



Family
Carers
Ireland

No one should have to care alone

THE STATE OF CARING 2020





CONTENTS

About the Research	5
State of Caring 2020	6
○ The financial impact of caring	9
○ Reconciling caring and paid employment	12
● Access to supports and services	14
● Carer health and wellbeing	16
Caring Through Covid: Life in Lockdown	19
○ Impact of the withdrawal of services on family carers	22
● Concerns over loved one's health and wellbeing	24
● Challenges of caring during COVID-19	25
● Family carers under increased financial pressure during COVID	28
● Concerns during COVID	29
● Protocols for hospitalisation	30
● Balancing work and care during the pandemic	31
● Priorities for Government	32
● Long-term impacts of COVID	33
○ Social solidarity whilst caring during COVID	34
Family Carers Ireland: How we are Supporting Family Carers Through the COVID-19 Crisis	35
Conclusions and Recommendations	36



ABOUT THE RESEARCH

In the winter of 2019/2020, before the outbreak of COVID-19, Family Carers Ireland undertook Ireland's first national State of Caring survey. Completed by some 1,250 family carers in online and paper form, the survey's findings paint a stark picture of carers' lives pre-COVID, with many struggling financially, facing indebtedness and without access to essential supports.

Before the findings of the State of Caring survey were published, the COVID pandemic reached Ireland and the situation that carers were in when they completed the survey suddenly became very different. The blanket withdrawal of supports such as homecare, respite, personal assistance hours and residential care during lockdown forced many carers to care alone, around the clock and without the support of extended family or friends. Parents of children with a disability lost the routine and relief of school, day services and essential therapies, placing the child at serious risk of regression. Older carers and those with underlying health conditions were expected to cocoon, isolated and became reliant on others. Even carers who were coping relatively well prior to the pandemic became mentally and physically drained, with many struggling to maintain their caring role.

In response, Family Carers Ireland made the decision to extend the State of Caring research to include a special module on carers' experience of 'Caring Through COVID'—the challenges they face, their worries and concerns and their suggestions on how frontline service providers and Government should respond to meet their needs. Some 1,307 carers responded to this online survey between 14th April and 5th May. This report 'The State of Caring 2020' presents both pieces of research, shining a light on carers' lives before and during COVID-19¹. The findings from the pre-COVID survey are presented firstly, followed by the research covering carers' experience of caring through COVID. Recommendations relating to both surveys are presented at the end of the report.

The report shows that family carers have long been lauded as the backbone of care provision

in Ireland, an essential yet hidden pillar in our healthcare system, however during COVID they became much more. They not only stayed at home themselves during the crisis but enabled older people, people with a disability, the sick and those with palliative care needs to stay at home as well.

WHEN SERVICES SHUT DOWN, THEY STEPPED UP AND CONTINUED TO CARE AROUND THE CLOCK TO ENSURE THEIR LOVED ONE STAYED AT HOME AND OUT OF HOSPITAL, WHILE FACING UNPRECEDENTED LEVELS OF RISK TO THEMSELVES.

Family carers have played a more significant role in suppressing the coronavirus than most and their essential contribution to the national healthcare response should be acknowledged and applauded. It is essential that they are supported to continue caring safely for their loved ones.



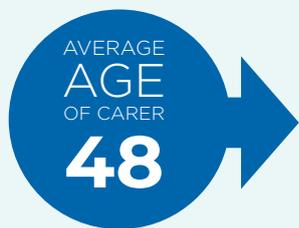
IRELAND'S 355,000+ Family carers have played their part in protecting and caring for Ireland's most vulnerable people during this crisis.

A FAMILY CARER IS SOMEONE WHO IS PROVIDING AN ONGOING SIGNIFICANT LEVEL OF CARE TO A PERSON WHO IS IN NEED OF THAT CARE IN THE HOME DUE TO ILLNESS, DISABILITY OR FRAILTY².

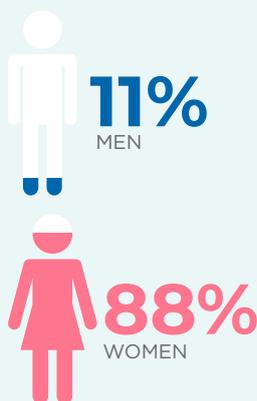
¹ Note that these two surveys are not directly comparable because they are both based on convenience samples, which means that different carers could have responded to each survey.

² Department of Health (2012). National Carers' Strategy – Recognised, Supported, Empowered. Department of Health, Dublin.

STATE OF CARING: PROFILE OF RESPONDENTS



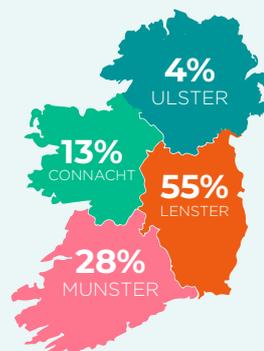
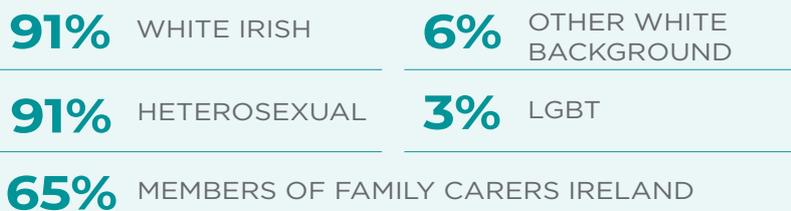
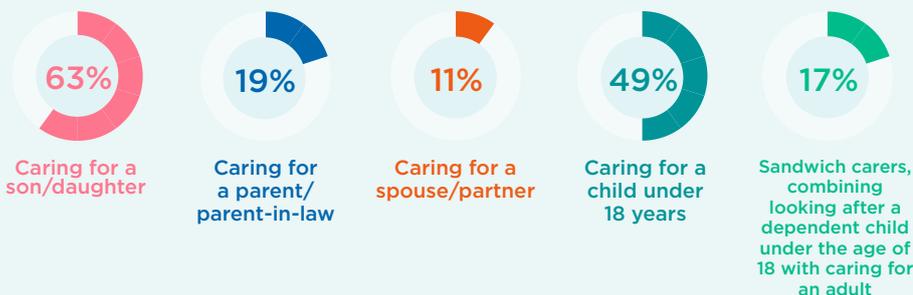
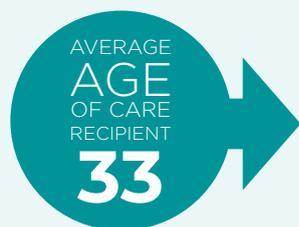
AGES RANGE FROM



LENGTH OF TIME CARING



HOURS CARING PER WEEK



This sample is not representative of the wider Irish carer population.

³Doesn't add up to 100% due to rounding

STATE OF CARING KEY FINDINGS



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. Moreover, significant life changes are often required to cope with the practical aspects of caring, e.g. moving house, undertaking adaptations to your home or purchasing an accessible vehicle. The economic impact of caregiving is not only experienced during the active years of caring, but can last a lifetime, as years spent on a low income or out of the workforce mean carers can't repay debt, build savings or contribute to a pension. If caring comes to an end while the carer is of working age, barriers to returning to work often result in carers being 'locked out' of the labour market. Even working carers, who manage to remain in employment, are likely to see their working lives adversely affected by having to reduce their hours of work, accept low-paid, precarious work options or sacrifice promotion and career opportunities.

More than half (52%) of carers who participated in the State of Caring survey live in households with a gross income of less than €30,000 per year. Almost 1 in 3 (29%) live in households with a total income of less than €20,000 and 39% of all respondents said their financial situation has deteriorated over the last year. In comparison with the general population, family carers were more likely to report themselves living in households with a gross income of less than €20,000⁴.

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 poverty⁵. When asked about their ability to cope financially, 70% said they find it hard to make ends meet. One in 5 (19%) said they could only make ends meet with great difficulty. In a survey analysing quality of life in the EU, only 7% of Irish respondents found it difficult to make ends meet, suggesting that family carers are an at-risk group for poverty and financial instability⁶. Carers of working age (18-65), those receiving Carer's Allowance and those who themselves have a health condition/disability are significantly more likely to struggle financially (73%, 75%, 75% respectively). These findings illustrate the very significant financial hardship and the risk of poverty faced by many family carers, despite the enormous contribution they make to society.

"I have to make sure there's enough for both rent and important bills and of course weekly food for two people. I spend what is left on his dressings, lotions and creams that helps manage pain and if there is a little left I can buy something for myself."

"I find it hard to pay gas and electricity."

”

⁴ Central Statistics Office (2016) Geographical Profiles of Income in Ireland 2016 <https://www.cso.ie/en/releasesandpublications/ep/p-gpii/geographicalprofilesofincomeinireland2016/incomeinireland/>

⁵ Eurofound (2016) European Quality of Life Survey 2016, https://www.eurofound.europa.eu/sites/default/files/ef_publication/field_ef_document/ef1733en.pdf

⁶ Ibid.

(i).



Implications on Savings and 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. **Over 1 in 10 (12%) are in arrears with their rent or mortgage and 15% are in arrears with utility bills. By comparison, 5% of the general population in Ireland are in arrears with their rent or mortgage payments and 9% in arrears with utility bills⁷.**

While reducing spending on non-essential items is not uncommon for any person experiencing financial difficulty, what is of grave concern is the incidence of carers cutting back on essentials such as food and heating in order to cope, with more than 1 in 5 (21%) carers who struggle financially reporting that they do this in order to make ends meet.

