



CARING THROUGH COVID:
LIFE IN LOCKDOWN



Family
Carers
Ireland

No one should have to care alone

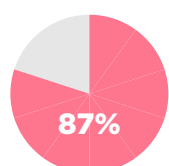
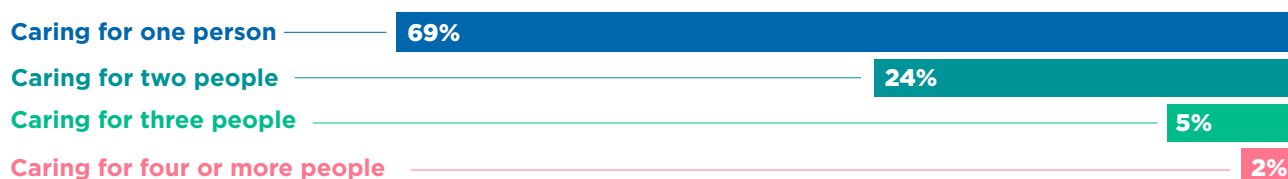
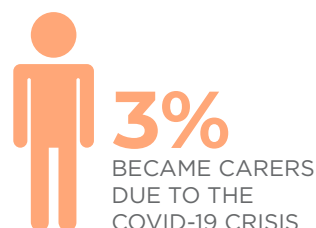
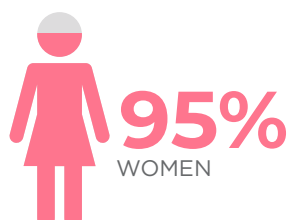
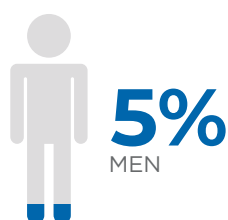
ABOUT THE RESEARCH

This report sets out the findings of a national survey undertaken by Family Carers Ireland between April 14th and May 5th 2020 which examined family carers' experience of caring during the COVID-19 pandemic. The online survey was completed by 1,307 current family carers representing a range of caring situations – parents caring for children with a disability, those caring for an adult, carers of older people and those caring for multiple people. The survey was open to respondents 18 years and older.

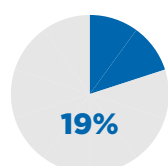
As not all respondents completed every question in the survey, a number of the figures given in this report, including those presented here, are based upon responses from fewer than 1,307 carers.

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 frailty¹.

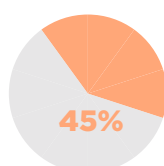
PROFILE OF RESPONDENTS



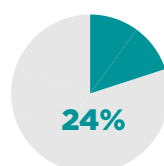
Living in same household as the person they care for



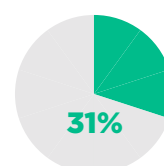
Caring for someone not in their household



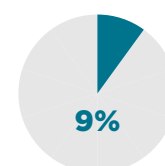
Caring for children under 18



Caring for a child over 18



Caring for parents/parents-in-law



Caring for their spouse/partner

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

¹ Department of Health (2012). National Carers' Strategy – Recognised, Supported, Empowered. Department of Health, Dublin.

INTRODUCTION

We are living through an unprecedented moment in history. The COVID-19 pandemic has affected every aspect of our society. As well as the tragic loss of life, over one million people are relying on State support for all or part of their income; businesses, schools and workplaces are closed and life as we have known it has changed beyond recognition.

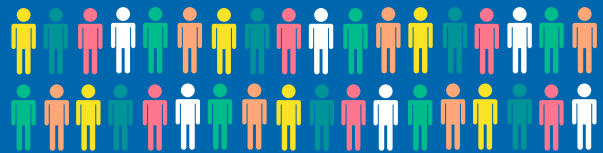
EVEN BEFORE COVID-19, THOUSANDS OF FAMILY CARERS ACROSS IRELAND WERE EXPERIENCING FINANCIAL DIFFICULTY, SOCIAL ISOLATION AND ILL-HEALTH². FOR THESE CARERS, THE PANDEMIC HAS MADE AN ALREADY DIFFICULT SITUATION MUCH WORSE.

