



# Family Carers Ireland

No one should have to care alone



**THE STATE OF CARING | 2022**



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## ABOUT THE RESEARCH

This report sets out the findings of Ireland's second national *State of Caring* survey undertaken by Family Carers Ireland between 19th January and 2nd March 2022. The online survey was completed by 1,484 current family carers who shared their views and experiences of what life is like for family carers in Ireland in 2022. These carers care for a total number of 1,984 people 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 and local carer hubs. As not all respondents completed each question in the survey, a number of figures in the report are based on responses from fewer than 1,484 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, MENTAL ILL-HEALTH OR ADDICTION.

# 500,000\*

people in Ireland are family carers



(that's one in every 8 adults)

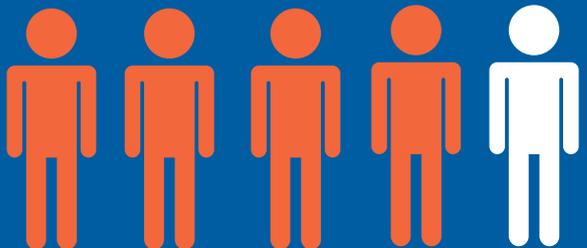
\*approx. figure

## Family carers save the State



EACH YEAR

## By 2030, 1 in 5



will be a family carer

## KEY FINDINGS

**13%**

**of carers** are in arrears with their rent or mortgage and **16%** are in arrears with utility bills. By comparison, **7%** of the general population in Ireland were in arrears with their rent or mortgage payments and **8%** in arrears with utility bills in 2020

**69%**

experience barriers accessing respite

**68%**

experience financial distress

**70%**

report difficulty accessing services for at least one of the people they care for

**71%**

feel left out of society

**51%**

are severely lonely since the onset of the pandemic

**23%**

who struggle financially are cutting back on essentials such as food and heat to make ends meet

**68%**

are not aware of the Assisted Decision-Making (Capacity) Act 2015

**88%**

feel the value of what they do is not recognised by society

**24%**

experienced a delay or reduction in the delivery of home support hours/packages due to a shortage of homecare workers

**52%**

said that at least one of the people they care for are currently on a waiting list

# STATE OF CARING 2022: CONTEXT

The first *State of Caring* survey took place just before COVID-19 reached Ireland. That study painted a stark picture of family carers' lives pre-pandemic, with many struggling financially, facing indebtedness and without access to essential supports. Two years on, the *State of Caring 2022* report shows that many of the pre-existing challenges have not abated and, in many instances, have gotten worse.

The impacts of the pandemic continue to unfold against the backdrop of an escalating cost of living crisis, with inflation in Ireland at the highest rate for 22 years, driven by soaring energy prices and increases in the cost of everyday items such as food and clothing. Whilst rising costs affect people across the country, research undertaken by the Vincentian Partnership for Social Justice on behalf of Family Carers Ireland showed, that regardless of income, households where high level care is provided to an adolescent child with a profound intellectual disability face significantly higher costs than those household without caring and responsibility needs<sup>1</sup>. With energy bills predicted to rise by 25% by the end of 2022 and with the cost of food and everyday items spiraling, carers are facing unprecedented financial pressure, with 68% or 2 out of every 3 carers already experiencing financial distress. Without additional and appropriate support, family carers could be pushed into poverty that will have a lasting impact on their finances and quality of life.

## 68%

or 2 out of every 3 carers are already experiencing financial distress.



Whilst caring can be extremely rewarding, it can also bring many challenges. Despite their immense contribution which is valued at €20 billion per annum<sup>2</sup>, the findings from this survey show that family carers are lonelier, more isolated and in poorer health than the average person in Ireland. Since the onset of the pandemic, severe loneliness amongst the carers who took part in the research has more than doubled, rising from 22% to 51%. Many respondents described the exhaustion of providing constant care and spoke of the loneliness and isolation of caring during the crisis. Reduced health and social care services created practical, psychological and emotional impacts for carers. At the same time, their informal social networks shrank, leaving many with few to rely on in times of crisis. These impacts were compounded by the fear of virus transmission and the need for increased vigilance since public health measures have been lifted. This has had wide-reaching impacts on carer loneliness and their sense of inclusion in Irish society.

Essential services such as day care, respite and homecare supports are a lifeline for many family carers and the people they care for, providing support, routine and a break from their caring role. Family Carers Ireland's 2020 *Caring Through COVID*<sup>3</sup> report illustrated the impact of the blanket withdrawal of supports and services in the early stages of the pandemic. The reduction in supports during lockdown had a severe

impact on people with disabilities and their families, with resilience levels decreasing. Despite commitments in the *Programme for Government* to restore adult disability day services and provide additional respite nights for people with disabilities, the findings from the 2022 survey show that many families continue to experience challenges accessing supports for the people they care for, with respite particularly problematic. Many are experiencing lengthy waiting times amidst a persistent staffing crisis in home support and social care.

## 76%



of those who experienced difficulty accessing services also increased the time they spent caring during the pandemic. This suggests that the reduction or withdrawal of services placed increased responsibilities and pressure on family carers.

While the pandemic has undoubtedly changed how services such as respite are delivered, supports for carers and the people they care for are as important as ever. COVID-19 must not be used to diminish expectations for appropriate supports and services.

The Assisted Decision-Making (Capacity) Act 2015 is due to be commenced in June 2022. Whilst the Act is rightly focused on people with diminished capacity or whose capacity may be called into question in the future, family carers are pivotal to the successful implementation of the legislation by assuming the role of a decision supporter. It is therefore concerning that 2 in 3 (68%) of respondents are not aware of the Capacity Act. Given the imminent commencement of the Act, it is critical that practical and financial supports are in place to help carers meet their obligations as decision-supporters under the Act.

The *State of Caring 2022* report presents an overview of high-level national findings from the snapshot survey of what caring is like in 2022 and through the pandemic so far. The report illustrates the impact that caring has on carers' lives and provides evidence-based policy recommendations to address issues affecting carers. Some comparisons are highlighted throughout the report to indicate variation between different groups of carers.

