accommodation for carers presents a complex picture, with significant portions of respondents reporting various deficiencies in their living environments that impact their ability to provide effective care.

34% stated that their accommodation is not suitable to meet the needs of the person they care for, highlighting a substantial gap in the suitability of their living spaces

Although 59% agreed that the current space in their accommodation is sufficient to comfortably provide care, 19% disagreed with this sentiment, indicating that nearly one-fifth of carers find their living spaces constraining.

Accessibility features, which are crucial for effective care, appear to be lacking in many homes. 27% of respondents disagreed or strongly disagreed that their accommodation is equipped with necessary accessibility features such as ramps and grab bars. This deficiency underscores a significant barrier to providing safe and efficient care, potentially increasing the risk of injury or inadequate care.

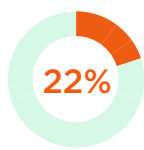
The functionality of specific areas within the home also came under scrutiny. For instance, 17% of carers expressed dissatisfaction with the overall comfort level of their accommodation, including aspects such as heating, ventilation, and lighting, which are essential for the well-being of both the carer and the care recipient. This indicates that a notable percentage of carers struggle with basic environmental conditions, which can affect the health and comfort of those involved.

25% disagreed or strongly disagreed with the statement that they have easy access to external support services like healthcare and social services from their current accommodation

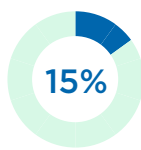
This lack of access can severely impact the effectiveness of care provided and increase the isolation and stress experienced by carers.

INADEQUATE HOUSING ADAPTATION GRANT

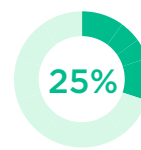
The need for home adaptations to allow the person with additional care needs to remain at home is a significant concern for carers, impacting their financial stability and ability to provide care effectively. The housing adaptation grant has not increased in over a decade, making it difficult to retrofit homes to make caring safe and sustainable. In the absence of a grant that meets the full cost of adaptations, carers in the survey reported their reliance on personal and community resources to finance these necessary modifications.



22% have had adaptations made to their accommodation financed by family and friends



15% have had adaptations partially financed by the Housing Adaptation Grant, indicating a gap between the needs and the support provided by available public funds



25% of carers still require further adaptations to their homes to adequately care for their loved ones



“
We have made significant modifications to our home at our expense as we did not qualify for means-tested grants - sacrifices were made to pay for the work!
”

My Dad has a shower over a bath. Due to hip replacement and regular falls, he can't shower at home. Twice I have tried to have the bath removed, but to no avail. In the past, I took Dad to the pool for exercise and shower. He is just out of hospital after sepsis and can't go to the pool. I haven't time to reapply for the grant and get quotes while caring for Dad too.

Specifically, carers highlighted various modifications that would enhance their caregiving capabilities:

- 21% noted that basic accessibility improvements like ramps, grab bars, and widened doorways would significantly enhance their ability to provide care.
- 26% indicated that additional space or rooms are crucial for accommodating care needs effectively.
- Another 26% emphasised the importance of adapting a room into a sensory space tailored to the specific needs of the care recipient.
- 12% pointed out the need for the installation of assistive technologies to improve the caregiving environment.

These findings are set against the backdrop of personal testimonies that reveal the extensive financial commitments carers must undertake, often exceeding the maximum support offered by the Housing Adaptation Grant.

I don't know the exact figure but we borrowed in excess of €20,000 from the Credit Union and a further €12,000 from my mother when building costs ran over as it's an old house and the builders weren't the best as I had to source them myself.

We fundraised within our community and raised €116,000. We financed the rest, €80,000.

We moved house and remortgaged to accommodate our son who is a full-time wheelchair user. This has made our lives more financially difficult.

These accounts highlight the considerable expenses involved in making homes suitable for disability, ageing and caregiving, often requiring families to go beyond their financial means and the assistance provided by grants. This situation underscores the need for a reassessment of the Housing Adaptation Grant to better meet the substantial and varied needs of carers, ensuring that they can provide care in a safe, accessible, and supportive environment without undue financial strain.

IMPACT OF HOUSING ON CARERS' ABILITY TO PROVIDE CARE - QUALITATIVE RESPONSES

Family carers shared varied experiences on how their housing situations affect caregiving. While 30% reported a positive impact, 42% saw no impact, and 17% experienced negative effects, illustrating the complex role of living conditions in family caregiving. We asked respondents to explain their answers. A thematic analysis of the 420 qualitative responses revealed key issues:

1. Physical Space and Adaptations

Space Limitations:

Many carers highlighted that the lack of space, particularly for specialized equipment like wheelchairs or for multiple care recipients, severely impacts their ability to provide care. Common issues include cramped bedrooms and insufficient bedrooms.