Many are now forced to care single-handed without the support of family, home care or respite. Some have been made unemployed and now face significant financial pressures while parents of children with a disability have lost the routine and relief of school, day services and essential therapies. Older carers and those with underlying health conditions are cocooned within their homes, isolated and reliant on others for their shopping, prescriptions and essential medical supplies. Social distancing and self-isolation, terms now synonymous with this pandemic, while difficult for us all, are almost impossible for family carers as no alternative care package has been made available in the event that a carer or the person for whom they care test positive for COVID-19. The psychological impact of this pandemic cannot be overstated; causing fear, anxiety, stress and grave uncertainty about the economy in the months and years ahead.

This report '*Caring Through COVID*' presents the findings of an online survey which was undertaken during the first phase of lockdown, from 14th April to May 5th 2020, and was completed by 1,307 family carers. It provides a snapshot of carers' experience of caring during the COVID-19 pandemic, the challenges they face, their worries and concerns and their suggestions on how frontline service providers and Government could respond better to meet their needs. Importantly, the report also

shares carers' experience of the many positive acts of kindness, social solidarity and community spirit which have shone a light into the dark corners of this pandemic. The report concludes with a number of practical and policy recommendations on how we can address the needs of family carers arising from the COVID crisis in the short and medium term.

Notwithstanding the many terrible aspects of COVID-19, this crisis has given us a once in a lifetime opportunity to re-evaluate and reshape our society in a lasting way. It has shown that profound positive change is possible when we are willing to adapt to new ways of doing things. Ireland's 355,000+ family carers have played their part in protecting and caring for Ireland's most vulnerable people during this crisis.



IRELAND'S 355,000+

Family carers have played their part in protecting and caring for Ireland's most vulnerable people during this crisis.

They have not only stayed at home themselves but have enabled older people, people with a disability, the sick and terminally ill to stay at home as well. They have played a more significant role in suppressing this virus than most and their essential contribution to the national healthcare response to COVID-19 should be acknowledged and applauded.

² 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>

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.



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.



IMPACT OF THE WITHDRAWAL OF SERVICES ON FAMILY CARERS

Prior to the COVID-19 pandemic, many carers already experienced difficulty accessing important supports such as homecare or respite³. 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. 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 for⁵.

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

³ 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>

⁴ These findings are from our annual State of Caring report which will be published later in 2020. 1,250 carers responded to the survey between 21st December 2019 and 17th February 2020.

⁵ *Ibid*

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 THROUGH 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 tests 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.

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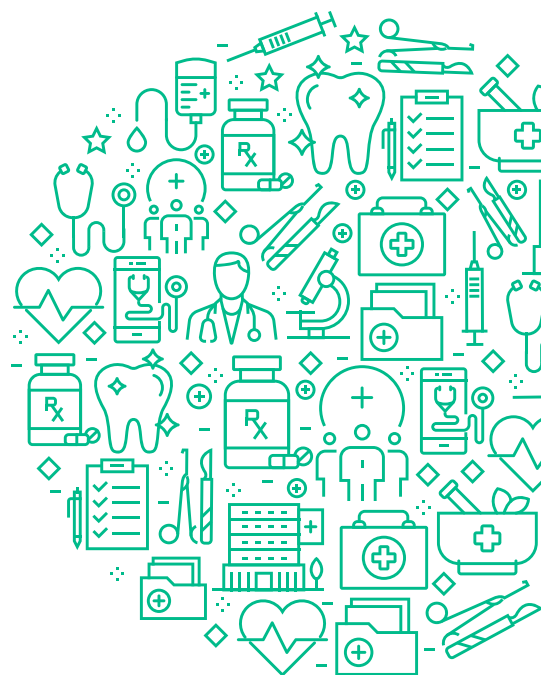
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I feel like I am in lockdown within a lockdown. Being a family carer is very challenging at the best of times. The limited support that we might receive is now gone, at a time when we need it the most. I feel that we have just been forgotten about. 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.