<sup>1</sup> MacMahon B., Boylan, H., Thornton R. (2022) Care at Home: Costs of Care Arising from Disability. The additional costs of a Minimum Essential Standard of Living for a household caring for an adolescent with a profound intellectual disability. Dublin: The Vincentian Partnership for Social Justice & Family Carers Ireland

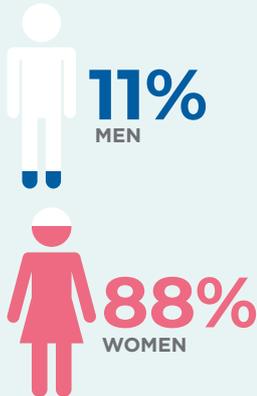
<sup>2</sup> <https://familycarers.ie/media/2381/counting-carers-carer-prevalence-in-ireland.pdf>

<sup>3</sup> <https://familycarers.ie/media/1394/caring-through-covid-life-in-lockdown.pdf>

# PROFILE OF RESPONDENTS



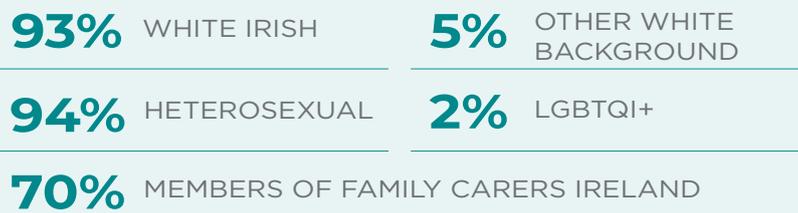
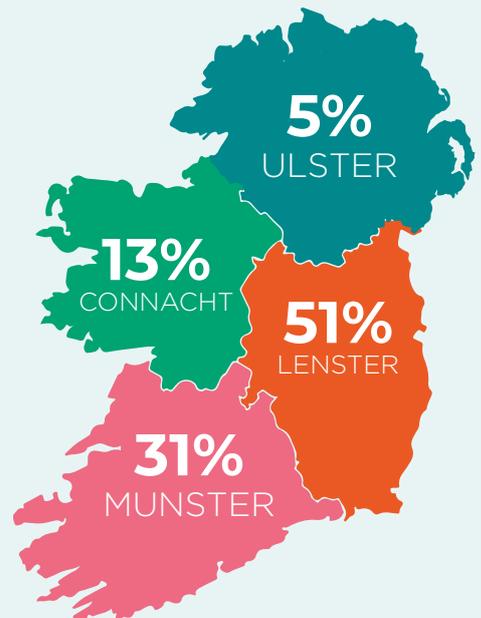
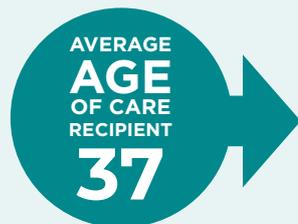
## AGES RANGE FROM



## LENGTH OF TIME CARING



## HOURS CARING PER WEEK



The sample is not representative of the wider Irish family carer population<sup>4</sup>. The 2016 census showed that the majority of carers are women (61%). The majority of respondents to the *State of Caring 2022* survey are also women but in much higher proportion (88%). The census shows that half of all carers (53%) are between the ages of 40 and 59, with the age group 50-54 accounting for almost 15% of carers. Two in three (66%) of respondents to the *State of Caring 2022* survey were between 40-49, with the age group 45-49 accounting for over 18% of all respondents. This suggests that, compared to the average carer in Ireland, respondents to the *State of Caring 2022* survey were more likely to be women and younger.

<sup>4</sup> We draw on the CSO's Census of Population 2016 for carer statistics. However, it is worth noting that the carer prevalence rate identified through the census has been consistently low and at variance with prevalence rates in other countries. 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>

# PROFILE OF CARE TASKS AND CARING RELATIONSHIPS

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 2022 survey show:



# TWO YEARS OF STATE OF CARING SURVEYS 2020-2022: CHANGES OVER TIME

The first *State of Caring* survey took place in January and February 2020, just before COVID-19 reached Ireland. That study painted a stark picture of family carers' lives pre-pandemic, with many struggling financially, facing indebtedness and without access to essential supports. Two years on, the *State of Caring 2022* survey shows that these pre-existing challenges have not abated and, in some instances, have been exacerbated as the impacts of the pandemic continue to unfold amidst a cost of living crisis. The most notable findings from the two surveys are compared and summarised below<sup>5</sup>.

## Comments on demographics

It is noteworthy that so many demographic characteristics of the two survey samples have remained similar over time, with female carers and those aged 36-64 years comprising the majority of all respondents. There does not appear to be any change over time in the proportion of respondents with caring roles of less than two years i.e. those who have become carers during the pandemic. This may be due to how the data were collected, with those in Family Carers Ireland's membership and network reach more likely to self-identify as a family carer. There is also evidence that male carers tend to perform different caring roles to women, which might explain why they are less inclined to self-identify as carers.

The high level of care provided on a daily/weekly basis has also remained consistent over time, highlighted by the large proportions of carers reporting more than 12 hours of care per day (or 90 hours per week). There was little change in the proportion of carers looking after two or more people (27% in 2022 and 26% in 2020).

The comparative underrepresentation of groups such as male carers, young adult carers, LGBTQI+ carers, migrant carers and those with shorter caring durations suggests that these are groups that are at risk of remaining hidden and may therefore warrant greater attention in advocating for increased support and recognition.

	Family Carers in 2020	Family Carers in 2022
Difficulty accessing services for at least one person being cared for	75%	70%
Difficulty accessing respite	51%	69%
Carers living in households with a total income of less than €30,000 per year	52%	47%
Finding it hard to make ends meet	70%	68%
Financial situation of the household has become worse over the last 12 months	39%	51%
Carers cutting back on essentials such as food and heat to make ends meet	21%	23%
Bad or very bad self-reported health	15%	14%
Moderate self-reported health	48%	44%
No awareness of the Assisted Decision-Making (Capacity) Act (2015)	73%	68%

<sup>5</sup> 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 be not representative of the carer population, they can be meaningfully compare

## **Finances**

- The 2022 report is fairly consistent with the *State of Caring 2020* findings, where approximately half of respondents lived in households with a gross income of less than €30,000. More than 2 in 3 carers in 2020 and 2022 found it difficult to make ends meet. Over a third (39%) of carers in the 2020 survey reported a deterioration in their financial circumstances in the previous 12 months. This rose to 51% in 2022. Carers attributed this deterioration to the cost of living crisis and the ongoing costs associated with caring.
- There is a common message across the two surveys. Carers have widely reported low incomes, often due to having to leave the paid workforce, and simultaneous high costs associated with caring, e.g. paying privately for services and out-of-pocket expenses such as medication and equipment. Low income and high expenditure often cause worry and stress for carers. It is clear that a large percentage of family carers experience financial stress<sup>6</sup>.