Unsurprisingly, those living in lower income households were significantly more likely to have to make the difficult choice between heating their homes or putting food on the table. These stark figures suggest that significant numbers of carers are suffering both fuel and food poverty, with 3% of those who struggle financially reporting use of food banks. These findings have important implications for addressing caring households at risk of poverty.

Bearing in mind that Carer's Allowance is currently framed by the Government as an income support to prevent carers from falling into poverty due to their caring responsibilities, it is particularly worrying

to note that those in receipt of Carer's Allowance were more likely to be in financial hardship across a whole range of measures, including more likely to be in lower income households, in debt, struggling to pay housing costs and cutting back on essentials.



21%

of carers who find it difficult to make ends meet are cutting back on essentials such as groceries and heating to cope financially.

Many carers who had managed to accumulate some savings before their caring role began describe using these savings to meet everyday expenses and essentials associated with caring and now face being in debt. Of carers who had savings, 1 in 3 (30%) have used all or almost all of their savings and 1 in 4 (23%) are using savings to pay for everyday living.

Together with declining household savings, many carers borrow or use credit to make ends meet. 24% rely on credit cards and loans from family and friends to make ends meet. Worryingly, 57% said they have experienced or are likely to experience debt as a result of caring.

Unsurprisingly, 66% of carers who also have a health condition or disability are more likely to find themselves in debt (compared to 57% of all carers) as they face the commensurate challenges of meeting the additional costs associated with disability as well as those associated with caregiving.

"I'm budgeting tightly, buying in second hand stores. I restructured my mortgage after being years in arrears, going without a proper lifestyle or any treats, holidays, purchases, etc. The home furniture needs replacing but I can't afford it, the car badly needs to be changed but I can't afford it."

"I'm getting loans off Peter to pay Paul. It's impossible to try keep up when there's more going out than what's coming in."

"It's impossible. Hospital appointments, diesel and medication that is not covered by the Medical Card is crippling us. I can't afford to go to my own oncology appointments. Paying for care workers to come in for a day is just not possible."

⁷EU Survey on Incomes and Living Conditions (EU-SILC) (2017)

(ii).



Implications on Social Activities, Supports and Health

Almost 2 in 3 (63%) carers struggling financially report that they regularly forgo non-essential items, with half (45%) of carers cutting back on seeing family and friends to save money while 2 in 3 (61%) reduced leisure activities.



ONE IN TEN
10%

carers who struggle financially report cutting back on supports which help with caring, such as home care hours and respite.

Cutting back on support services to make ends meet places carers who are already struggling at even greater risk. Further reductions could make their situation even more unsustainable and have a serious impact on the carers' physical and mental health.

Challenging financial circumstances can lead to poor health outcomes for carers. Over half (56%) of respondents feel their financial circumstances are affecting their health. More than 1 in 4 (29%) carers didn't go or delayed a visit to a healthcare practitioner such as a doctor, dentist or chiropodist because money was needed for other essentials.

Amongst those who struggled to make ends meet, 36% didn't go or delayed a visit to a healthcare

practitioner due to the costs involved. Poor health often contributes to reduced income and low income can lead to poor health, leading to what is known as the 'health-poverty trap'. Carers in this position may find this vicious circle very difficult to escape.

ONE IN FOUR of carers said they cannot prepare for future care needs as they have no savings and live on a low income.
25%

ONE IN THREE 1 in 3 (36%) of those carers who are struggling financially didn't go or delayed a visit to a healthcare practitioner due to the costs involved.
36%

Going without essentials such as groceries or heat is likely to have a detrimental impact on a carer's health whilst cutting back on hobbies and seeing friends can add to the sense of isolation carers often feel, further impacting their wellbeing. Given that this data was collected before the COVID-19 crisis, it is likely that many of these carers are in even greater financial distress than at the start of 2020.

“

I go without my medication to try to make ends meet.

”

“

I'm trying to juggle important bills like ESB, groceries and fuel as our only source of heating is an open fire for a one-bedroom house. We rarely go out and we don't own a vehicle. At least we have internet access so we can communicate with other people to avoid further isolation. Our weekly income is just enough for both of us, but not enough for his respite, so I cannot leave his side.

”

“

We are looking at selling our home and moving very far away from family and friends purely to free up equity in our home and reduce our outgoings (mortgage) but we could end up even more isolated.

”

(iii).



Out of Pocket Expenses and Additional Costs Associated with Caring

Caring households undoubtedly face additional costs associated with the purchase of goods and services relating directly to their caring role. Some carers pointed to higher energy bills as a result of the person they care for needing a warmer than average house because they couldn't regulate their own body temperature. Others reported higher than average use of household items such as washing machines or the costs involved in making long trips for specialist hospital care or special schools.

When asked if they face any additional costs associated with providing care:



Higher utility bills



Extra costs on prescription charges



Extra costs for housing adaptations



Extra costs associated with specialist foods or drinks



Facing higher food bills

42% of carers said they face additional costs for household cleaning and personal care items such as disinfectants, disposable gloves and aprons. One in four (27%) paid for incontinence pads. Incontinence and frequent laundering contribute to the need for the regular replacement of bedsheets, with 38% of carers stating that they frequently have to purchase replacement bedsheets. One in three (34%) also reported spending additional money on clothing for the person they care for as a result of frequent washing, ripping and tearing or having to pay for specially made clothing to make it easier to put on and take off, for example. These additional costs are not insignificant, with **almost 1 in 3 (31%) spending more than €150 per month from their own pocket to meet these additional expenses.**

“

My daughter has a compromised immune system so cannot use public transport. It's a huge expense running a car on such a small income.

”

“

It's hard because my son only likes certain foods and doesn't like wearing clothes indoors so I have to keep the heating on and some weeks can't afford shopping.

”

“

We have to do more care ourselves within the family to save on the cost of private carers.

”

“

The heating costs are crippling as the person I care for needs constant heat. We're not entitled to the Fuel Allowance.

”

A further significant cost associated with caring is the lost or reduced earnings that a family carer forgoes as a result of taking on caring responsibilities. This is referred to as the 'opportunity cost of caring'. The next section focuses on some of these lost opportunities.

RECONCILING CARING AND PAID EMPLOYMENT

Taking on caring responsibilities while also working in paid employment can present significant challenges for carers and their families. Often, many carers are forced to reduce their working hours, forgo promotion opportunities, taking a job with less responsibility or leaving their job entirely to provide care.

In Ireland, the majority of family carers (57%) are in the labour force⁸. Family Carers Ireland estimate that as many as 1 in 9 employees juggle paid work alongside a caring role. More than 1 in 4 (28%) of the carers who responded to the survey are in this position. This figure rises to 30% amongst the 18-65 age group.

Carers working outside the home, including those over 66, can be broken down further as follows:



Full-time employees



Part-time employees



Full-time self-employed



Part-time self-employed⁹



THREE IN FOUR
75%

of full-time workers juggle work while providing over 50 hours of care per week. Some carers are effectively carrying out two jobs, finding themselves under considerable pressure.

The consequences of balancing paid employment with caring responsibilities without adequate supports is clear. More than half (55%) of the carers responding to this survey had given up work to care, with a further 23% reporting they had reduced working hours to support the person they care for. 16% used annual leave to care. More than a quarter (27%) turned down training/educational opportunities and 14% have turned down a promotion or taken on a job they are overqualified for in order to fit around caring responsibilities. 5% said they work the same hours but their job has been negatively impacted by having to juggle appointments with paid work or through tiredness or stress, for example. 7% have changed industry and 5% have retired early. Just 3% said that caring had no impact on their ability to work.

“

I have had to decline many positions as a clinical nurse manager as they required me to work full time and/or shifts, which I can't do with my caring role.

”

“

In the past I worked full-time then went to part-time, but ended up having to give up work as my parents' illness progressed.

”

Carers who have given up work, reduced their hours or retired early gave the following top reasons for doing so:

- 59% did not have enough time to do everything.
- 58% said it was the stress of juggling work with care.
- 26% said services needed for the person they care for were not available.
- 15% could not negotiate suitable working hours.
- 14% reported insufficient leave available to manage caring and paid work.

⁸ CSO, 2016. Profile 9 Health, Disability and Carers.

⁹ Doesn't add up to 100% due to rounding.

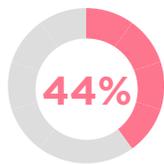
Losing carers from the workforce is not only damaging to individuals and their families, but also detrimental to employers and the wider economy. Reflecting the loss of valuable skills and experience, 1 in 5 (22%) carers responding to the survey said their skills were out of date due to time out of the workplace. Almost half (47%) had been out of work for five years or more as a result of caring and 1 in 5 (20%) have been out of work for 13 years or longer. Only 3% of carers said caring had no impact on their capacity to work.

Unsurprisingly, carers' financial circumstances can be negatively affected when they have to leave the labour market or change their working hours, often leading to permanent damage to carers' careers and earning potential. When asked to estimate how much they would now expect to earn if they were not a carer, almost **1 in 3 (29%) carers believe they have lost between €15,000 and €30,000 a year**, whilst a further 1 in 5 (19%) estimate a loss in earnings between €30,000 and €50,000.

Support for family carers who balance paid work with care is critical to their ability to successfully manage both roles simultaneously. **When asked to choose what policies would most help working carers remain in the workforce:**



Flexible working hours



Policies allowing reduced hours



More support from managers would help carers remain in the workplace



Working from home opportunities¹⁰

As our population ages with a commensurate need for an increase in the number of family carers available to provide care, the risk of losing carers from the workforce will increase. Family Carers

Ireland is working with a number of large employers to improve supports for working carers and to enable them to remain in employment. This not only benefits carers, but also delivers real benefits to employers. The Caring Employers Programme assists employers to build a supportive and inclusive workplace for staff who are, or will become, carers.