Home Adaptations:

There is a high demand for essential modifications such as ramps, stairlifts, and accessible kitchens and bathrooms to meet the physical needs of care recipients and alleviate carers' strain.

An accessible bathroom would provide safer accommodation.

Need ground floor bedroom to future proof the house with roll in shower/accessible ensuite.

2. Financial Constraints

Cost of Adaptations:

The high costs of home modifications pose significant barriers, often not covered by grants.

Housing Costs:

Carers face challenges from high rents or mortgages, which limit their financial capacity to secure resources or save for better housing.

If we didn't have such high rent, maybe we could finally save up for a house, but as it stands, every penny goes to covering rent and medical expenses for my care-dependent child.

I would have to buy all the aids myself. I already bought a stair rail. Can't afford to get bathroom adapted. We haven't got a medical card. I think it's so unfair. We worked all our lives and paid high taxes. Still paying tax on the little amount of private pension we get.

We are in constant fear of an eviction notice coming through the door. That alone, has a negative impact on our outlook. Then with the security issues, no maintenance being carried out on the house, inadequate insulation. It all has a negative impact on daily life. Our landlord knows we won't question anything as we have nowhere else to go. This, of course, has an impact on the day to day care of our son and his younger sister. We are always worried about it.

3. Emotional and Psychological Impact

Stress and Burnout: Inadequate and unsuitable housing exacerbates carers' stress and emotional burnout.

Isolation:

Some carers feel isolated due to their housing situation, which can be exacerbated by being in remote locations or having homes that do not support social interactions due to layout or safety concerns.

A wet room is required but due to arrears in rent, the house is not eligible. There is dampness which makes the conditions difficult for living. There are heat issues that have not been rectified. The house is isolated and far from all therapies and care needs

The lack of respite and disrepair of facilities means I'm burnt out and struggle emotionally and physically to provide the best care needed.

It's the fear that at any point you might end up on the streets. No one wants to house people like us. The rents are more and more unaffordable. It's scary.

4. Safety and Accessibility

Risk of Injury:

Several responses highlighted concerns about the risk of falls and injuries, both for the care recipients and the carers, due to inappropriate home layouts that do not accommodate mobility aids or lack safety adaptations.

Accessibility Issues:

Many homes are not originally designed with the needs of disabled or older people in mind, requiring significant modification to make them accessible.

Where she currently sleeps, there are cracks all over the room due to subsidence and it is causing a lot of anxiety.

The bathroom is a constant hazard. It's not suited for someone with severe mobility issues like my mother. I'm terrified she'll slip one day, and I won't be able to catch her.

5. Long-Term Security and Planning

Housing Security:

The instability of rental situations adds stress concerning the ability to make long-term adaptations.

Future Planning:

Concerns about the future, especially as the care recipient's needs evolve or as carers themselves age, are prominent. Many express a desire for housing that can adapt to changing needs over time.

My daughter will want to live with her friends one day and have a support care package. Her parents will die. She wants a plan.

As her condition worsens, I'm increasingly worried about our future here. This house isn't equipped to handle her needs, and I'm not sure how we'll manage as she requires more care.

6. Environmental Concerns

Heating and Ventilation:

Issues with heating, dampness, and poor ventilation compromise both health and comfort, with many homes needing better insulation and heating systems.

Our home is perpetually damp and cold, which not only makes it uncomfortable but also aggravates my son's respiratory issues. Despite our best efforts, we can't afford the necessary upgrades to insulation and heating.

These findings underline the need for targeted housing adaptations, financial support, and policies to enhance carers' ability to provide care effectively.

UNMET NEEDS AND ACCESS TO FORMAL SUPPORTS

For many carers, a core part of their role includes coordinating the necessary supports and services for those they look after. Essential services like day centres, homecare, and respite are designed to assist individuals needing extra care. When these services are available, accessible, and suitable, they not only support the care recipients but also empower family carers to provide care safely and maintain their own health and well-being.

Daycare services have been slashed by the HSE since Covid. Slashed from 30 hours a week to 4 hours a week. Not enough home support help. No respite care.

In 2024, family carers continue to confront significant challenges in securing adequate formal support for those they care for. Three quarters (74%) of carers reported that the individuals they support do not receive sufficient formal support. This highlights the ongoing disparity between the needs of care recipients and the support provided.

We have had minimal supports due to lack of access and inadequate services... As a result, I am also in charge of homeschooling - a task that I don't mind performing, but find challenging as I am not trained and have no supports to help me find the training to help educate this person properly, fully.