**The 2022 report is fairly consistent with the State of Caring 2020 findings, where over half (52%) of respondents lived in households with a gross income of less than €30,000**

## **Access to Services**

- Respite, or more specifically the need to take a break from caring, is clearly an ongoing issue for carers. Data from the two surveys demonstrate the time-consuming and extensive nature of caring responsibilities and the limited opportunities to take breaks from their caring role when needed. Whether provided through traditional respite options or more innovative approaches, the need to provide carers with respite from their role is abundantly clear, as is the insufficiency of current options.
- In 2022 69% said they experienced barriers accessing respite, with many citing a lack of availability as a key challenge. This represents an increase of 18% since 2020 when 51% experienced barriers accessing respite. This is likely due to the reduction in respite since the start of the pandemic and how it has not fully resumed for the majority of those who had access to respite prior to the pandemic. Results from the two surveys also speak to the persistent and ongoing challenges carers face when trying to arrange a break from their caring role.
- In 2022, 70% stated they experienced difficulties accessing services for the people they care for. This has reduced slightly from 75% in 2020. However, whilst access to some services may have improved, the overall shortfalls remain significant at 70%. It is also worth noting that whilst 70% experienced challenges accessing formal services in 2022, the pandemic has also meant a reduction in or loss of informal support from family and friends for many carers.
- Several concerns regarding services were raised in both 2022 and 2020: lengthy waiting lists for vital services and therapies; many were forced to pay privately for services due to the lack of availability because of waiting times; there was a lack of information about what was available and how to access it; and many noted that services only became available in times of crisis.
- Loneliness and social isolation were investigated in detail in the 2022 survey using several different measures. Across these measures, carers were found to be lonely and isolated. Whilst measures on loneliness were not included in 2020, many carers expressed feelings of loneliness in their roles, describing the isolation and emotional burden they experience.

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<sup>6</sup> MacMahon B., Boylan, H., Thornton R. (2022) Care at Home: Costs of Care Arising from Disability. The additional costs of a Minimum Essential Standard of Living for a household caring for an adolescent with a profound intellectual disability. Dublin: The Vincentian Partnership for Social Justice & Family Carers Ireland <https://familycarers.ie/media/2457/care-at-home-costs-of-care-arising-from-disability-2022.pdf>

## Health & Wellbeing

- Results from the 2022 survey validate those from 2020, with carers consistently reporting poorer health than the general Irish population. The proportion of carers reporting poor health (15%) remains unchanged over the two years although there was a slight increase in those reporting good health, from 38% in 2020 to 43% in 2022. However, this modest increase pales when compared to the 83% of the general population reporting good health.
- Overall, survey results indicate persistent negative wellbeing outcomes for carers. The results of the two surveys indicate that there are multiple aspects to carers' wellbeing such as financial distress, depression and loneliness. Future work will continue to investigate the factors that contribute to this.

## Legislation & policy reform

- Given the imminent commencement of the Assisted Decision-Making (Capacity) Act 2015 and the important role that family carers will play in bringing the legislation to life, it is deeply concerning that the 2022 findings show that 2 in 3 (68%) family carers have no understanding of the Act. Carers of adults over 18 were more likely to have heard of the Act than those caring for children, suggesting that those whom the Act will have an immediate impact on are better informed.
- In 2020, 73% of carers said they were unaware of the Act, so there has been a slight increase in awareness over time. Nonetheless, it is troubling that significant numbers of carers in 2022 continue to be unaware of the Act at all, despite its commencement in June 2022.

### 2022 findings show that 2 in 3 (68%) family carers have no understanding of the Assisted Decision-Making (Capacity) Act 2015



### Carers providing intensive and complex levels of care

- Over half (52%) of all respondents in 2022 said they took on new caring tasks during the pandemic. When asked to describe their caring roles, many carers indicated they were providing complex care that would usually be provided by trained professionals, highlighting the critical role they play in supplementing the health system. However, many also indicated that they were providing high-levels of care even before the onset of the pandemic. What has changed since then is that many are now caring more intensively with fewer supports. This fits with other data collected through the 2022 and 2020 surveys which indicated that when carers experience challenges accessing vital supports and services such as respite, occupational therapy, speech and language therapy and psychological services, they try their best to fill in the gaps.
- In 2022, almost 1 in 12 (7%) of carers surveyed indicated they started caring in the last two years since the onset of the pandemic, with men making up 20% of this group. 73% of these carers provide over 50 hours of care per week, suggesting many of those who became carers during the pandemic provide high levels of care.

# CARING, LONELINESS AND SOCIAL EXCLUSION

Even before the pandemic dramatically altered the ways in which people across Ireland socialise, loneliness was understood as a key public health challenge. Research has shown that loneliness has a serious impact on people's physical and mental health and quality of life, with loneliness comparable to risk factors such as smoking and obesity in terms of its impact on life expectancy<sup>7</sup>. Carers are particularly at risk of loneliness and social exclusion as the caring role often limits the time available for socialising and the associated costs of caring can make social activities less affordable.

## Carers providing intensive and complex levels of care

Different people experience loneliness in different ways. For example, 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 2022* survey, we measured emotional loneliness before and since the onset of the pandemic by asking carers about their satisfaction with the quality of their social relationships<sup>8</sup>. Many carers indicated that they were severely lonely prior to the pandemic. Worryingly, the number of severely lonely carers has more than doubled since the pandemic began.

	Pre-COVID Loneliness	During COVID Loneliness
None/low loneliness	40%	8%
Moderate loneliness	38%	32%
Severe loneliness	22%	51%

Many factors are associated with high levels of loneliness amongst carers since the onset of COVID-19. Age and loneliness were significantly related, although loneliness did not increase linearly with age. **For example, almost 2 in 3 (61%) carers aged 36-45 were severely lonely whereas 2 in 3 (68%) of those aged 75 and over experienced moderate loneliness.** Better health was also associated with less loneliness. Whilst 79% of the respondents with very bad self-rated health were in the severely lonely group, a concerning 31% of those with very good health were severely lonely. This suggests that some caring circumstances are linked to lonelier care experiences and the links between age and loneliness are complex. Future analysis will untangle the complex story of carer loneliness and help identify specific groups who are particularly at risk.

“

*I find it hard to listen to those who feel they have been isolated since the start of the pandemic - that is my life all the time whether there is a pandemic or not.*

”

<sup>7</sup> Holt-Lunstad, J., Smith, T.B., Baker, M., Harris, T. and Stephenson, D. (2015) Loneliness and social isolation as risk factors for mortality: a meta-analytic review. *Perspectives on psychological science*, 10(2), pp.227-237

<sup>8</sup> The level of emotion (subjective) loneliness before and during COVID-19 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 categorized and responses ranging from 0 to 4 were defined as no/low loneliness, 5 to 6 as moderate loneliness, and 7+ as severe loneliness.

“

*I'm alone. No-one understands unless they are in this position. Friends don't fully understand or you don't want to burden them. You lose yourself in so many ways. You become isolated, you stop going out because your family's needs become so overwhelming that you don't have time or money for yourself.*

”

“

*I'm not able to go out on a summer evening as my husband is in bed by 8pm. It's very hard to go anywhere or see anyone.*

”



### Carers experiencing social exclusion

Family carers are often at risk of being socially excluded, with many reporting having to give up or reduce their employment, experiencing financial difficulties and worsening mental and physical health problems<sup>9</sup>. It is generally accepted that social exclusion, the feeling of being excluded from society, is both a risk factor for and a consequence of poor mental and physical health and poorer quality of life.