I can't work unless there is a Homecare Package in place.

If I wasn't caring I would be working full time and eligible for a pension when I get older. But because I'm an unrecognised carer my entitlement to a State Pension may be at risk.

When my son turned 18, he lost his transport. I had to give up my job to take him to his training centre.

I will have no pension due to years of caring. I'm worried to the point of anxiety/panic about my future years.

I'm now on a career break as I've no more leave entitlement. So I'm trying to set up a private business in which I can work around appointments and sickness and build in time to sleep during day if I'm up through the night.

I had to give up my career to care for my son full-time. It's been years now. No career. No income. No pension. Nothing left.

I had to leave work to care for my daughter. My mother used to mind her after day care centre but it got too hard for her. I miss work and the social aspect of it very much.

Working full time and caring is stressful and tiring and affects my energy and health. I am less likely to move role or job as I could not cope with the stress on top on caring. I feel I have lessened my career opportunities as a result.

¹⁰ Covid-19 should have some impact on working from home opportunities and perhaps allow for more opportunities to do so.

ACCESS TO SUPPORTS AND SERVICES

Ireland’s health and social care system depends on family carers. Without the estimated €10 billion in unpaid care they provide each year, the health service would collapse. Despite the enormity of their contribution, too many carers are going without the support they need and too often they are going without any support at all.

Services such as day centres, homecare and respite are clearly there to assist people who require additional care—but these services often benefit carers too. Despite their importance **75% of carers experienced difficulties accessing services for at least one of the people they care for. Half (51%) had difficulty accessing respite services specifically.** Of those who encountered problems accessing respite, 1 in 3 (34%) do not know how to access respite and 25% said they cannot afford it. 19% said respite is not available in their area or is too far away.

ONE IN FOUR 1 in 4 (23%) carers have seen a decrease in the level of service their loved one has received during the past year (prior to the COVID pandemic). **23%**

It is important to acknowledge that access to services does not automatically equate to a break for carers, due to inadequate allocations or the in loco parentis rule¹¹, for example. Half of carers (57%) who were able to access support said that services do not allow them to take a break. 59% said that the services the person they care for receives does not give them time to look after their own health needs. 61% said these services do not enable them to engage in paid work.

“I was caring for my son and my mother who had terminal cancer. The only help I got was 15 minutes a day to help give my mother a bath. Neither could be left alone and there was no one else to help. In the end I lost my job.”

Family and friends can often provide practical support and can be a source of comfort for family carers. However, when asked about the level of support they receive from family and friends with regard to caring, **almost one third (30%) said they do not receive any help.** A further 30% only receive occasional support from family and friends. Since many struggle to access services, this suggests that a significant number of family carers care alone, with limited support from either the State or family and friends.

“I had no information on respite care for the first ten years of caring.”

“There’s not enough respite to give carers a break. There’s no such thing as time off for the likes of me. We depend so strongly on respite to keep our mental health just as much as a rest. However we are rarely given that break for both ourselves and our family member.”

“I’m constantly told that there are little to no facilities in our area or that we would have to wait years to get day services or respite.”

Missing Out on Financial Supports

The National Carers’ Strategy highlighted the importance of identifying carers who may be unaware of or even reluctant to recognise their own caring role. This is a critical issue – many people providing care do not see themselves as a carer but instead as a parent, son, daughter, partner or friend who is supporting someone they love. Not identifying as a family carer can be a significant barrier to accessing relevant financial and practical supports.

¹¹ Under this rule, parents/guardians of a sick or disabled child, who are in receipt of a home care package, are required to be present with home care staff at all times. This rule has impacted on carers and is further contributing to an environment where parents feel trapped in their own home.



70%

of carers felt they had missed out on support as a result of not getting the right information and advice early in their caring journey.

Of those who felt they missed out on support, 75% were not given advice about entitlements and 57% did not realise support was available. More than one third (37%) incorrectly believed they would not be entitled to support, even though they were.

One in 4 (23%) recognised themselves as a family carer immediately. However for 61% of respondents, it took more than one year for them to identify as a carer, with 17% taking over eight years to recognise their role. The length of time it takes for a carer to see themselves in their caring role can make a huge difference. Those who missed out on support are more likely to have been in debt as a result of caring (34%, compared to 30% of all other carers). Even a few months of missed financial supports can make the difference between families being able to adjust to the financial impact of caring or falling into debt, or families feeling supported to care or reaching crisis point as a result of caring alone. Missing out on financials supports can also have long term implications by leaving carers at risk of a reduced pension or indeed no pension entitlement when they reach retirement age due to an insufficient number of PRSI contributions.



34%

of those who missed out on support have been in debt as a result of caring.

Parents of children under 18 were more likely than other carers to feel they missed out on support because they didn't receive the right advice or information (73% compared to 70% of other carers). 68% of parents of children over 18 feel they missed out and 13% of these did not recognise themselves as carers for over eleven years.

“

I was repeatedly told I couldn't get any supports after my Carer's Benefit ran out only to discover four years later that I could have been entitled to the respite care grant [Carer's Support Grant].

”

“

I still do not know what I'm entitled to, I know there is DCA [Domiciliary Care Allowance] but I'm so exhausted and stressed I cannot fill out the application.

”

“

I didn't consider myself a carer even though I'm knowledgeable about services. It was my friend who told me I was.

”

“

I found out about benefits by accident and had to fight for everything.

”

“

There's very little or no information given to first time carers about what support is actually out there or where to go to for advice and help. Health professionals across the board do not provide this information for carers either.

”

“

I initially took a career break to be able to care. Then I was told about Carer's Leave. But because I had taken a career break, I was ineligible for paid Carer's Leave after working for 16 years.

”

CARER HEALTH AND WELLBEING

Caring for a loved one is associated with a number of benefits, such as emotional rewards, personal growth and a sense of accomplishment in the caring role¹². However, research also indicates that caring can have significant adverse impacts on a person's health and wellbeing¹³. 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	General Population aged 15 and over ¹⁴
Very good	6%	41%
Good	32%	42%
Moderate	48%	14%
Bad or very bad	15% ¹⁵	3%

Over 8 in 10 (83%) of people aged 15 years or older in Ireland perceive themselves to be in good or very good health. Only 4 in 10 (38%) family carers responding to this survey reported being in good or very good health. Almost half (45%) of carers surveyed have a long-term illness, health problem or disability and 80% of these carers feel their caring responsibilities have affected their illness or disability.

Considering the personal cost that often comes from providing long hours of care, it is not surprising that 16% of those caring for over 50 hours a week and 20% of sandwich carers reported bad or very bad health.

In terms of their quality of life in the future, almost one third (29%) expect their quality of life to decline in the next twelve months. Those caring for less than one year were more likely to expect their lives to get worse, highlighting the importance of support at the early stages of the caring journey. 60% of all carers thought their quality of life would stay the same, whilst only one in ten (11%) thought it would get better in the next year.

When asked if their GP knows about their caring role, only 11% said their GP knows they are a carer and has offered extra support. Given that GPs have the potential to reach the majority of carers throughout the care trajectory, there is an

opportunity for carers to really benefit from the care and support of primary care teams. Indeed, international research has highlighted the importance of a GP as the first point for contact for carers when seeking advice and information, with some research suggesting that GPs were the main source of formal support associated with reduction of burden for family carers¹⁶. As such, the role of the GP cannot be overstated.

“
The stress of doing it alone is taking a toll on me emotionally, mentally and physically.”

“
I myself am at present recovering from a significant health event while within weeks my mum had a fall and a prolonged hospital admission...I am now her full-time carer in my home whilst also trying to recover myself.”

“
My wife had a physical and mental breakdown as a result of being primary carer for our child. I retired early to look after both and give my wife a chance to recover her health.”

“
The pressure of caring and juggling affected my own physical and mental health and I had to give up work.”

¹² 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.

¹³ 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.

¹⁴ Central Statistics Office, 'Irish Health Survey 2015' <https://www.cso.ie/en/releasesandpublications/ep/p-ihs/irishhealthsurvey2015/ct/> [accessed 25th April 2019]

¹⁵ Doesn't add up to 100% due to rounding.

¹⁶ Parmar, J, Anderson, S, Abbasi, M, et al. (2019) Support for family caregivers: a scoping review of family physician's perspective on their role in supporting family caregivers. *Health and Social Care in the Community*. 28(3):1–18. doi:10.1111/hsc.12928.

Changing the Legal Landscape for Family Carers: The Assisted Decision-Making (Capacity) Act 2015

Almost five years have passed since the Assisted Decision-Making (Capacity) Act received presidential assent. Described as a ‘Broadly lauded as a ground breaking piece of legislation’, the signing into law of the Capacity Act was a significant milestone in Irish legal history¹⁷. Essentially the Act means that those who experience difficulty making decisions about their finances, healthcare or living arrangements, for example, will be helped, where possible, to make these decisions for themselves. 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 legislates for. But by virtue of ‘volunteering’ to act as a decision supporter, they are accepting very considerable additional responsibilities, on top of what is often a round-the-clock caring role.

Given that family carers are one of the cornerstones of the Act, it is concerning that the majority of family carers who responded to this survey have little or no understanding of the Act or the implications it has on them or the person for whom they care.

Of those who were aware of the Act;



62%

said they need more information and advice about the Act and its provisions.

“

I understand the principle behind this, but it is poorly understood in general.

”

“

I know nothing about it. Recently I had difficulty with our family GP who refused to give me my mother's prescription because my mother who has advanced Alzheimer's had not signed a consent form.