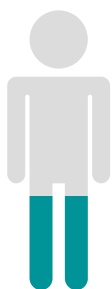
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Access to food, prescriptions and other essential supplies

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 (69%) respondents found it hard to make ends meet and one in five (19%) said they could only make ends meet with great difficulty⁶. 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 debt⁷.

”

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.

⁶ These findings are from our annual State of Caring report which will be published later in 2020. 1,250 carers responded to the survey between 21st December 2019 and 17th February 2020.

⁷ 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

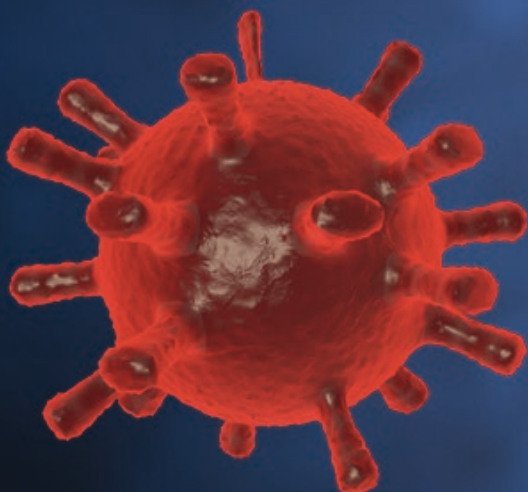
Whilst caring for someone can be a rewarding experience, the impact on carers' physical and mental health has been illustrated in previous research. As well as the usual stresses of making sure that the person is well looked after, the COVID-19 pandemic has added additional pressure and worry on carers. 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.

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 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.

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.

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

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.

"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 IMPACT OF COVID-19



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.

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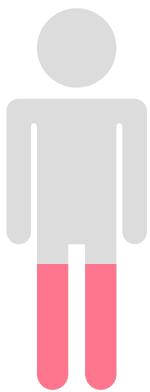
“

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 spirit.



34%

of 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.**
- **Carers Emergency Support 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.**

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.



RECOMMENDATIONS

Short term recommendations (during the COVID crisis)

i. Recognition of family carers as a priority group:

Throughout the COVID crisis, there has been a focus on protecting vulnerable groups and those most at risk of contracting the virus. While groups including the homeless, refugees, Travellers and members of the Roma community have rightly been named as vulnerable groups, Family Carers Ireland is disappointed by the failure to recognise the vulnerability of family carers. While carers may not present the same clinical risks as those with underlying conditions, or living in congregated or close settings, their vulnerability lies in the essential role they play in caring for people with a lifelong condition, illness, disability or mental illness and keeping them out of our hospitals at a time when we are all advised to 'stay at home'. In providing this care, carers themselves have 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. By classifying carers as vulnerable during this crisis, they would have access to dedicated guidance documents, contingency protocols and access to priority testing.

ii. Contingency planning for family carers who contract COVID-19:

One of the greatest concerns of family carers during the pandemic is what will happen if they, or the person for whom they care, contracts COVID-19. If the carer contracts the virus, then who will step in to provide alternative care? If the cared for person contracts the virus, then how can they self-isolate given their care needs? What will happen if they are admitted to hospital and the carer can't be with them? Or worst of all, will the virus be fatal to them? Unfortunately, there have been cases where carers have contracted COVID-19 and contingency arrangements were not available, meaning the carer either had to continue to

care while infected, rely on family or admit their loved one to emergency residential care, for which they have had to pay. Clear guidance and contingency plans should be put in place by the HSE setting out the protocols to be followed in the event of a carer having COVID-19 or displaying symptoms and how replacement care will be made available.