**SIX IN TEN** perceive themselves to be socially excluded.  
**58%**

**NINE IN TEN** agreed that the value of what they do is not recognised by others.  
**88%**

The European Quality of Life Survey uses the 'Social Exclusion Index' to measure the extent to which people feel disconnected from society. The index is made up of four questions outlined in Figure 1. The average score for carers was 4.2, notably higher than the average score of 2.2 for the general population in Ireland<sup>10</sup>. Taken together, agreement with these statements strongly suggests that carers do not feel integrated into Irish society, with only **10% feeling socially included and 58% feeling socially excluded.**

### Carers who felt socially excluded had poorer health outcomes compared to carers who felt socially included.

**ONE IN FIVE** who perceive themselves to be socially excluded have bad or very bad health  
**20%**



<sup>9</sup> Greenwood, N., Mezey, G. and Smith, R. (2018). Social exclusion in adult informal carers: A systematic narrative review of the experiences of informal carers of people with dementia and mental illness. *Maturitas*, 112, pp.39-45.

<sup>10</sup> The perceived Social Exclusion Index is based on Eurofound's European Quality of Life Survey (EQLS). The index measures the extent to which people actually feel excluded, based on responses to several questions.

**Figure 1: Social Exclusion Index Items Carers & Irish General Population**



**“**  
*I'm not meeting people as I'm not out working, I can't afford to socialise and I'm feeling really isolated from others.*  
**”**

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 social exclusion than those in paid employment.



**of carers not in the paid workforce perceive themselves to be socially excluded.**

Moreover, not being able to participate in social activities due to the pressure that caring can put on household finances can mean carers become socially isolated, losing touch with friends and social networks. It is therefore concerning that cutting back on hobbies and seeing family and friends are common strategies employed by family carers to make ends meet.



**of carers struggling financially cut back on seeing friends and family**

**“**  
*I'm 28 and have missed out on so much. I'd make plans and then have to cancel because my mam would need me or because my money is gone on everything in the house. So I choose between petrol, food or going out which never happens.*  
**”**

## An absence of social supports for many carers

Carers were asked hypothetical questions regarding whether they could get support in certain situations<sup>11</sup>. Family relations play an important support role for carers, with family members the most commonly cited source of support. However, a sizeable number of carers reported a complete absence of moral and practical support, with 25% saying they had ‘nobody’ when asked who they would rely on when needing help if they were ill or help looking after the person they care for. In a survey analysing social supports in the EU, 11-15% of Irish respondents said they had ‘nobody’ when asked similar questions<sup>12</sup>, suggesting carers are an at-risk group for a lack of social supports. This is especially concerning since high-quality social connections are essential to good mental and physical health and wellbeing.

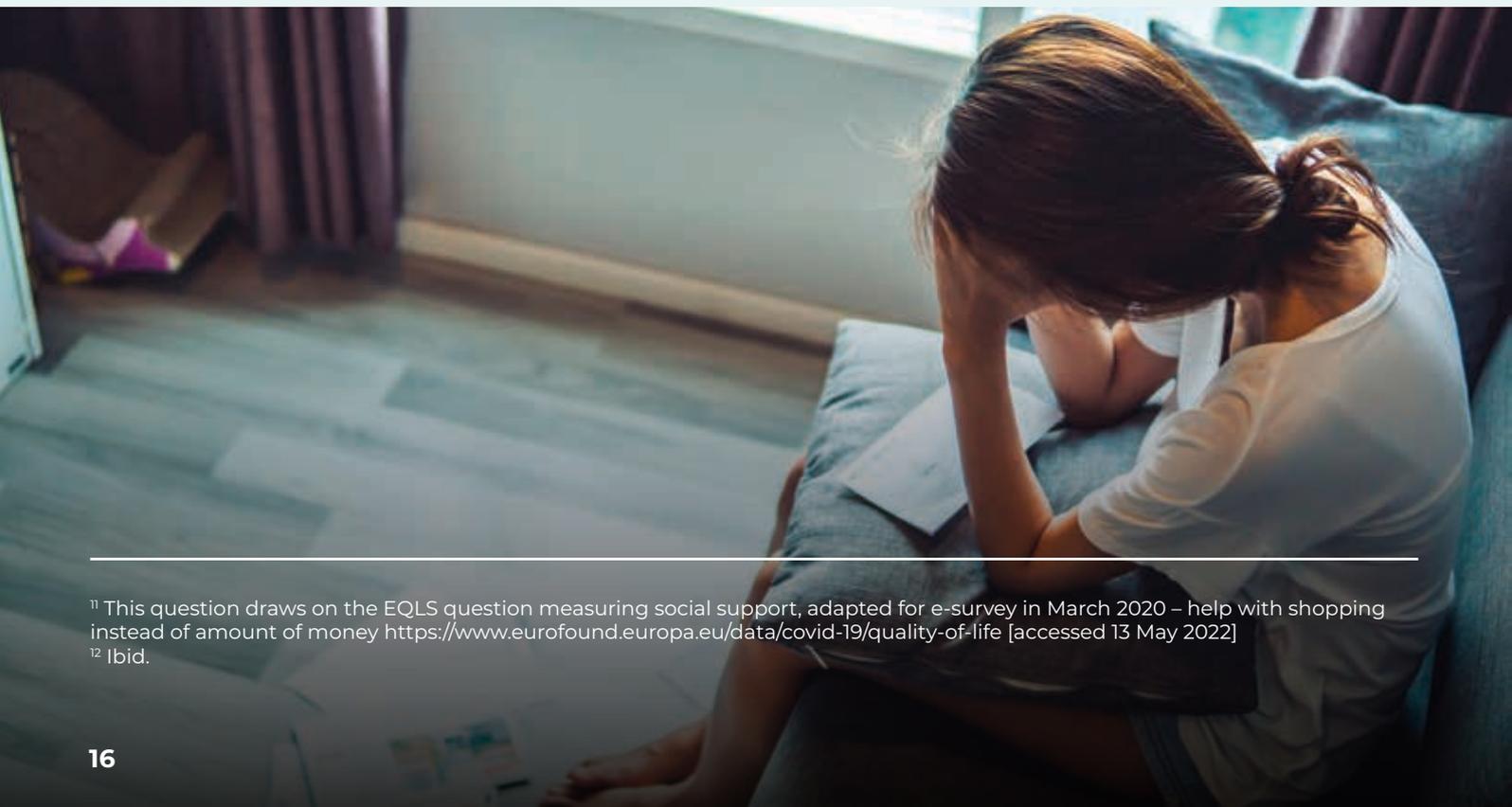
“Lack of support means I don’t get to see friends or have leisure time; mom can only be left alone for an hour or two here and there, enough to get some shopping done but that’s about it; I can take the odd 30 min walk but am tied to the house in the mornings...I do it with a heart and a half as I love my mother to bits, but find it difficult to deal with when people can’t accept or understand that choice or the restrictions it puts on me.”

“At times it’s overwhelming, financial pressure and constant caring can leave me utterly lost, depression and hopelessness at a seemingly never-ending situation can sometimes get too much. Were it not for family supporting me I don’t know what I would have done.”