”

“

I have not heard of this before.

”

“

I'm aware of the Act but don't know whether it applies to my son as his intellectual disability is profound

”



THREE IN FOUR

73%

carers are not aware of the Act.



13%

said they are aware but do not understand it.

¹⁷ 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/>



CARING THROUGH COVID: LIFE IN LOCKDOWN

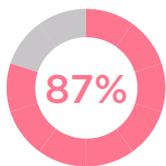
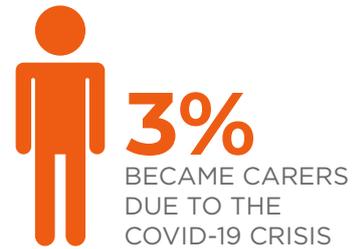
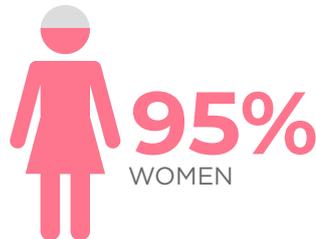
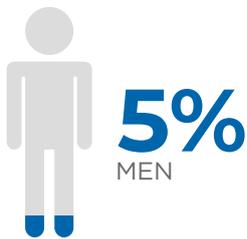
The following section explores the findings from the Caring Through COVID research conducted between April 14th and May 5th 2020, examining family carers' experience of caring during the Covid-19 pandemic. This research was published in May 2020.



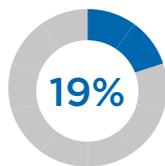
CARING THROUGH COVID: PROFILE OF RESPONDENTS



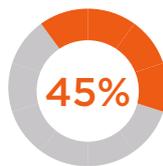
AGES RANGE FROM



Living in same household as the person they care for



Caring for someone not in their household



Caring for children under 18



Caring for an adult child



Caring for parents/parents-in-law



Caring for their spouse/partner

This sample is not representative of the wider Irish carer population.

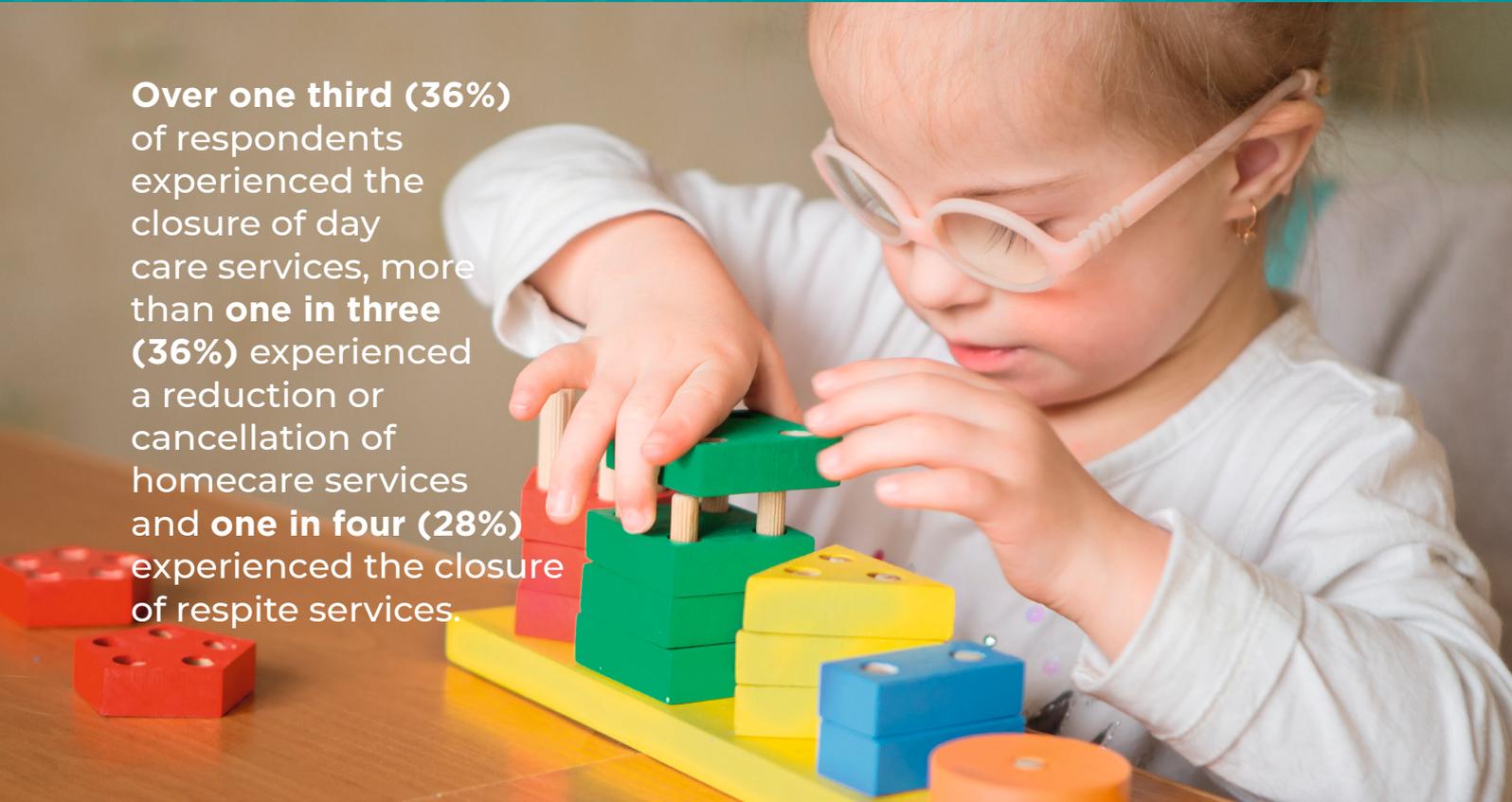
CARING THROUGH COVID KEY FINDINGS

Family Carers Ireland's survey into the experiences of **1,307 family carers** who are caring during COVID-19 found that the outbreak is having a profound impact on the majority of carers' lives. Not only are they caring without practical supports, they are also struggling financially and are worried about what the future holds for them and the people they care for.



IMPACT OF THE WITHDRAWAL OF SERVICES ON FAMILY CARERS

Over one third (36%) of respondents experienced the closure of day care services, more than **one in three (36%)** experienced a reduction or cancellation of homecare services and **one in four (28%)** experienced the closure of respite services.



Prior to the COVID-19 pandemic, many carers already experienced difficulty accessing important supports such as homecare or respite¹⁸. This has been clearly exacerbated by this crisis, with many carers and their loved ones going without vital services throughout this emergency.

Before COVID-19, many family carers were already providing high and unsustainable levels of care⁴. However, during the crisis and in the absence of vital services, many carers' workloads have increased - many are caring seven days a week, round the clock and often throughout the night. Many respondents described the exhaustion of providing constant care and spoke of the loneliness and isolation of caring during the crisis. Having time to look after their own health and wellbeing was a challenge for many carers before the outbreak, however this has been now been intensified, **One third (37%) are worried about becoming more socially isolated, 60% worry about a decline in their**

own mental health and wellbeing and 15% feel they are not coping during this pandemic time. Many of these carers highlighted the need for respite and emotional support given their intensification of their caring role had intensified to such a degree as to become unmanageable.

PRIOR TO THE CORONAVIRUS OUTBREAK, 75% of carers had trouble accessing services for the people they care for.

DURING THE CRISIS AND IN THE ABSENCE OF VITAL SERVICES, MANY CARERS' WORKLOADS HAVE INCREASED

¹⁸ 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>

Whilst caring during COVID-19 has clear challenges for many carers, some respondents feel that not much has changed for them during the lockdown.

This is because they feel accustomed to the restrictions that can come with caregiving such as difficulty leaving the house, social isolation and caring with limited support. Nonetheless, the vast majority of carers feel that the withdrawal of supports during the pandemic has placed even greater pressure on them.

The people I care for are becoming more emotional, more melt downs, outbursts and aggression. Having no break or support is affecting my own well-being which affects the level of care I can give.

“

I was already burnt out from caring 24/7 but now doing it without school, respite, home support and night nurses I'm totally exhausted and since we can't see any other family I feel forgotten.

”

“

My mental health is suffering, I have always been strong and a solid 'coper'. I have navigated many challenges in life but this is by far the most difficult. I have many skills and know how to keep busy and healthy. I keep in contact with friends and family and I practice mindfulness and I meditate. Despite possessing these skills, I feel weak, frightened and lonely most of the time.

”

I'm caring 24/7 without a break or any respite while in a state of constant fear.

Exhaustion. It's physically and mentally more demanding than normal.



CONCERNS OVER LOVED ONE'S HEALTH AND WELLBEING

The impact of lockdown restrictions, including the withdrawal, reduction and cancellation of services has led to a loss of routine for carers and those for whom they care. Carers are worried about the impact these changes are having on the cared-for person's health, psychological wellbeing and emotional development not only now but in the long-term.

A knock-on effect of COVID-19 is that routine medical appointments and therapies such as speech and language, occupational therapy, physiotherapy and psychology are being cancelled or postponed. **Almost two thirds of respondents (63%) have experienced delays in or cancellations of medical appointments, treatments or surgery and nearly one in four (23%) experience delays in responses from healthcare professionals regarding non-COVID-19 related health issues.** The closure of schools is also of significant concern as many vital services are delivered to children with special needs through the school system, e.g. speech and language therapy and occupational therapy.

Concerns about long-term regression and relapse as a result of the closure of services and halt to vital therapies such as behavioural therapy were prominent in carers' responses.