iii. Access to appropriate PPE for family carers:

Despite many family carers providing intimate personal care, they have not had access to public supplies of PPE for the duration of this crisis, placing both the carer and the person for whom they care at greater risk of infection. Instead, carers have had to source and pay for their own PPE or rely on the donations of privately sponsored supplies made available through charities like Family Carers Ireland. As has been the model in other European countries and the UK, we are calling for family carers to be given access to public supplies of PPE in line with that provided to homecare workers.

iv. Minimising the financial impact of COVID-19:

Like many families, households where care is provided have seen a significant increase in their weekly spending. However, unlike non-caring households, family carers incur additional care-related expenses including PPE, medication, costs of replacement care, diet supplements, continence wear, accessible transport and increased fuel costs as older people and those with underlying conditions require warmth throughout the day. In some cases, carers have been further financially penalised as they have 'voluntarily' given up work due to the risk of infecting a clinically vulnerable household member. However, they are not entitled to any of the emergency pandemic payments as they were not formally laid off. While Family Carers Ireland commends Government on their efforts to support people at this time, we believe a number of practical measures would help support carers financially during this pandemic including (i) an increase in the annual Carer's Support Grant (ii) extending eligibility for the Pandemic Unemployment Payment to include carers who have had to give

up work due to the risk of infection (iii) provide emergency respite free of charge to carers who test positive for COVID-19 or have to self-isolate and (iv) provide PPE for family carers from public supplies so they are not forced to pay privately.

v. Supporting the mental health and wellbeing of family carers:

The COVID-19 pandemic has induced a considerable degree of fear, worry and concern amongst us all. However, it is perhaps most acutely felt by those most at risk of the virus including older people, those with underlying conditions and the family carers trying to protect them. This fear and anxiety is compounded by the impact of lockdown restrictions on people's usual activities, routines and livelihoods, with levels of loneliness, depression, harmful drug and alcohol use and suicidal behaviour expected to rise (WHO, 2020). Priority must be given to supporting the mental health and wellbeing of those most affected by COVID-19, with adequate resources and funding made available to the charities and service providers who support them.

Medium term recommendations (as we emerge from the crisis)

i. Opportunity to re-evaluate how we care:

This crisis has given us an 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 vulnerable citizens. Family Carers Ireland is calling for a re-evaluation of the current nursing home led model of eldercare towards a greater focus on homecare and supporting people to remain at home for as long as possible. This will include the creation of a Statutory Homecare Scheme which will give fulltime family carers access to a guaranteed basket of supports and services

including respite.

ii. Roadmap for the reinstatement of supports:

Family Carers Ireland is calling for a roadmap towards the reinstatement of homecare and Personal Assistance supports for the families who have either had this support withdrawn or chose to voluntarily suspend it due to risk of infection. We must ensure that those who need support can have it reinstated if/when needed.

iii. Addressing waiting lists:

Before the COVID-19 crisis, some 7,200 people, medically assessed as in need of homecare, were on a waiting list for home support. Plans must be put into place to support these people who are now further disadvantaged due to the suspension of homecare services and who now have less prospect of receiving support under current conditions.

iv. Access to respite:

Respite care is recognised as one of the most important interventions to support the health and wellbeing of family carers and enhance the sustainability of the care they provide. While Family Carers Ireland accepts the unavoidable closure of respite services during the pandemic, we are concerned that the provision of respite may be gravely hit in the long-term, as its already inadequate provision will be further reduced due to social distancing requirements. Family carers cannot be expected to care indefinitely without a break. As we emerge from this crisis, plans must be put in place to reopen respite services as soon as it is safe to do so and where necessary, innovative solutions put forward as an alternative to traditional residential models of respite.

ACKNOWLEDGEMENTS

We would like to warmly thank all the family carers who generously gave up their time to complete this survey, ensuring their voices are heard during the COVID-19 pandemic.

FIND OUT MORE

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