ONE IN FOUR  
**25%**



said they had nobody to turn to if they needed help when ill or help looking after the person they care for



<sup>11</sup> This question draws on the EQLS question measuring social support, adapted for e-survey in March 2020 – help with shopping instead of amount of money <https://www.eurofound.europa.eu/data/covid-19/quality-of-life> [accessed 13 May 2022]

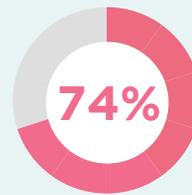
<sup>12</sup> Ibid.

# THE FINANCIAL IMPACT OF CARING

For many families, taking on caring responsibilities results in long-term financial hardship, with the loss of income from employment exacerbated by higher household costs.

Almost half (47%) of carers who participated in the *State of Caring 2022* survey live in households with a gross income of less than €30,000 per year. Almost **1 in 4 (24%) live in households with a total income of less than €20,000**. By comparison, 18% of the general population live in households with a gross income of less than €20,000<sup>13</sup>. Moreover, in 2016 the CSO reported that the median gross income per household in Ireland was over €45,000, demonstrating that a substantial number of carers who participated in the *State of Caring 2022* survey receive a considerably lower income than the median income of the general population. The huge financial sacrifices routinely made by carers as a result of their caring role were evident in multiple written responses. This is especially concerning given the sharp increase in the costs of living in Ireland.

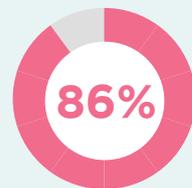
*“ I have no financial independence. I receive no help financially or physically from my husband who works nights. He does not help at weekends. I feel completely stuck in my situation both financial and in my life. ”*



**74%** of carers in receipt of Carers' Allowance find it hard to make ends meet.

*“ I have never been so poor in my life and struggle to make ends meet. This, on top of caring for someone else, makes life quite hard at times. I feel burnt out. ”*

*“ I can't seem to make ends meet, especially the electric and gas, and I'm in rent arrears. ”*



**86%** of carers living in households with gross incomes of less than €20,000 find it hard to make ends meet.

**When asked about their ability to cope financially, more than 2 in 3 (68%) carers said they find it hard to make ends meet.**

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<sup>14</sup>. When asked about their ability to cope financially, more than 2 in 3 (68%) carers said they find it hard to make ends meet. One in 7 (16%) said they could only make ends meet with great difficulty. In a survey analysing quality of life in the EU, almost 6% of Irish respondents could only make ends meet with great difficulty, suggesting that family carers are an at-risk group for poverty and financial instability<sup>15</sup>. Unsurprisingly, those in low income households and those receiving Carer's Allowance were more likely to experience financial distress than those on higher incomes. Despite the enormous contribution made by family carers to society, these findings illustrate that many carers are at risk of poverty and can experience very significant financial hardship.

<sup>13</sup> Central Statistics Office (2016) Geographical Profiles of Income in Ireland 2016 [https://www.cso.ie/en/releasesandpublications/ep/p\\_gpii/geographicalprofilesofincomeinireland2016/incomeinireland/](https://www.cso.ie/en/releasesandpublications/ep/p_gpii/geographicalprofilesofincomeinireland2016/incomeinireland/) [accessed 13 May 2022]

<sup>14</sup> Eurofound (2016) European Quality of Life Survey 2016, [https://www.eurofound.europa.eu/sites/default/files/ef\\_publication/field\\_ef\\_document/ef1733en.pdf](https://www.eurofound.europa.eu/sites/default/files/ef_publication/field_ef_document/ef1733en.pdf) [accessed 13 May 2022]

<sup>15</sup> Central Statistics Office (2021) Survey on Income and Living Conditions (SILC) <https://www.cso.ie/en/releasesandpublications/ep/p-silc/surveyonincomeandlivingconditionssilc2021/povertyanddeprivation/> [accessed 31 May 2022]

## Impact of increases in the cost of living

As energy prices soar and households across Ireland face increased fuel and household bills, **over half (51%) of respondents said their financial situation has deteriorated over the last year.** When asked to explain this deterioration, the majority of carers attributed their worsening financial situation to the rise in the cost of living primarily. Many also contend with spiralling costs alongside additional costs associated with caring, such as having to pay privately for vital therapies and homecare hours and for COVID-19 related expenses such as personal protective equipment (PPE).

“ I have to buy PPE and a lot of cleaning products. Inflation means energy, household, cleaning products and food has gone up a lot. Leaving all our windows open is making us use more heating. Buying online and paying courier and delivery charges add to the burden of a small income. ”

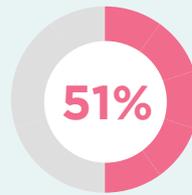
“ I'm spending between €90 to €110 on taxis to hospitals, depending on how many appointments per week. ”



“ I now work 21 hours per week so fall outside the threshold for Carer's Allowance and have to pay for a lot of medications on prescription. ”

## Implications on household expenditure, arrears & indebtedness

Given the financial challenges faced by caring households, it is not surprising that many carers describe struggling to meet normal household bills such as rent, mortgage payments, insurance or phone bills.



**51%** said their financial situation has deteriorated over the last year

“ Everything has gone up significantly even his private therapies but my wages haven't so the things that he likes to do which are vital for his social skills like cinema, pet farms and restaurants can't be done. ”

**More than 1 in 10 (13%) carers are in arrears with their rent or mortgage and 16% are in arrears with utility bills. By comparison, 7% of the general population in Ireland were in arrears with their rent or mortgage payments and 8% in arrears with utility bills in 2020<sup>16</sup>.**

Whilst people across the country are reducing their spending on non-essentials due to the increased costs of living, many carers are making difficult decisions to cut down on the amount they eat or keeping their home warm to manage their finances. **One in four (23%) carers who struggle financially are cutting back on essentials such as food and heat to make ends meet. This rises to 30% for those living in households of less than €20,000 per year.**

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.

“ I was refused gloves, aprons, masks, bin liners, etc. for his personal care when he had COVID-19. I had to purchase the same out of my Old Age Pension. I cannot afford this. ”



**carers who struggle financially are cutting back on essentials such as food and heat to make ends meet.**

“ Utility bills have increased and so have fuel costs. Both myself and my husband are on Carer's Allowance so no Fuel Allowance. ”

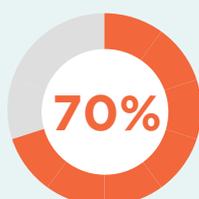
In order to meet these essential costs of living, 38% are using the savings they managed to accumulate. Not only does this reduce financial resilience, it significantly impacts their ability to plan for the future, including the long-term care needs of the people they care for, as well as the ability to set aside funds for retirement.

Alongside depleting household savings, carers are at risk of experiencing debt to make ends meet, with many relying on credit cards (24%), borrowing from family (29%), taking out loans (15%) and overdrafts from the bank (19%).