"I'm worried about being hurt badly by one of my daughters. Her aggression has escalated hugely since the closure of school and restrictions. I'm black and blue."

"Keeping my adult child engaged with activities is a big challenge. I'm terrified she will withdraw and regress without services, supports, courses and friends."

"I'm watching my kids regress before my eyes and there's nothing I can do to stop it."

"As a result of my child's underlying conditions, she cannot attend hospital or GP surgery as the risk is significant. She is having repeated issues which we are trying to manage with GP."

"I think his inability to continue his outings (bridge, church, community dinner) has increased his dependency on me and I think this will be irreversible. I think my caring role will be more full-time from now on. My availability to work will be diminished. Because I don't qualify for Carer's Allowance, this is difficult."

"My daughter's supports were almost exclusively provided in school. Since school closed there has been no replacement."



63%

are worried about a decline in the health and wellbeing of the person they care for.



56%

expressed concern about their loved one displaying increased challenging behaviours, as a result of a lack of routine for example.



56%

are worried about the person they care for becoming more socially isolated as a result of the pandemic.

CHALLENGES OF CARING DURING COVID-19

Access to appropriate Personal Protective Equipment (PPE)

Many carers are understandably concerned about exposing themselves and the person they care for to the coronavirus.



As a result,
14%

of households made the difficult decision to temporarily suspend the

homecare supports they normally receive in order to reduce the risk of infection by homecare workers, placing significantly more strain on themselves. Many carers are concerned about homecare workers coming into their homes without adequate PPE and the subsequent risk of spreading infection. Carers are also concerned about their own access to PPE with **47% unable to access appropriate PPE during the pandemic**. These carers are extremely worried about the resultant risk to both themselves and the person they care for.



86%

worry about the person they care for becoming infected



84%

fear getting the virus themselves



47%

do not feel prepared to provide care to someone who has tested positive for COVID-19



33%

said they are somewhat prepared to provide care to someone who tested positive for COVID-19

I chose to cancel all home supports in March as I am so fearful of COVID-19 coming into our home. I do not have a back-up plan should I get sick. There is simply nobody to take over from me. At the same time I do feel that the often 13 hour days I currently find myself working, without any let up, leave me concerned for my own physical health. This is something I worry about daily.

“

The nurse said they don't provide PPE to carers, that it's for front line staff.

”

“

I worry that I'm doing the right thing by continuing to have carers coming in to help.

”



Lack of contingency planning for family carers



84%

of respondents worry about not being able to care for their loved one due to getting COVID-19.



75%

are extremely worried about what would happen to the person they care for in the event of the carer contracting COVID-19.

HSE guidance for family carers advises that **they develop contingency plans** in the event they are unable to provide their usual care due to becoming ill or having to self-isolate. Despite this guidance, **many carers responding to the survey feel unable to put contingency plans in place.** Some do not have family members or friends nearby who can take on their caring responsibilities, whilst the complexity of the care needed is a barrier for others. Comments show that carers are extremely worried about the lack of an explicit contingency plan from Government regarding how gaps in care caused by the self-isolation or illness of family carers would be addressed. These issues are especially apparent amongst the 10% of carers who had already been advised to self-isolate—the majority of these felt they had no option but to carry on providing care, despite the risks to their loved ones, because they simply did not have anyone else to take over their caring responsibilities.

“

I continued caring for my daughter whilst I had suspected COVID-19. We were not tested or confirmed. The GP knew I continued to care, changing nappies with heavy chest pain, exhaustion, etc. It was horrendous. I got masks from a friend and Family Carers Ireland sent PPE but I had all this whilst also sorting out my will and documents.

”

“

There's a lack of a clear plan by the Government on how families like mine would be helped if the carer is ill and needs to self-isolate. There is no plan.

”

“

I feel like I am in lockdown within a lockdown. Being a family carer is very challenging at the best of times. The limited support that we might receive is now gone, at a time when we need it the most. I feel that we have just been forgotten about. I am terrified that I will get COVID-19. There is no-one else to fill my role. What happens then? Not knowing keeps me awake at night. When I do sleep, it gives me nightmares. The uncertainty fills me with fear.

”

Access to food, prescriptions and other essential supplies

While many supermarkets have introduced measures to help vulnerable people and family carers to shop safely, many carers reported they are facing challenges accessing food, medication and other essential supplies.



26%
worry about their access to essential supplies such as groceries.



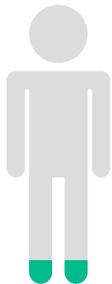
20%
are concerned about access to essential medications and health products.



7%
experienced a shortage of essential care products such as incontinence pads.



6%
are finding it difficult to source specialist foods or drinks.



13%
report delays in accessing repeat prescriptions and/or medications.

“
Shopping is something of a challenge. We don't necessarily receive all the foods we've ordered in a delivery. Under normal circumstances this would not be a difficulty. However, as my mother is on a specialist diet, not all foods are suitable.
”

“
Shopping for groceries is a nightmare. Have the stress of looking online daily for a delivery slot. We're cocooning as the person I care for is immunocompromised.
”

“
We are running low on incontinence wear for my child but have no contact with our Public Health Nurse.
”

“
I'm unable to get food shopping delivered. One of my sons is peg fed and I'm finding it difficult to access the correct feed for him.
”

FAMILY CARERS UNDER INCREASED FINANCIAL PRESSURE DURING COVID

Before the COVID-19 outbreak, many family carers already faced significant financial difficulty as well as additional expenses associated with caring.

Research carried out by Family Carers Ireland in the weeks prior to the pandemic found that two in three (70%) respondents found it hard to make ends meet and one in five (19%) said they could only make ends meet with great difficulty. Given the significant economic implications of COVID-19, these financial challenges have become even greater for many family carers.

The coronavirus is likely to have a lasting impact on many people's finances. This research on the experience of caring during COVID-19 found that more than one third (39%) of respondents worry about the financial costs and implications of the pandemic. Almost half (48%) requested more financial support to help them with the additional costs of caring during COVID-19.



48%

requested more financial support to help them with the additional costs of caring during COVID-19.

“

Being a carer has decimated us financially. Now, with COVID-19 job loss, our money is even tighter. The need to buy extra groceries, pay for higher heating bills, medication, home physio aids, games and aids for motor skills development has cleared out our savings.

“

We are really feeling the financial burden. Shopping in the local shops is so much more expensive and some of the bigger supermarkets have increased their prices. As the people we care for now are at home all the time our utilities have increased - we have to have heat all the time.

”

“

I've lost my part-time job due to being in the high risk category resulting in the loss of earnings and getting into debt¹⁹.

Many carers are also experiencing an **increase in household spending** since the start of the pandemic. Carers described spending more money on food and utilities because they are unable to access larger grocery stores and family members are at home throughout the day.

“

I've very little money to buy the basic necessities. I cannot go to the Community Welfare Officer for help because I'm terrified of bringing the virus back to the person I care for, so we've no oil or coal to keep ourselves warm.

”

“

We've had to cocoon, so we order everything online, which means ordering from a more expensive supermarket, which comes to over twice the price of our usual shop. Add in the extra costs of being home, PPE, cleaning supplies, it's very difficult to make the Carer's Allowance stretch to cover all these added costs.

With so many family carers already finding it difficult to make ends meet even before this crisis, these additional costs are likely to make their financial position even more precarious.

¹⁹ Family carers who had to give up work to protect the people they care for are not entitled to the Government's COVID-19 Pandemic Unemployment Payment.

CONCERNS DURING COVID

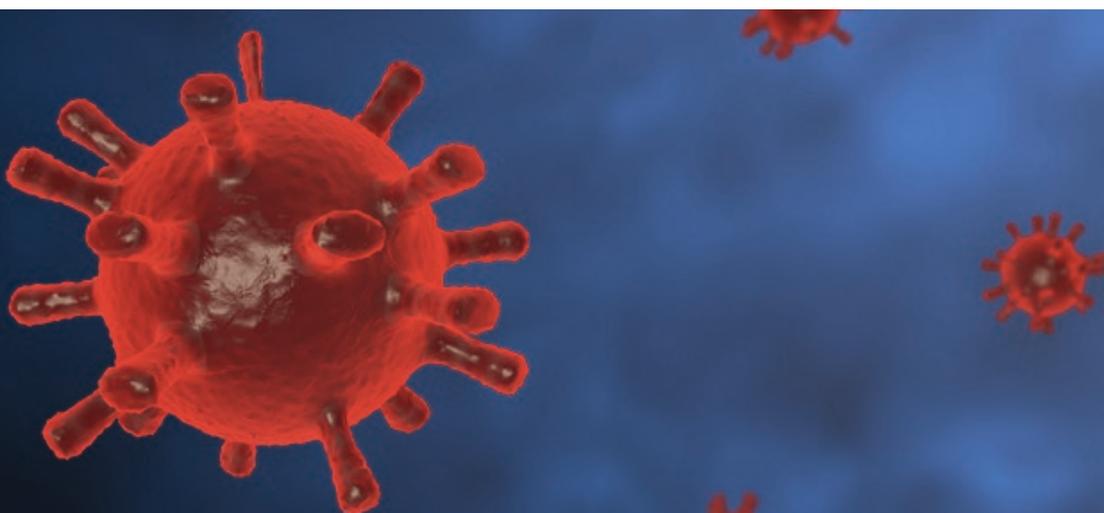
Whilst caring for someone can be a rewarding experience, the impact on carers' physical and mental health has been illustrated in previous research. As well as the usual stresses of making sure that the person is well looked after, the COVID-19 pandemic has added additional pressure and worry on carers. Carers were asked to describe their greatest concerns whilst caring during COVID-19. Respondents shared five significant concerns in their open-ended responses. Carers' top priorities were:

1	Concerns about behavioural problems and long-term decline in the mental and physical health of the person they care for
2	A decline in their own physical and mental health as a result of the increased stress of caring without supports and the additional responsibility of keeping the person safe and well
3	How to keep the person safe from the virus, especially when having to leave the home for groceries or work, without adequate PPE
4	How to continue caring without adequate supports such as respite, homecare and special schooling, and the worry that these will not be restored in the long-term
5	The lack of clear and specific guidance regarding what would happen to their loved one should the carer or cared for person get sick

“
My biggest concern is who will care for them if I can't or their Dad can't. None of our family will want to care for them if they have it. All I've been told is that things will be put in place. But this is the worst nightmare, not knowing and having to leave your disabled children on their own. Worry is the worst part of this.
”

“
I don't know what impact this is having on my child. The absence of services and intervention could cause lifelong problems. We simply don't know, it's so concerning.
”

“
I'm concerned about my mental health during this time. This is further hampered by the withdrawal of services in my home. It frightens me at times as to my ability to keep going.
”



PROTOCOLS FOR HOSPITALISATION

As well as a lack of contingency planning, many carers were concerned about the practical arrangements in the event their loved one needed hospitalisation. These carers wanted clarity on whether they would be allowed to remain with the person they care for should they be admitted to hospital, particularly where the person relies on their carer to communicate on their behalf or where the carer is best placed to understand the person's condition and care needs. At the heart of this issue is the need to reconcile supporting the cared-for person with infection control procedures in the hospital setting. On 20th April, following representations from Family Carers Ireland amongst others, the HSE issued new guidance to hospital clinicians about supporting a person with a disability that expressly highlighted the role of family carers as a source of assistance and support particularly in understanding an individual's behavioural responses to illness/pain/discomfort. Managers were encouraged to consider the situation of family carers sympathetically on a case by case basis.

I'm so worried about being separated from my child should he get the virus and be hospitalised. He is utterly unable to look after himself or even express his basic needs.

Some carers raised concerns about the allocation of life-saving resources in the event the health service experienced a shortage in supply of ICU beds. These carers are very worried that their loved one would not receive life-saving treatment, such as ventilators, because of their disability or underlying health condition. On 7th April, the Department of Health published supplementary guidance on Ethical Considerations relating to Critical Care in the context of COVID-19. This information related specifically to the rights of people with disability and reiterated that people with disabilities must be equitably cared for in the event that they contract the virus and become critically ill. The document stated that people with physical and intellectual disability have equal rights to the highest attainable standards of health and to a high standard of healthcare.

I'm worried that my mother would have to go to hospital and I may not be allowed to accompany and care for and advocate for her whilst there. I care for her 24/7. She needs assistance mobilising with frame, washing, toileting, getting up and down, administering medicines, etc. She would be hugely distressed and lost and confused in a hospital on her own and unable to communicate sufficiently with doctors or nurses.

We need the Government to issue clear instructions that people with disabilities will be guaranteed their human rights to medical care if they contract the virus.



BALANCING WORK AND CARE DURING THE PANDEMIC

A number of family carers who responded to the survey are also healthcare workers. This group are very worried about the risk of exposing household members to the virus as well as describing the practical challenges of balancing their front-line work with childcare responsibilities.

10% of respondents fear losing their jobs or businesses as a result of COVID-19. Some carers feel they had no choice but to give up work due to the risk of infecting a medically vulnerable household member. However, because they were not formally laid off by their employer, they are not eligible for any of the emergency pandemic social welfare supports.

I have to use sick days as I'm afraid if I go to work that my Dad will be at a higher risk.

My partner is taking time out of work to protect our daughter and is getting no financial support which adds to the stress of caring."

I am a nurse, my husband is also an essential worker. We both have to go out to work. We both take turns to care. There's a very high risk of bringing COVID-19 home to at-risk people in the house. Nothing we can do about it. Also as I have had to work more due to crisis I am physically exhausted and then having to pick the pieces up and care for the house when I return. I feel my physical health is at risk as I am burning the candle at both ends and not in a nice way.

Some working family carers have been forced to use sick days or annual leave to balance their work and caring responsibilities.



PRIORITIES FOR GOVERNMENT

The vast majority of family carers who responded to the survey feel they have not been sufficiently recognised in the national response to coronavirus.



61%

think there is not enough information and advice targeted at family carers about COVID-19



74%

feel Government has not responded well to the needs of family carers during the pandemic.

“ I feel forgotten and invisible by our Government. It’s only a matter of time before the Government makes cuts to services, supports, allowances, medical cards, etc. I wonder will I be able to continue to care? I’ve my own health concerns, will I make it? Will I be here to care when COVID is over? ”

“ There are no supports put in place by the Government to help carers with a child / family member with severe disabilities. ”

Carers were asked to describe what actions the Government should take now to help family carers through this emergency. The following reflect the top five responses:

1. Recognition of the role of family carers as critical in protecting vulnerable people from COVID-19 by:
 - (a) Including family carers in the priority list for testing for COVID-19
 - (b) Giving appropriate personal protective equipment (PPE) to family carers and the home care workforce. On 21st April the HSE changed its guidance to require all home care workers to wear surgical masks when conducting Home Support visits, in addition to other measures to reduce the risk of transmission of infection.
 - (c) Providing official carer identification in order to be able to prove that they are a carer (for Garda checkpoints and supermarkets);

2. Provide additional financial support to reflect, for example, the additional costs of caring;

3. Publish clear and targeted guidance for family carers;

4. Clear contingency plans setting out what alternative care arrangements will be put in place if a family carer is not able to continue to provide care due to showing symptoms or testing positive for COVID-19;

5. A roadmap towards the reinstatement of homecare, respite and support services at the earliest opportunity.

LONG-TERM IMPACTS OF COVID



36%

think there will be long-term impacts of the pandemic on their caring role specifically.



43%

of carers worry that services such as respite and day care would not be restored to their previous level after the crisis.

Many family carers are worried about the long-term impact of COVID-19 on the Irish economy, including cuts to social welfare and health and social care services.

A number of carers expressed concern about the phased lifting of restrictions and the ongoing vulnerability of the people they care for.

“

Carers have never had it easy and if cuts come in the future, we will be hit again. Will we get our respite hours and home supports back? With a recession coming up, will we be forgotten?

”

“

When restrictions are lifted, how can I maintain cocooning for a very vulnerable person?

”

“

I'm worried that the limited funding for day services and respite will be cut or withdrawn, leaving us under more pressure.

”

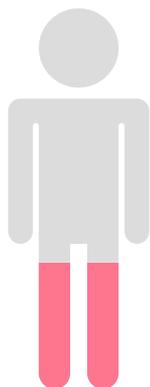


As we move through the phases, it won't be safe to go out to my day job, with a medically fragile child at home with a life limiting condition. However, I will have no official excuse to stay in.



SOCIAL SOLIDARITY WHILST CARING DURING COVID

Whilst the COVID-19 pandemic is a very worrying and difficult time, it has brought about some wonderful displays of social solidarity and community support.



34%

carers have experienced some positive displays of social support and kindness during the pandemic

- neighbours dropping off food, local pharmacies and shops ensuring delivery of essential groceries and medications, family members in touch more often and an increase in empathy from others about the

everyday reality of being a family carer. Some feel less isolated than before as a result. There is hope that this empathy could turn into positive reforms for family carers into the future. However, despite evidence of increased community spirit and social solidarity, **52% of respondents have not felt such positive effects of the pandemic**, with many saying they were completely overwhelmed, isolated and had received little support since the crisis began.

“

Family members who don't live with us are shopping and looking after all our needs, also neighbours are checking in by phone to see if we're okay for everything.

”

“

We are on our own. Full stop. Isolated. Lonely.

”

“

I have felt general community spirit but nothing to help me specifically with my special needs child. We are alone in this and no one to help or care while he regresses on a daily basis.

”

”

Lots have offered to help with shopping. Local community support services is a great service something that should be provided long term to family carer.

”

“

People are more aware now how hard it is to care for an elderly parent.

”

FAMILY CARERS IRELAND: HOW WE ARE SUPPORTING FAMILY CARERS THROUGH THE COVID CRISIS

Before COVID-19, thousands of family carers across Ireland were already experiencing financial difficulty, social isolation and ill-health. Carers are now facing even greater pressure as a result of the pandemic; caring without vital services whilst trying to keep themselves and the people they care for safe and well. Family Carers Ireland has responded to this crisis by developing a coherent contribution to the national response effort. These efforts will continue over the coming weeks and months, however to date they have included:

- **Working collaboratively with Government and state agencies to ensure family carers are recognised as a vulnerable group throughout this crisis and that their needs in relation to information and guidance, financial supports, access to PPE, access to COVID-19 testing and contingency planning are in place.**
- **Engagement with the Department of Employment Affairs and Social Protection (DEASP) to highlight the financial challenges facing carers as a result of the pandemic.**
- **Securing a number of donations specifically aimed at supporting family carers during this unprecedented time including €350,000 from Irish Life, €50,000 from Tesco Ireland and donations from JP McManus, Aspen Grove, PJ Power & Power Property Limerick and Tullamore D.E.W. These donations are being used to:**
 - Deliver in-home respite hours for family carers who need a break from increased caring pressures during and post pandemic.
 - Provide emergency transition cover to address a family carer's greatest fear - 'what happens if I can't keep caring?'
 - Purchase and distribute PPE across the network.
 - Develop new and innovative ways of supporting family carers through online

forums and communities as well as through our Freephone Careline and Intensive Wellness Support Project.