Disability Services have a waitlist of two years for Early Intervention. The boat has past before the children are seen, resulting in us having to get private services which we can't afford.

Several critical factors contribute to the unmet needs of family carers and the people they care for:

- **Staffing Shortages:**
The most cited concern, identified by 2 in 3 (67%) is inadequate staffing, which substantially hinders the availability of formal support. This underscores a critical need for systemic improvements in workforce planning within the care sector.
- **Unmet Requests for Support:**
More than half (56%) have reached out for services and support but have not received them pointing to significant gaps in services.
- **Accessibility Issues:**
Challenges with the proximity and ease of access to services were reported by 14% pointing to a geographical disparity in service distribution that requires addressing.
- **Reluctance to Seek Help:**
One in ten (9%) believe they do not receive adequate support because the person(s) they care for is/are unwilling to accept help. This suggests a need for more sensitive engagement strategies to encourage acceptance of support.
- **Lack of Information:**
One in ten (10%) are unsure where to seek support, signalling a gap in information dissemination and the need for more accessible guidance on available services.



I am terrified of the future. My sibling will never be able to live independently. He has never been involved with support services as they did not exist where he lived when growing up. I am trying to plan for his safety and wellbeing should I predecease him. I never get a reply from any agency or body I contact. We are utterly alone. I pray every night that I will live even one day longer than him as he will have no one.

49%

have paid privately for a product or services that are, in theory, publicly provided to support their caring role e.g. Assessment of Need, wheelchair, specialised beds

I'm in poor health myself and haven't got the time or energy to chase up supports.

The findings suggest that many turn to the private market to pay for products and/or services that should be publicly available to support their caring role.

MISMATCH BETWEEN CARERS' NEEDS AND RESPITE AVAILABILITY

Respite care stands as a cornerstone of formal support for family carers, offering them breaks from the demands of care. The State of Caring 2024 survey delved into carers' access to and the barriers they face in obtaining respite services. This exploration is vital as respite not only provides temporary relief, enhancing carers' well-being, but also supports them to continue to provide care sustainably.

In 2024, **an overwhelming majority of family carers (72%) have never received respite care**, pointing to a significant gap in the provision of this critical service. Carers' preferences for respite frequency present a stark contrast to their current experiences. While 23% report they do not need nor want respite, a notable proportion of carers wish for more regular support, with 2% preferring daily, 11% weekly, and significant portions requesting monthly and yearly respite. This highlights a mismatch between carers' needs and service availability as well as the necessity for flexible respite solutions.

BARRIERS TO ACCESSING RESPITE CARE

The challenges in accessing respite are manifold:

- **Availability:**
18% of carers report that respite is simply not available in their area, indicating a geographical disparity in service distribution.
- **Appropriateness:**
18% find the available respite inappropriate for their needs, suggesting a mismatch between service provision and the needs of care recipients.
- **Care Recipient Reluctance:**
Notably, 23% of carers state that the person they care for is reluctant to use respite care services.
- **Lack of Information:**
The lack of clarity or information in how to apply for respite deters 16% of family carers.
- **Affordability:**
Financial constraints are a barrier for 12% of carers, making cost a factor in accessing respite.
- **Quality Concerns:**
A smaller portion, 7%, is deterred by the perceived poor quality of respite care offered.
- **Other Barriers:**
Additional barriers, such as the need for specialised care, inadequate duration, and inflexibility in timing, affect 14% of carers.

PREFERRED MODELS OF RESPITE CARE

The challenges with the current model of respite care suggest that alternative approaches may be more suitable. Carers have expressed a variety of preferences for the type of respite care they require:

- **In-Home Respite:**
The highest preference is for in-home respite (28%), indicating a significant demand for services that allow care recipients to stay within the comfort of their own home.
- **Overnight Residential Respite:**
1 in 5 (20%) are in favour of overnight stays in residential settings, highlighting a need for short-term, intensive respite options.
- **Day Care Respite:**
14% opt for day respite services, emphasising the need for daily structured activities and support.
- **Informal Care Networks:**
The reliance on care provided by friends and family (17%) underscores the importance of personal networks when formal services fall short.

The 2024 findings highlight the pressing need for more accessible, flexible, and personalised services that allow for trust in the quality of the care to be developed and maintained.

The only respite available is in another county with no transportation offered. So no respite, just added work.

The respite house is being used by HSE for emergency placement so we've had no respite available for almost one year.

My daughter has complex medical needs. I wouldn't trust a respite home to provide this.

Due to the dementia my mother rejects carers and when they get pushy it upsets her in the extreme so I've no choice but to care alone. Plus the carers who did come around for a year or so, were routinely swapped around, so multiple different people were constantly coming to the house. There was no consistency which is obviously not going to work for someone with dementia who needs familiarity... I cannot build trust with a revolving door of people.