<sup>16</sup> EU-SILC Survey (2020) [https://ec.europa.eu/eurostat/databrowser/view/ILC\\_MDES07\\_\\_custom\\_89725/bookmark/table?lang=en&bookmarkId=5e7a2d65-6863-40a6-aac4-e8435bbdc521](https://ec.europa.eu/eurostat/databrowser/view/ILC_MDES07__custom_89725/bookmark/table?lang=en&bookmarkId=5e7a2d65-6863-40a6-aac4-e8435bbdc521) [accessed 13 May 2022]

# ACCESSING VITAL SUPPORTS AND SERVICES

For many carers, a core part of their role involves organising access to the supports and services needed by the people they care for. Services such as day centres, homecare and respite are clearly there to support people who require additional care but these services, when available, accessible and appropriate, also enable family carers to care safely and look after their own wellbeing. Despite their importance, many carers are going without the support they need and often without any support at all. This has been exacerbated since the onset of the pandemic for many, with 70% of carers reporting difficulty accessing services for at least one of the people they care for. This rose to 76% for those who have increased the time they spend caring during the pandemic, suggesting the reduced access to services is putting increased pressure and responsibilities on carers.



**70%** of carers report difficulty accessing services for at least one of the people they care for.

*“ We didn’t risk respite during the pandemic, we hope to apply again but her needs have increased greatly since she was last in respite so as yet we don’t know if she will get any. ”*

*“ Aged out of children’s hospital for medical issue. Consultant in adult hospital showed no understanding of her condition. Not on any waiting list anywhere because issues are not acknowledged. ”*

## Barriers to accessing appropriate respite

Respite has been identified as one of the most necessary and effective strategies to preserve and improve the well-being and quality of life of family carers<sup>17</sup>. Respite care, which provides carers with the opportunity for a temporary rest from their caregiving duties, can relieve their stress, renew their energy and restore a sense of balance to their lives.

It is therefore deeply concerning that almost three quarters (69%) of carers experience barriers in accessing respite. **14% were currently on waiting lists for respite services, with over half (53%) of these waiting over two years. Two in 3 (66%) said they had never received respite and 9% said it has been over two years since they received respite.**

*“ When my daughter moved to adult services, I was told not to apply for respite because there was none available. I find my daughter’s service provider very hostile to us, and do not like to ask them for anything. I would not be able to relax if I left her in a respite centre with hostile caregivers. ”*

*“ Waiting lists even for private therapists are massive in Cork and cost has increased (they justified the increases with additional PPE costs). I am waiting for OT for my daughter since last year even in the private sector. ”*

**Worryingly, more than 1 in 10 (12%) said that their respite has not resumed at all since the pandemic began. Only 4% said the respite had fully resumed and returned to its pre-COVID-19 level.**

<sup>17</sup> Lund DA, Utz R, Caserta MS, Wright SD. (2009) Examining what caregivers do during respite time to make respite more effective. *Journal of Applied Gerontology*. 28(1):109–131. doi: 10.1177/0733464808323448.

When asked about the barriers they face in accessing respite, many carers said it was simply not available in their area and that they had been flatly refused the service or left languishing on waiting lists. In many cases, even when respite is available, families are unwilling to use it due to the risk of injury to their loved one, the lack of specialist care, its age-inappropriateness or the risks of COVID-19 infection. Respite on an 'as needed' basis was the most common response when carers were asked how frequently they would like respite but many also said they needed regular weekly or monthly respite. This suggests there is a lack of regular, flexible and appropriate respite options available to many caring households.

“ One year waiting for occupational therapy meant I had to figure it out, bought bed guard, installed safety rails, wheelchair myself as couldn't do without them. ”

“ We were put on a waiting list for respite when my son was 12. He's nearly 19 now and we never heard any more about it. ”

“ I'm not looking forward to the tsunami of health issues that are the inevitable result of no routine or preventative medicine for two years. ”

“ I am totally and utterly exhausted from fighting with the HSE, from respite to her day service to her transport to her wheelchair...months and months of waiting for things, nothing happening unless you injure yourself or simply can't cope anymore. I feel angry at the toll this has taken on my mental health and on the mental health of my children. ”



would like respite on a weekly or monthly basis



would like to receive respite 'as needed'

**Waiting lists for healthcare and community supports**

Each waiting list statistic represents a child or adult waiting for care they desperately need whilst potentially deteriorating clinically. This puts increased pressure and responsibilities on carers. **Over half of respondents (52%) reported that at least one of the people they care for are currently on a waiting list.** The below table shows that many carers reported delays of over two years for many vital supports, with procedures, therapists, needs assessments, consultants, respite and Child and Adolescent Mental Health Services (CAMHS) the most lengthy and common waiting lists. Reasonable waiting times were not available even to those families who managed to find the financial resources to pay privately for treatments and therapies.

“ Respite is mostly offered from Monday to Friday. I feel that weekend respite would be most beneficial as that's when my friends are free to go somewhere. ”

WAITING LISTS FOR SERVICES	Waiting 0-3 months	Waiting 4-6 months	Waiting 7-12 months	Waiting 13-18 months	Waiting 19-24 months	Waiting 24+ months	Number and % of respondents who reported waiting for each saervice
To see a consultant (adult or paediatric)	8%	11%	14%	17%	12%	39%	36% n=532
To have a procedure (day or in-patient)	9%	15%	16%	19%	10%	32%	18% n=260
To see a therapist (e.g. speech & language, occupational therapy)	9%	7%	11%	13%	11%	49%	36% n=528
An assessment of need (for disability/education services)	7%	10%	13%	14%	10%	47%	19% n=276
Respite services	14%	7%	10%	6%	10%	53%	14% n=203
Child and Adolescent Mental Health Services	7%	11%	8%	12%	10%	52%	12% n=178

“  
*Homecare package is not being fulfilled. I'm supposed to have 42 carer hours per week but only have 20 due to staff shortages. My mum is a two-person hoist assist. I am now hoisting her by myself half of the week.*  
 ”

“  
*We are still waiting for a care company to take up an additional hour's night time care we have been granted by the HSE. It's to help with the bedtime routine and getting them both to bed. Not one care company has offered to take on the 9pm-10pm shift!!*  
 ”

Whilst the number of carers and the time spent on waiting lists is deeply concerning, many respondents also indicated in written comments that they were not registered on a waiting list because their issues were not acknowledged or they had been flatly refused a service. This suggests that these figures do not reveal the true extent of the issues.