- **Re-designing our Carer Support activities in the light of current restrictions, with new initiatives launched to deliver peer support, training, counselling and information using online and telephone channels (including access to emergency PPE supplies and specialist advice and support on managing COVID-19 in a family caring context).**
- **Designing a structured process to support any family carers who may be struggling in the wake of losing Home Support hours over coming months.**
- **Emergency Card Scheme - this new process will give family carers the assurance that, in the event of a sudden crisis or emergency in their lives, Family Carers Ireland will endeavour to ensure good quality continuity of care for their loved one.**
- **Providing carer identification cards to members who require them to assist with social isolation guidance.**
- **Piloting a new model of intensive assessment and support for family carers of children and adults with a disability who have been referred to Family Carers Ireland by the HSE Disability Services.**

We will also be using this research to advocate for more support for carers from Government and the HSE and to inform our own activities in response to the pandemic.

CONCLUSIONS & RECOMMENDATIONS

The first section of this report provided a snapshot of what caring was like for Ireland's 355,000+ family carers at the start of 2020, just before COVID-19 restrictions came into place. The widespread social and economic impacts of the pandemic prompted Family Carers Ireland to rapidly conduct research in order to better understand the situation of Ireland's carers—this research is covered in the second section of the report. Taking the findings from these two pieces of research together illustrates that many of the challenges experienced by carers before COVID have been exacerbated during the pandemic. Many carers are finding themselves in increasingly vulnerable positions when faced with the additional pressures of uncertain information, unstable finances, limited services and the loss or reduction of social supports.

DECLINING HEALTH AND WELLBEING

At the start of 2020, many family carers report being in moderate, bad or very bad health. Many carers responding to the second survey outlined the impacts of the pandemic on their mental health, with a significant proportion worried about a decline in their own mental health and wellbeing, anxious about the implications of contracting COVID-19 on their caring role, and experiencing increased social isolation.

DETERIORATING FINANCES

At the start of 2020, many family carers were struggling financially. The additional costs of caring combined with the challenges of reconciling paid work with caring were notable pressures prior to the pandemic. The considerable impacts of COVID-19 on employment and the increased costs associated with being at home all day have had an obvious knock-on effect on carers' finances.

INADEQUATE RECOGNITION OF CARERS ROLE

Prior to the pandemic, many carers' expressed that they did not feel adequately recognised nor acknowledged for their caring role. This has become even more of an issue since March, with carers needing recognition of the level of care they provide and a response to their need for support, guidance and protection.

CARING ROLE

Even before the COVID-19 pandemic, family carers were already providing high and unsustainable levels of care. COVID-19 has significantly increased those pressures, with carers identifying increases in the amount and intensity of care provided during restrictions. Concerns about regression, relapse and worsening health as a result of the withdrawal, reduction and cancellation of services and medical appointments is a significant source of concern for carers.

LOSS OF INCOME AND SOARING UNEMPLOYMENT

The challenges of balancing caring roles and employment were clear prior to the pandemic. As a result of COVID, carers, like other members of their communities, experienced and were worried about reduced employment and income. Some were able to work from home during restrictions – whilst this flexibility was often valued, there were considerable challenges for carers maintaining their employment responsibilities while caring for someone at home.

COLLAPSE OF SUPPORTS AND SERVICES

Carers faced difficulties getting adequate access to services prior to the pandemic, with many experiencing decreases in the level of service provision their loved one received. When restrictions came into force, carers experienced the blanket withdrawal of supports such as reduced access to respite and day services, making their situation even more unmanageable and unsustainable than it was at the start of the year.

The findings from the 'State of Caring 2020' and the 'Caring Through COVID' surveys will continue to be analysed and disseminated as part of Family Carers Ireland's ongoing work in advocating for and supporting family carers. Learning from both these surveys will inform the development of future State of Caring surveys which will allow Family Carers Ireland to continue to understand the needs and experiences of carers across Ireland.

STATE OF CARING POLICY RECOMMENDATIONS



RECOGNISE RATHER THAN PATRONISE FAMILY CARERS AND PROTECT THEM FROM FINANCIAL HARDSHIP

- i. **Recognise family carers as a unique group in Government policy:** Family carers are unique from a policy perspective on a number of grounds. Firstly, carers who receive Carer's Allowance are the only recipients of social welfare required to work full-time for their payment – at least 35 hours per week – and receive just €16 more than the basic social welfare rate for doing so; in undertaking this work, they save the State an estimated €10 billion each year that would otherwise have to be met by the exchequer; the State is consistently adding to their costs (waste charges, withdrawal of certain health services and supports) and burden of care (e.g. reporting requirements under the Assisted Decision-making (Capacity) Act 2015); providing care brings with it significant personal costs, including financial, health and wellbeing costs as well as longer term consequences for their pension entitlement; and carers bear additional costs associated with their caregiving role that are not compensated for by the State, as is the case with other groups who receive travel allowances and material and training grants, for example. An Irish citizen fostering a child, for instance, receives a minimum of €352 per week (not means tested or taxable), with weekly payments of more than double this available to those fostering children with complex care needs. Foster parents are also afforded priority access to relevant State services and supports. A family carer looking after their own child with profound needs only receives a maximum rate of €219 per week and access to services for their child(ren) is subordinate to children in foster care. In the context of Covid, carers themselves have often had to cocoon and self-isolate in order to protect their loved one. However, this has been without the support and services offered to other vulnerable groups. As such, Government's treatment of carers must shift in recognition of their unique role, including recognising the additional costs incurred by family carers when assessing eligibility for financial supports, housing grants and third level college grants.
- ii. **Improve access to Carer's Allowance for full-time family carers:** Despite the many plaudits recognising their immense contribution, full-time family carers of people with complex needs continue to be denied Carer's Allowance due to the means test. Only households with a gross total income of less than €37,500 per year will qualify for a full Carer's Allowance. Those with a gross household income of between €37,500 and €62,000 qualify for a much-reduced rate. Any household with a gross income above €62,000 including savings and assets are not eligible, regardless of how considerable their caring responsibilities are. These are families who typically have higher than average household costs due to caring and where very often one member has had to give up work to provide care. Despite increasing steadily during the period 2000 to 2008, the income disregard for Carer's Allowance has remained stagnant for the last 12 years, meaning Government has failed to achieve the commitment set out in Towards 2016 to expand the income disregard for Carer's Allowance so that those on average industrial incomes can qualify²⁰. The failure to ensure that the income disregard kept pace with average earnings is compounded by the fact that the current rate of Carer's Allowance of €219 is €1.50 less than it was in 2009, despite a 6.9 percent increase in the Consumer Price Index (CPI) during this period. In order to deliver on previous commitments made in relation to the Carer's Allowance income disregard, Family Carers Ireland recommend that the disregard be increased from €332.50 to €450 (single person) and from €665 to €900 (couples). We are also calling for the capital formula – which has not changed since 2005 – be increased from €20,000 to €50,000 in line with the Disability Allowance where the first €50,000 of capital is disregarded.
- iii. **Prevent long-term financial hardship by protecting carers' pension entitlement:** It is long accepted that family carers, the vast majority women, are most at risk of falling into a 'pension gap' whereby they don't qualify for a State Pension Contributory due to extended periods out of the workforce to provide care or for a State Pension Non-Contributory due to its modest means-test. While the Total Contributions Approach to the calculation of the State Pension Contributory, due to come into effect in 2021, includes

²⁰Average earnings in Quarter 1, 2020 were €801 while the income disregard for Carer's Allowance remains at €332.50/€665 (couple).

the welcome introduction of up to 20 years of credits for periods of caregiving, this is only granted where the carer has a minimum of 520 paid contributions. For some carers, particularly those with a child who has a disability or illness, remaining in the workforce to secure the 520 contributions is not possible. These carers are further penalised when they also don't qualify for the State Pension Non-Contributory often due to their partners' income or land that is owned in farming situations. While we acknowledge the challenges associated with rectifying this anomaly, none are insurmountable and we urge Government to consider the introduction of a safety net Carer's Pension for the small number of carers affected in line with commitments made in the Programme for Government to improve access to pensions for family carers.

- iv. Deliver a 'Carers Guarantee' to provide a basket of services to carers across the country** Family Carers Ireland welcomes the Programme for Government commitment to deliver a Carer's Guarantee and is calling for annual funding to be made available in 2021 to begin implementation. Now more than ever as we emerge from the COVID pandemic, carers must be given a guarantee of access to a core basket of supports including respite, homecare and training. Inconsistent funding, based on historical funding arrangements, means that access to these supports is currently subject to a postcode lottery whereby where a person lives, rather than what they need, will determine if they can access a service or not. Family Carers Ireland's 'Carers Guarantee' proposal sets out how we will guarantee the delivery of a core basket of services to carers across the country regardless of where they live. These services will include: targeted support groups and networks and access to information and advocacy clinics in local community centres, primary care centres and hospitals; a suite of training programmes ranging from basic care skills workshops to QQI accredited 'Caring with Confidence' training; intensive one-to-one support for carers in crisis; access to emergency respite. If Government fails to ensure the uniform delivery of supports across the country, even more carers will reach crisis point, bringing the sustainability of their caring role into question.
- v. Provide a response fund for family carers experiencing financial difficulty:** The State of Caring 2020 research has shown the very significant struggle many carers experience in trying to make ends meet. A recent project delivered by Family Carers Ireland which included the administration of small grants²¹ demonstrated the immense benefit of targeted short-term supports. These small grants assisted carers to meet the costs of practical items such as sensory equipment or minor housing adjustments to help make their caring role a little easier or ease the financial pressures they face. Family Carers Ireland recommend that a similar model of grant funding be made available through philanthropic funding to enable Family Carers Ireland to continue to provide small grants to family carers helping them to sustain their caring role.