The offer of respite is usually only a few days notice so I can't make the most of the 2/3 nights off.



FINANCIAL IMPACT OF CARING

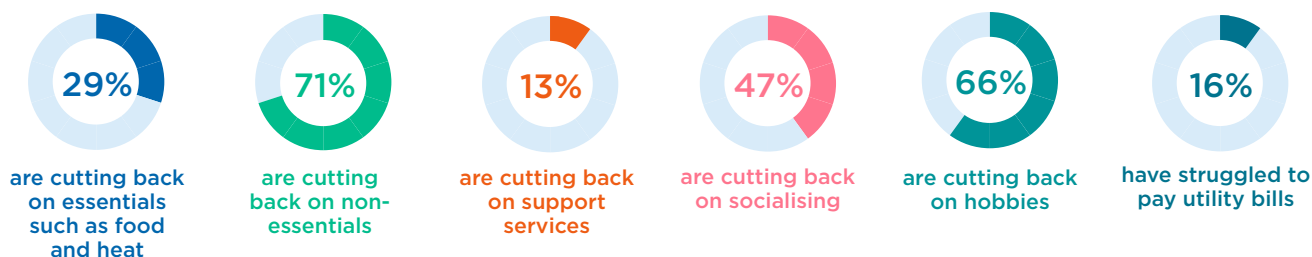
Stepping into the family carer role often plunges households into financial stress. As carers lose potential income due to the difficulties of balancing work and care, they also grapple with the rising expenses associated with caring that stretch their household budgets even thinner. Even before the cost of living crisis, households caring for a child with a profound disability face an additional €244 per week in direct costs associated with care and disability – more than the maximum amount of Carer’s Allowance (McMahon et al, 2019).

Almost 2 in 5 (39%) of carers reported a household income below €30,000 annually, starkly lower than the national median of €55,149 (CSO SILC, 2024). Worryingly, a quarter of them managed on less than €20,000 a year. 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, 2016). When asked about their ability to cope financially, more than 2 in 3 (69%) find it difficult to make ends meet, 15% with great difficulty. Amongst the general population, half (48%) of households had at least some difficulty making ends meet, with 6% experiencing great difficulty (CSO SILC, 2024). This stark difference highlights the critical level of poverty risk that family carers are contending with.

IMPLICATIONS ON HOUSEHOLD EXPENDITURE

Given the financial difficulties many 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 carer population given their increased risk of loneliness and the implications of not being able to keep their home warm.

Amongst the 69% of those experiencing financial distress:



These stark figures suggest that significant numbers of carers are experiencing fuel and food poverty, with a small number of those struggling financially reporting reliance on food banks (5%) and charities such as St Vincent de Paul (9%) to get by.

“*It is hard as I need to have money everyday to keep my son busy going out to places to play centres, etc. We have not got the space for swings, etc. in the house so it's extremely hard to keep up with expenses. I don't have any family to help me so I have to do it on my own.*”

ACCESS TO CARER'S ALLOWANCE AND OTHER FINANCIAL SUPPORTS

We asked carers about the social welfare payments and financial supports they receive. Over half (56%) receive Carer's Allowance (incl. half-rate Carer's Allowance) and 7% receive Carer's Benefit. Almost half (44%) receive the Carer's Support Grant⁸ and 40% reported that their child received Domiciliary Care Allowance. Only 17% receive Fuel Allowance. Out of the carers not receiving benefits, 18%—representing 376 participants—offered insight into their reasons. A thematic analysis of these explanations brought to light the following key themes:

1. Income and Means Testing:

A recurring theme is the challenge posed by means testing, where either the carer's own income, their spouse's income, or household income exceeds the threshold for eligibility.

2. Work and Employment:

Many carers are in full-time or part-time employment, which disqualifies them from receiving Carer's Allowance or makes them feel they are not entitled or would not qualify for assistance.

3. Bureaucratic Barriers:

Some carers describe the difficulty and stress associated with filling out complex forms and navigating the application process, which can be a deterrent to seeking financial support.

4. Limited Awareness and Access to Information:

There are indications that some carers are not fully aware of their entitlements or how to access support, reflecting a need for better communication and information dissemination.

5. Health and Disability:

Some carers themselves have health issues or disabilities that complicate their ability to apply for or receive carer payments.

6. Administrative Delays and Obstacles:

Carers report long waits for applications to be processed, as well as denials and appeals, which contribute to their lack of welfare support.