“  
*Pre-pandemic I went out to work and my parents had a carer calling from the HSE to help with personal care. Once it started in March 2020 we lost the carers help and it has never been returned. I took on those duties then. This is a worry as I am expected back to the office but my parents' mobility issues have increased in lockdown with the lack of exercise.*  
 ”

## Homecare and staff shortages

Homecare providers across Ireland, including Family Carers Ireland, have for many years faced a staffing crisis, whereby people who are medically assessed by the HSE as needing homecare are not able to access home supports due to a shortage of staff. This crisis in staffing has become more acute in recent years, impacting on families in multiple ways. For example, homecare worker shortages can make the caring role unsustainable or mean that the hours are delivered at times which do not suit the client. It is therefore deeply concerning that 24% of carers responding to this survey experienced a delay or reduction in the delivery of home support hours/packages due to a shortage of homecare workers. **Over one third (39%) of those currently on a waiting list for homecare supports or a homecare package said they were waiting over two years for the service.**

“

*We were approved 15 hours home care per week four years ago but only received seven hours, those hours were withdrawn during the pandemic.*

”

ONE IN FOUR  
**24%**

experienced a delay or reduction in the delivery of home support hours/packages due to a shortage of homecare workers



## Accessing schools & supports for children with additional needs

Over 2 in 5 (44%) respondents cared for at least one child under 18 with additional needs. In written comments, many parents said their children were not getting the services they need due to unfilled positions and waiting lists. Many had gone to great expense to secure private psychological and educational assessments and services (such as speech and language therapy) for their child/ren. Even when services were available, many parents indicated concerns about their appropriateness for their child/ren.

*“ No services and lack of education resulted in regression for my child especially as I was redeployed and was required to work substantially more hours meaning I could not make up the gap. In addition, my child's sleep deteriorated. Am totally exhausted and have been diagnosed with cancer which I attribute in part to the stress of providing care to a child for last 12+ years within a system which is totally under resourced and therefore unable to provide even a very basic level of timely services both therapeutic and medical. ”*

Education is a particular concern for many parents. All children, including those with disabilities, are legally entitled to an education. The Education for Persons with Special Education Needs (EPSEN) Act states that schools and other education providers must offer ‘reasonable accommodation and individualised support’ to ensure that children with disabilities get free and inclusive education in their own communities at all levels, to give them the maximum academic and social development and skills ‘to the level of their capacity’. It is of grave concern that **1 in 4 (27%) carers of children with additional needs said they were not satisfied with their child's school place**. Many indicated a lack of appropriate school-based support and suitable places for their children. Some children were on reduced timetables whilst others were home-schooled because an appropriate school place was not available. Others were refused entry to school based on their level of need despite no special school space being available to them. Parents wrote many comments describing not only the impact of these systemic failures across health and education on their children, but also on their own health and wellbeing.

*“ I'm absolutely exhausted, a mind, body and soul type of exhaustion that I didn't know was possible. I'm also angry at being trapped in this vicious cycle of begging for the basic human rights of my child to be met and how every single little thing is a battle to get support with. ”*

*“ I feel very tired and exhausted. With COVID-19, the kids been out of school and routine. It's very hard when you have two disabled sons to look after. ”*

“

*It has been suggested by school I reduce her daily hours because they didn't have the staff.*

”

“

*My daughter had to stop going to school because her needs weren't being met. She now has to be home schooled by me with no support from the school.*

”

# CARER HEALTH AND WELLBEING

Caring for a loved one can be a positive experience, allowing carers to grow personally and experience a sense of competency in the caring role<sup>18</sup>. However, research also indicates that caring can have significant negative impacts on a person's health and wellbeing – putting them at increased risk of poor health outcomes such as depression and physical pain<sup>19</sup>.

Compared to the general population, family carers who responded to this survey are more likely to have poorer health and a long-standing disability, illness or health condition.

Self-reported Health status	Family Carers in 2022	General Population aged 16 and over <sup>20</sup>
Very good or good	43%	85%
Moderate	44%	12%
Bad or very bad	14%	3%

Over 8 in 10 (85%) of people aged 15 years or older in Ireland perceive themselves to be in good or very good health. Only 4 in 10 (43%) of family carers responding to this survey reported being in good or very good health, whilst over 4 in 10 (44%) said they had moderate health. A similar percentage (43%) of carers surveyed have a long-term illness, health problem or disability.

Carers most at risk of adverse outcomes such as poor mental and physical health, were identified using the Carer Wellbeing Index<sup>21</sup> (CWBI) – a short screener that captures key aspects of a carer's psychological wellbeing. Over 4 in 10 (43%) carers had high scores on the CWBI and 15% were identified as high risk. This is particularly concerning as carers with higher CWBI scores are more likely to report distress, anger and depression and be caring for someone that is later admitted to long term care.

Considering the personal cost that often comes from providing intense levels of care without adequate support, it is not surprising that those caring for two or more people are significantly more likely to have poor health. Almost 1 in 5 (18%) of those caring for two or more people had bad or very bad health whilst 12% of those caring for one person reported poor health. Inadequate access to supports was also associated with poor health outcomes.

**For example, 66% of those with very good or good health faced challenges in accessing supports whilst 83% of those with bad or very bad health experienced difficulties accessing support.**

Given that a long-standing objective of Government policy is to support care at home for as long as possible, it is essential that carers most at risk of negative outcomes are adequately supported to develop sustainable caring routines.



<sup>18</sup> Pysklywec, A., Plante, M., Auger, C., Mortenson, W., & Eales, J. (2020) 'The positive effects of caring for family carers of older adults: a scoping review', International Journal of Care and Caring, 4(3) pp.349-375.

<sup>19</sup> Family Carers Ireland, College of Psychiatrists of Ireland & University College Dublin (2019) Paying the Price: The Physical, Mental and Psychological Impact of Caring, Ireland: Family Carers Ireland. <https://familycarers.ie/wp-content/uploads/2019/05/Paying-the-Price-The-Physical-Mental-and-Psychological-Impact-of-Caring.pdf>

<sup>20</sup> Central Statistics Office, 'Irish Health Survey 2019' <https://www.cso.ie/en/releasesandpublications/ep/p-ihsmr/irishhealthsurvey2019-mainresults/healthstatus/> [accessed 10th May 2022]

<sup>21</sup> Betini, R., Hirdes, J. et al. (2018) Development and validation of a screener based on interRAI assessments to measure informal caregiver wellbeing in the community. BMC Geriatr 18, 31. <https://doi.org/10.1186/s12877-018-0986-x>

# CHANGING THE LEGAL LANDSCAPE FOR FAMILY CARERS: THE ASSISTED DECISION-MAKING (CAPACITY) ACT 2015

The Assisted Decision-Making (Capacity) Act 2015 was signed into law in December 2015 and is due to be fully commenced in June 2022<sup>22</sup>. 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) will be appointed as a decision supporter.

While the Act is rightly focused on people with diminished capacity or those whose capacity may be called into question in the future, family carers are central to bringing the legislation to life by undertaking the various roles it provides for. However, by 'volunteering' to act as a decision supporter, they are accepting very considerable additional administrative and legal burdens on top of their caring role.

**TWO IN THREE**  
**68%**

**carers are not aware of the Act**



**61%** of those caring for people with intellectual disabilities or dementia are not aware of the Act



**52%** of those caring for people over 18 are not aware of the Act

Given that family carers are one of the cornerstones of this important piece of legislation, it is critical that they understand the provisions contained within the Act. It is therefore troubling that significant numbers of carers are not aware of the Act at all, despite its imminent commencement. This is particularly concerning for carers of adults over 18 with diminished capacity whom the Act will apply to immediately once commenced.