SUPPORT PEOPLE TO BE CARED FOR AT HOME

- vi. Increase homecare hours and introduce a Statutory Homecare Scheme²²:** Government's commitment to introduce a Statutory Homecare Scheme²³, increase home support hours and provide an additional 4.7 million home support hours as part of the HSE's 2020 Winter Plan is welcome and should go some way towards helping the 75% of respondents to the Caring Through COVID survey who have experienced difficulty in accessing services. Deficiencies with the current system of home support, including the cumulative impact of years of underfunding and the resource led nature of homecare has resulted in a pattern of delayed transfer of care whereby people are stuck in hospital or forced into nursing homes when they could have returned home or stayed at home if appropriate care was available. As well as respecting people's preference to be cared for at home, prioritising homecare also makes economic sense. According to the ESRI a 10% increase in per capita homecare supply could lead to 40,000 fewer inpatient beds each year²⁴. With hospitals and nursing homes required to operate at reduced capacity due to social distancing and evidence of people delaying admission to long-term care or leaving nursing

²¹ Grants were funding through donations from Irish Life and Tesco Ireland. See evaluation of Family Carers of People with a Disability: Intensive Wellbeing Review Project at <https://www.familycarers.ie/publications/research-hub>

²² Family Carers Ireland has lobbied for the Statutory Homecare Scheme to be available to adults of ages in need of care, not only older people.

²³ Committed to in the Programme for Government 2020.

²⁴ An Analysis of the Effects on Irish Hospital Care of the Supply of Care Inside and Outside the Hospital <https://www.esri.ie/system/files/publications/RS91.pdf>

home care due to concerns about COVID-19, there will be a commensurate and considerable increase in the number of people needing home care. This will only add to the already overburdened home care service, where prior to the pandemic some 8,000 people were on a waiting list. Family Carers Ireland are calling for the introduction of an integrated statutory scheme for the provision of home and long term care that will include the right to a Carer Needs Assessment and 20 days respite each year for all full-time family carers in line with the annual leave entitlement of paid workers.

- vii. Resumption of disability, community and older persons services:** Even before the COVID crisis, many carers already experienced difficulty accessing supports such as day services, transport, home care and essential therapies such as OT, Speech and Language, Physiotherapy and Psychology. This has been exacerbated with the outbreak of COVID-19 and the subsequent severe curtailment or blanket withdrawal of supports and services. Some seven months into the pandemic many carers are now feeling exhausted, burnt out, isolated and gravely concerned that the supports and services they relied on prior to the pandemic will not return. This fear has been reinforced by statements made in the HSE's Resumption of Adult Disability Services Framework which concedes that 'service capacity will be reduced' (page 4) and 'service users will receive a reduced quantum of supports' (page 5). While Government's plan to draw down €10 million from the National Action Plan on COVID-19 to fund provision of day services for adults with disabilities and support packages for children and young people with complex needs is welcome, it is not enough to address the issue. Notwithstanding the very real challenges that COVID and the subsequent public health guidance present to service providers, the COVID crisis should not be used as a reason to rationalise services, but rather as an opportunity to improve them. Where residential or centre-based services are no longer available, in-home alternatives should be considered but only where they meet the needs of the service user and their family. In a similar way to how childminder and schools have reopened using play-pods, social pods could be considered for adults with a disability who enjoy peer and social support. Where service-based transport cannot be provided, people with a disability and their families must be given a cash payment towards meeting transport costs, as happened prior to 2013 with the Mobility Allowance. Where residential respite is limited alternative models of respite should be considered including supported hotel stays, in-home respite, host family respite, day break services or summer/weekend camps. We cannot allow people with a disability and their families to suffer further as a result of COVID-19.
- viii. Support people to meet the additional costs associated with transport by introducing the Transport Support Scheme:** Promised since 2013 when both the Mobility Allowance and Motorised Transport Grant scheme were withdrawn on the grounds of age discrimination, older people, people with a disability and their carers have been denied access to transport support leaving them either have to meet the cost of transport themselves or go without. The failure to replace these schemes means that the only transport support available to families is the Disabled Drivers and Passengers Scheme, which is available only to those with severe physical disabilities, with no support available to those with an intellectual disability or cognitive impairment. Given the withdrawal of transport to disability day services due to COVID-19 and public health advice to avoid public transport, it is now more imperative than ever that the Transport Support Scheme committed to since 2013 is introduced to help people with a disability meet the additional costs of accessing services.
- ix. Building awareness and understanding of the Capacity Act among family carers:** It is deeply concerning that just 73% of the State of Caring survey respondents are aware of the Capacity Act and its implications on their role as a family carer. A further 13% are aware of the Act but don't understand it. If family members and friends are to fulfil the responsibilities required of decision supporters, then it is critical that a range of measures are in place to inform and support them. These should include dedicated training and information workshops, making available online resources and guides, providing a dedicated help line, delivering information packs and, for more complex cases, the support of a dedicated key worker.

SUPPORTING FAMILY CARERS' HEALTH & WELLBEING

- x. **Ensuring carers don't miss out:** For many carers, looking after an ill, older or disabled loved one does not have a name, it is 'just something you do'. However, not recognising you are a carer means missing out on help, advice and information that can have serious personal and financial implications. A duty on health professionals to identify carers would help prevent them from missing out on important supports and ensure professionals take a 'whole family' approach, helping embed carers as expert partners and helping achieve better health outcomes for all involved. Having awareness and understanding of the carer population is a key starting point. Establishing a voluntary 'carers register' enabling access and entitlement to carers' supports and benefits, is one way to ensure carers receive the support they need.
- xi. **Full-time family carers should have a right to a Carers Needs Assessment:** Full-time family carers should have a right to a Carer Needs Assessment that assesses their physical and mental health and emotional needs, identifies any supports or services that they require and allows them to make contingency plans if they are ill or unable to continue to provide care. The Carer Needs Assessment tool developed by InterRAI, the HSE and carer representatives, and currently being piloted in CHO 2, should be rolled out nationally and available to all fulltime family carers.
- xii. **Extend the GP Visit Card to all full-time carers in receipt of the Carer's Support Grant:** The introduction of GP Visit Cards for carers in receipt of Carer's Allowance and Carer's Benefit is a welcome first step in recognising the health and wellbeing needs of carers. In order to reach a greater number of full-time carers the GP Visit Card should be made available to all carers in receipt of the non-means tested Carer's Support Grant.
- xiii. **Training for healthcare providers to recognise and support carers:** 'Think Carer' models in the UK and Australia provide awareness-raising events and training for health care professionals regarding the needs of carers. In Australia, for example, a programme called 'Think Patient, Think Carer' encourages primary care services to consider the needs of carers who may be supporting a person with a chronic condition. Adopting a similar community health initiative in Ireland could help identify family carers, signpost them to existing supports, resulting in better health and wellbeing outcomes.

SUPPORT CARERS TO REMAIN IN EMPLOYMENT

- xiv. **Introduce a tax break for companies that incur expenses through establishing carer-friendly workplaces:** One in 9 Irish workers juggle caring responsibilities with paid employment, with this figure likely to increase significantly over the coming years as Ireland's older population, rate of disability and the incidence of people living with a chronic condition continues to increase steadily. Estimates suggest that the proportion of family carers in Ireland will need to double by 2030 if we are to avoid a massive increase in public expenditure on community-based health care. The personal costs of juggling care with career are also significant, with recurring disruptions to work undermining career goals and the burden of care responsibilities causing severe stress and poor mental health. Many carers are forced to reduce their hours, forego career opportunities or leave the workforce prematurely. The costs to employers from avoidable loss of talent, experience and institutional knowledge, plus productivity and turnover costs, are also significant. As the demands on working carers increase, employers who create a culture of care, where the challenges for working carers are understood and flexible working is mainstream, will be best-placed to attract and retain employees. Introducing tax breaks for those companies who incur expenses while establishing carer-friendly workplaces can support employers to retain and manage employees with caring responsibilities.

- xv. Implement the European Directive on Work Life Balance for Parents and Carers:** In June 2019 the European Council adopted a Directive on Work Life Balance for Parents and Carers which aims to increase the participation of women in the labour market and the take-up of family-related leave and flexible working arrangements. The Directive lays down minimum requirements related to paternity leave, parental leave and carers' leave, and to flexible working arrangements for workers who are parents, or carers. Specifically, the Directive allows for the (i) introduction of a minimum 5 days carers' leave each year for workers providing care and (ii) the right to request flexible working arrangements for the purpose of providing care. Although Ireland is already well to the fore in Europe when it comes to statutory leave for carers, this additional five days of leave to care for or make arrangements for the care of ill relatives will undoubtedly benefit the 16% of carers who used annual leave to care. This additional leave can act as a pre-cursor to Carer's Leave for those carers who do not need/want longer blocks of leave from their employment. While each EU member state has been given three years to implement the Directive, Family Carers Ireland are calling on Government to act quickly and generously in their interpretation of the Directive to ensure working carers are supported to remain in the workforce.
- xvi. Opportunity to re-evaluate how we care:** This crisis has given us a once-in a lifetime opportunity to re-evaluate and reshape our society in a lasting way, including how we prioritise and legislate for the care of our older and disabled citizens. Family Carers Ireland is calling for a re-evaluation of the current nursing home led model of care towards a greater focus on homecare and supporting people to remain at home for as long as possible.

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FIND OUT MORE

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