These themes highlight the diverse and complex barriers family carers in Ireland face when it comes to receiving social welfare support. The findings underscore the need for a more carer-friendly welfare system that considers the realities of carers' financial situations, reduces bureaucratic complexity, and ensures that carers are adequately informed about their entitlements.

I had to give up my job and independence, and I do not qualify for any form of financial support as it is means tested on my husband's income. I have paid my own way since I was 18 and now, financially, I have to rely on someone else.

DCA form is too stressful to fill in. I get emotionally triggered from it causing anxiety and depression.

We have been saving for a mortgage but every time we get close there is a medical event or a piece of equipment is needed. We feel like giving up, we have had to stop paying for private therapy because we can't afford it on top of the medical costs and equipment costs.

*Carer's Benefit will end this year. I don't know how we will manage!
The means test for Carer's Allowance will exclude me from receiving this allowance.*

⁸The data presented indicates that 56% of respondents receive Carer's Allowance (including Half Rate Carer's Allowance) and 44% receive the Carer's Support Grant. It is important to note that all recipients of Carer's Allowance are automatically entitled to the Carer's Support Grant. The apparent discrepancy in these figures may arise from survey respondents' misunderstanding of the grants they receive or the timing of the survey relative to the grant distribution cycles. Further investigation will clarify these findings.

I was receiving Carer's Allowance but I went back to college to try and get a better job. I got a letter stating I'm cut off from Carer's Allowance even though my partner was on campus with me.

The State recognises that I have to provide 24/7 care to my severely disabled child by awarding Domiciliary Allowance but yet I can't get Carer's Allowance due to a partner's income!!

It's not clear what I am entitled to. And the application process seems very arduous (I am 81 years old).

I have to fill out the form for the Carer's Support Grant this year even though nothing has changed in 20 years. I hate filling in the form so have put it off the last year. I don't receive Carer's Allowance because of the means test which makes me totally dependent on my husband from no fault of my own. He may earn a good wage but no other job (which being a family carer is) would take into account your husband's wage.



CARING AND LONELINESS

Loneliness has been identified as a significant public health challenge. Recent studies continue to underscore that loneliness profoundly impacts physical and mental health, reducing quality of life and curtailing life expectancy—its effects can be as detrimental as those of chronic smoking and obesity. Family carers face heightened risks of loneliness due to the inherent demands of caregiving. These responsibilities can sharply limit opportunities for social engagement, while the financial burdens associated with caring often render social activities unaffordable. In addition, the isolation experienced by carers can exacerbate stress and diminish access to community support, further increasing their vulnerability to loneliness.

47% feel left out most of the time

24% lack companionship most of the time

THE WORLD SHRINKS

Different individuals experience loneliness in unique ways; some may feel isolated despite frequent interactions, while others might have minimal social contacts yet not feel lonely. The State of Caring 2024 survey measured emotional loneliness amongst carers⁹, focusing on their satisfaction with the quality of their social relationships. This recent data reveals a concerning trend.

Level of loneliness	
None/low loneliness	24%
Moderate loneliness	28%
Severe loneliness	48%

Almost half (48%) of carers experience severe loneliness, despite the majority of respondents living with the people they care for. The persistent high rates of loneliness since 2020 highlights not only the persisting impacts of the pandemic on social structures but also the increasing strain on carers' social and emotional well-being. The data underscore the critical need for targeted support and interventions to address the deepening loneliness crisis among family carers, ensuring they have more robust and supportive social networks to rely on.

32% cut back on seeing friends/family to make ends meet

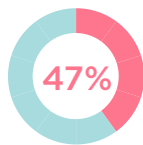
As caring often affects carers' employment, with many moving to part-time paid employment or leaving work altogether resulting in considerable loss of income, it is not surprising that carers out of the paid labour force feel higher levels of loneliness than those in paid employment.

I can't leave my husband alone. So I'm house bound full-time.

⁹The 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.

Our findings show a clear link between how healthy family carers feel and how lonely they are. Carers who feel healthier tend to feel less lonely. For instance, among carers who report their health as 'Very Good', only a small number feel very lonely (16%). However, as carers' health worsens, the number who feel very lonely increases sharply. More than half of the carers who say their health is 'Moderate' report feeling very lonely (54%), and this number jumps even higher for those who rate their health as 'Bad' (79%). This pattern highlights the critical need for more support for family carers, not just for their physical health but also to help them connect with others and reduce loneliness.