<sup>22</sup> Further information on the Assisted Decision-Making (Capacity) Act 2015 and its relevance to family carers can be found at <https://familycarers.ie/your-questions-answered-assisted-decision-making/> and <https://familycarers.ie/carers-supports/help-guidance/carers-and-capacity-briefing-for-family-carers-on-the-capacity-act>



## **Addressing carer loneliness and social exclusion**

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.

### **• Recognise the economic and societal value of care**

Unpaid care typically happens behind closed doors, remaining hidden and undervalued. The pandemic has highlighted how care work is propping up the health and social care sector. Yet despite their significant contribution to Irish society, the majority of carers responding to this survey felt that the value of what they do is not recognized by others. This, and the high prevalence of social exclusion amongst family carers, suggests that carers not only feel isolated, but also undervalued. It is critical that the economic and social value of care is clearly articulated in the Constitution, as recommended by the Citizens' Assembly, adequately compensated for through a reformed and modernised Carer's Allowance scheme and supported through a range of measures including respite.

### **• 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, isolation or financial hardship. 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. This is even more pressing in the context of COVID-19, where many employees with caring responsibilities are more isolated than ever. 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.



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.

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

Research by the Vincentian Partnership for Social Justice published in 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 intellectual disability to meet a Minimum Essential Standard of Living (MESL)<sup>23</sup>. These households, which are representative of many caring situations, incur additional weekly costs of €244 compared to a similarly composed household with no disability or care needs. The gross inadequacy of Carer's Allowance is clear, with 74% of carers in receipt of Carer's Allowance in 2022 struggling to make ends meet. The *State of Caring 2022* research also shows that 45% of caregivers who were struggling financially had to make up for the shortfall by cutting back on seeing friends and family. Financial security is therefore key in any plans to alleviate loneliness. Family Carers Ireland recommends that the weekly rate of Carer's Allowance be significantly increased to reflect the additional costs incurred by caring households and in recognition of society's reliance on the care they provide. Family Carers Ireland is calling for an increase in the rate of Carer's Allowance to at least €325 in Budget 2023.

- **Undertake a review of Carer's Allowance to ensure it is gender-balanced and provides an adequate income for all carers**

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.

- **Extend eligibility for the Fuel Allowance**

Extend eligibility for the Fuel Allowance so that family carers in receipt of Carer's Allowance and Half-Rate 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 an eligible payment.



## Improve access to supports and services

- **Introduce the statutory home support scheme<sup>24</sup> 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 70% of respondents who have experienced difficulty in accessing services and the 24% who have experienced delays or a reduction in the provision of home support hours/packages. 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.

<sup>23</sup> MacMahon B., Boylan, H., Thornton R. (2022) Care at Home: Costs of Care Arising from Disability. The additional costs of a Minimum Essential Standard of Living for a household caring for an adolescent with a profound intellectual disability. Dublin: The Vincentian Partnership for Social Justice & Family Carers Ireland. <https://familycarers.ie/media/2457/care-at-home-costs-of-care-arising-from-disability-2022.pdf>

<sup>24</sup> Family Carers Ireland has lobbied for the statutory home support scheme to be available to adults of ages in need of care, not only older people.

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 home care 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.

- **Ensure every child with additional needs has an appropriate school place**

Almost half of the people who responded to the 2022 survey are caring for at least one child under 18 with additional needs. Many of these children regressed during the pandemic whilst facing lengthy waiting lists for vital services, therapies and assessments, and often denied an appropriate school place. It is imperative that children with additional needs are fully supported to thrive and access their constitutional rights. All children, including those with additional needs, have a constitutional right to an education and the State has a role in them accessing that right. Whilst there is no 'one-size-fits-all' model, a rights-based and child-centred approach to education will allow children with additional needs to thrive and fully access their right to education. Family Carers Ireland calls on the Department of Education to create a pathway to a system where all children are able to access that right through the introduction of increased monitoring, better planning for future demand and the completion of reforms to which the Government has already said it is committed but which have yet to be achieved. The review of the EPSEN Act in 2022 is also an opportunity to ensure that the legislation on education for students with additional needs is informed by the lived experience of children and their families and sufficiently resourced.

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

Over half (52%) of respondents in the *State of Caring 2022* survey said that at least one of the people they care for are currently on a waiting list. Many were waiting longer than two years 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. Whilst Family Carers Ireland recognises the efforts being made to address waiting lists, including the €4m allocation to address psychology waiting lists and the recruitment of additional staff, we are also sceptical that attempts to reduce waiting lists can be achieved through the public system alone. Rather, we are calling for the extension of the National Treatment Purchase Fund to include not only psychology but also other essential supports, such as speech and language, occupational therapy and physiotherapy, to clear the waiting lists for each of these essential therapies. Children, particularly those with disabilities, have been most severely affected by the blanket withdrawal of services during the COVID-19 crisis. Every effort must now be made to ensure the long-term impacts of the withdrawal of services are minimised.

## **Supporting carer health & wellbeing**

- **Enshrine in the statutory home support scheme 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 be the difference between maintaining the caring role or having no alternative but to seek other long-term care options or cease or reduce employment.

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 and we are calling for this to be included in the statutory home support scheme legislation. 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.

Family Carers Ireland understands that to address the growing requirement for respite services, the current estimates process is proposing €10m investment and targeted alternative models of respite provision such as extended days,

weekends, in-home and overnight respite. While welcome, the amount sought does not address the latent unmet need for respite. The Capacity Review to 2032 found that the cost of meeting the level of unmet need for respite recorded in 2017 could be €16m to €20m a year but with latent unmet need, this is likely to be significantly higher.



## ***Providing support to carers on the Assisted Decision-Making (Capacity) Act 2015***

- **Provide ring-fenced funding to support decision-supporters**

While Family Carers Ireland welcomes the introduction of legislation to support people in their decision-making, it is concerning that many family carers are not aware of the Assisted Decision-Making (Capacity) Act 2015 due to commence in June. We are concerned that aspects of the Act's implementation could bring about unintended consequences causing undue hardship for families and carers, and denying access to justice for the most vulnerable in society. If family members and friends are to fulfil the demands required of decision supporters, then it is critical that a range of measures are in place to support them. Family carers and those who will assume the role of a Decision-Making Representative (DMR) should not have to bear the cost of making an application to the Circuit Court or pay for medical reports. Costs should be borne by the relevant person and where they do not have income or assets in their own right should fall to the exchequer. The Legal Aid scheme should be extended to ensure adequate resources are available to meet increased demands on the scheme due to the commencement of the Act. Moreover, we have concerns about the Courts' ability to meet the demands arising from the DMR applications before the court, projected to be 1,200 applications in the early stages of the Acts commencement. We urge that practical steps be taken to address some of these concerns.



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## FIND OUT MORE

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