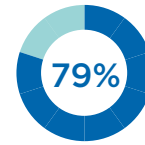
While looking at family carers of various ages, there is not a clear pattern that ties carers' age directly to feelings of severe loneliness. Although the highest levels of severe loneliness are seen in the 25 to 35 age group at about 56%, it gradually decreases with age, especially noticeable in the oldest group (76 and older) where only 19% report feeling very lonely. This suggests that age alone doesn't predict how lonely someone might feel.



feel isolated from others most of the time



feel lonely most of the time



of carers with bad health are severely lonely



CARER HEALTH AND WELLBEING

Being a family carer often comes with moments of personal growth and a feeling of proficiency in providing care (Pysklywec et al, 2020). Yet, studies show that caregiving can take a toll on one's health and wellbeing, potentially leading to challenges like depression and chronic pain (Family Carers Ireland et al, 2019).

The data from the 2024 survey points to a sobering reality: family carers tend to report lower levels of health compared to the broader Irish population and are more likely to experience ongoing health issues, including disabilities and illnesses.

Self-reported health status	Family Carers in 2024	General Population Aged 15 and over ¹⁰
Very good or good	40%	83%
Fair	44%	9%
Bad or very bad	16%	2%

The majority (83%) of people aged 15 and older in Ireland consider their health to be good or very good. However, the narrative changes for family carers, with less than half (40%) reporting they are in good or very good health. Nearly an equal proportion describe their health as moderate. Moreover, roughly 43% of carers also reported a long-term health issue or disability.

Navigating a relationship with a spouse who is living through depression is relentless. I've become lost to myself, in trying to support my partner. This has resulted in costing both of us more, personally, in the long run.

The lack of respite and the disrepair of [our] facilities means I'm burnt out and struggle emotionally and physically to provide the best care needed.

Life satisfaction usually reflects our general feeling about our life and how pleased we are with how it is going (Boehm & Kubzansky, 2012). Research shows that there are multidimensional factors that contribute to life satisfaction, such as work, relationships, personal development and health. We asked carers to rate their satisfaction with life. Only a small fraction (4%) feel very or extremely satisfied with their lives, while almost half (46%) fall into some bracket of dissatisfaction. One in seven (15%) hover in the middle, neither satisfied nor dissatisfied, or just somewhat content with their lives.

When examining life satisfaction in terms of family carers' self-reported health status, results from the State of Caring 2024 indicate that those with very good or good health were more likely to indicate some level of life satisfaction (63%) than life dissatisfaction (24%). Whereas carers who perceived their health as very bad or bad were more likely to be dissatisfied (82%) than satisfied (8%) with life. In terms of employment status, 50% of respondents who were in some form of employment, either full or part-time, indicated some level of life satisfaction compared to 32% of those in a full-time caring role. Family income and the ability to make ends meet were also indicative of perceived life satisfaction, with family carers experiencing some difficulty more likely to be dissatisfied (53%) compared to those who expressed a certain degree of ease (33%) making ends meet.

Supporting the health and financial security of carers is not only a matter of improving individual quality of life but is also crucial for the overall resilience and satisfaction of family carers. Targeted interventions that address these areas are critical for enhancing the wellbeing and life satisfaction of family carers.

¹⁰ Central Statistics Office (2022) 'Census of Ireland, Health, Disability and Volunteering' <https://www.cso.ie/en/releasesandpublications/ep/p-cpsr/censusofpopulation2022-summaryresults/healthdisabilitycaringandvolunteering/> [Accessed 17.04.24] Note this does not add to 100% as 6.7% did not report their health status.

STATE OF CARING 2024 RECOMMENDATIONS

The State of Caring 2024 recommendations build on the ongoing relevance of many recommendations from the 2022 survey, introducing new priorities such as enhancing housing accessibility and security, and explicitly advocating for the abolition of the means test for Carer's Allowance. We have also preserved several recommendations from 2022 where they continue to be applicable.

MAKING HOUSING SUITABLE FOR CARING, DISABILITY AND AGEING HOUSEHOLDS

- **Address the inadequacy of the maximum Housing Adaptation Grant Scheme limit**

Currently, the maximum grant limit under the Housing Adaptation Grant Scheme (HAGS) is €30,000, which can cover up to 95% of approved costs of works. However, the spiraling cost of living, and building material price increases, coupled with labour shortages within the sector have contributed to record levels of building inflation, which means maximum grant limits fall far short of what is required to meet the actual costs involved. Family Carers Ireland calls on the Department of Housing, Local Government and Heritage to increase the maximum grant amount available to reflect not only the rate of construction inflation but also consider households' ability to contribute 5% or more to the cost of the adaptation after meeting the very substantial costs of caring and disability.

- **Increase income thresholds for the HAGS means test**

Family Carers Ireland believes that the income thresholds for the HAGS are outdated, inadequate and bear no resemblance to the actual disposable income of households where high-level care is provided. Because the means test is applied to gross rather than net income and does not apply disregards to mortgage repayments, dependent children, college fees, Fair Deal contributions, medical costs, etc., it does not reflect the reality faced by families who are struggling to make ends meet. We also believe the decision to include the income of other adults living in the household over the age of 18 if not in full-time education, is grossly unfair and penalises older parents who due to the housing crisis have little choice but to allow adult children to remain living with them temporarily. Family Carers Ireland calls on the Department of Housing, Local Government and Heritage to increase the income thresholds and

put an end to the unfair inclusion of the income of adult children living in the household not in full-time education.

- **Ensure family carers do not face higher rents under the Differential Rent Scheme**

The autonomy of local authorities to set and collect rents on council-owned properties is laid down in Section 58 of the Housing Act 1966, however, is subject to broad principles set out by the department, including that rent levels should be based on income and reflect tenants' ability to pay. The discretion of local authorities to apply different approaches to the setting of rents under the Differential Rent Scheme has led to significant geographic variations and inequality in the rent charged to caring households. Family Carers Ireland urges the department of Housing, Local Government and Heritage to be cognisant of the unique situation of family carers and the substantial costs they face as a direct result of their caring responsibilities. Specifically, we call on the department to adopt the following three recommendations as standard in the Differential Rent Scheme:

1. Carer's Allowance will be disregarded at the basic social welfare rate across all local authorities;
2. Half-rate Carer's Allowance will be disregarded in full across all local authorities;
3. Disability Allowance received by children aged between 16 and 18 years will be disregarded in full, in line with the existing uniform disregard of Domiciliary Care Allowance received by children under 16 years¹¹.

¹¹ Domiciliary Care Allowance is fully disregarded in all Local Authorities.

- **Deliver appropriate and accessible housing options with universal design principles at their core**

Although national housing policy, encapsulated by 'Housing for All', pledges to prioritise affordability and inclusivity through a variety of housing designs catering to all ages and abilities, the findings in the State of Caring 2024 highlight the gap between policy and practice. To address this, every new home should be built with Universal Design principles at its core so the homes of carers and the people they care for meet their needs. Moreover, Family Carers Ireland calls for the implementation of the commitments contained in Housing for All and the National Housing Strategy for Disabled People 2022 – 2027,

ensuring dedicated social housing provision appropriate to the needs of disabled people is delivered matching the scale and extent of the need identified for their region.

- **Planning for future housing needs of carers and the people they care for**

Comprehensive planning to forecast and address the future housing requirements of family carers, disabled people and the ageing population is critical. This should involve a detailed analysis of current housing situations and proactive strategies to ensure an adequate supply of affordable, accessible, and suitable housing to meet the anticipated needs of these groups in the future.

IMPROVING THE FINANCIAL SITUATION OF CARERS

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

- **Abolish the means test for Carer's Allowance**

Despite the many plaudits recognising their immense contribution, many full-time family carers of people with complex needs continue to be denied Carer's Allowance due to the means test. As more people in Ireland take on more intensive caring responsibilities, it is important to consider how we can provide a fair income support system for family carers, one that recognises the gendered dimensions of informal care and supports carers' participation in education and employment. As such, Family Carers Ireland is calling for an independent review of Carer's Allowance to ensure it provides an adequate income for all family carers, is gender-balanced and supports participation in education and employment.

Family Carers Ireland has repeatedly called for an overhaul of the Carer's Allowance scheme, which was first introduced 33 years ago, and this remains our priority. We are calling on the Government to increase the Carer's Allowance income disregard by €125 (single)/€250

(couples) in Budget 2025 and Budget 2026 with the abolition of the Carer's Allowance means test and the introduction of a Family Carer Payment (i.e. Participation Income) for full-time family carers by 2027¹². Under the Family Carer Payment, all existing eligibility criteria attached to the Carer's Allowance scheme would remain except the means test.

- **Provide family carers with an adequate income**

Research by the Vincentian Partnership for Social Justice published in April 2022 shows that even before the cost of living crisis, income supports for family carers were inadequate in supporting low-income households caring for a child with a profound disability to meet a Minimum Essential Standard of Living (MESL). These households, which are representative of many caring situations, incur additional average weekly costs of €244 compared to a similarly composed household with no disability or caring needs. These costs can include,

¹² For more information about a Participation Income please see the report by Maynooth University and Family Carers Ireland (Murphy, Cullen & Gough, 2023)

but are not limited to, medical expenses, transportation, specialized equipment, and modifications to the home. The MESL analysis has demonstrated a reduction in the adequacy gap between social welfare rates and the cost of an MESL. The MESL is widely accepted as a credible measure of adequacy and as such, should be applied as a benchmark for determining appropriate rates of Carer's Allowance to ensure that caring households have adequate incomes.

- **Extend eligibility for the Fuel Allowance**
Extend eligibility for the Fuel Allowance so that family carers in receipt of Carer's Allowance payments would be entitled to receive this vital support towards their rising fuel and household bills. This would include increasing the €120 excess to €140 and making Carer's Allowance a qualifying payment.

ADDRESSING CARER LONELINESS

The alarmingly high prevalence of loneliness and social exclusion amongst carers and its associations with poor health are major challenges for society. Preventing and alleviating loneliness and social exclusion requires a multi-pronged and multi-level approach that includes Government, individuals, community organisations and society.

- **Targeted support for family carers through interventions designed to tackle loneliness**
The range of interventions designed to mitigate loneliness and social isolation is diverse, with a frequent emphasis on creating opportunities to bring people together, creating networks and friendships and promoting activities that help to overcome the risks and poor health outcomes experienced by many individuals who are lonely or socially isolated. 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 carers 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 'Carers' Guarantee' is an important mechanism to helping address loneliness and social isolation amongst carers, by giving them respite cover to pursue hobbies, meet friends, or participate in training. The 'Carers Guarantee' also aims to provide peer support for family carers through support groups where they can meet and form friendships with other carers in a similar situation. In order 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 carers and prevent them from experiencing loneliness or isolation. To reduce the negative impact of loneliness and isolation and to support 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 carers but also help employers retain staff. Peer to peer support for carers, 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 carers to remain engaged in the workforce.

IMPROVE ACCESS TO SUPPORTS AND SERVICES

- **Introduce the statutory home support scheme and address the shortage of homecare 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 74% 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 homecare workers available across the country. Even before the statutory home support scheme is launched, the acute shortage of homecare workers is having a detrimental effect on the sector, with homecare providers frequently unable to deliver funded home support services due to a lack of staff.

This is not limited to rural communities, but is increasingly experienced in towns and cities where staff simply are not available. Family Carers Ireland is calling for proactive efforts to be made by Government to promote employment and attract workers to the homecare sector. This includes a call for improvements to the terms and conditions for homecare workers, such as paid travel time and expenses, and a new pricing structure that facilitates different pay based on qualification and type of care provided. Domestic or care work should also be included as an eligible category in the issuing of work permits by the Department of Enterprise, Trade and Employment.

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

Half of respondents (49%) have paid privately for any product or services that should be publicly provided to support their caring role, including Assessments of Need (AON) and therapies. Qualitative responses from carers 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. Under the Disability Act 2005, children with additional needs have a constitutional right to an AON. However, at the start of 2023, some 4,600 children were on a waiting list for an assessment. Of these, 3,155 have been waiting more than three months. We know these figures underestimate the actual number of children in need of and waiting for an AON.

Whilst Family Carers Ireland recognises the efforts being made to address waiting lists, we are also sceptical that attempts to reduce waiting lists can be achieved through the public system alone. Rather, we are calling for extension of the National Treatment Purchase Fund (NTPF) to include timely assessment for both child and adult psychological services (as committed to in the PfG) and extend it to include occupational therapy, speech and language therapy and physiotherapy until backlogs are cleared. We are also calling for immediate financial relief for parents and family carers who have been forced to pay privately for assessments and therapies by allowing the cost to be either reimbursed or paid for through the NTPF.

SUPPORTING CARER HEALTH AND WELLBEING

- **Give carers the right to a minimum 20 days respite each year**

Equitable access and early referral to respite care, both planned and emergency, are critical to ensure the health and wellbeing of carers and the sustainability of the caring role. In many cases, lack of access to respite care can force caregivers to choose between continuing their caregiving role or seeking alternative long-term care solutions, potentially leading to changes in employment status.

Family Carers Ireland believes full-time family carers should have a right to a minimum of 20 days respite each year, provided free of charge, in line with the statutory entitlement afforded to other workers. Where people provide

complex and intensive levels of care, there should be much more than 20 days available. It is deeply concerning that despite the critical importance of respite, there is no national database or figures on respite availability. We believe that a national respite register should be established to allow family carers to register their need for respite along with the age and details of the person for whom they care. This would provide a geographical inventory of respite need by age group and condition type.





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FIND OUT MORE

If you have any queries in relation to this research report, please contact:
Catherine Cox, Head of Communications and Policy, Family Carers Ireland

E: ccox@familycarers.ie

Family Carers Ireland National Office, Market Square, Tullamore, Co. Offaly, R35 PW50

Freephone Careline 1800 24 07 24

CHY 10962

www.familycarers.ie