Family Carers Ireland
No one should have to care alone

# Listening to Family Carers

## Life After Lockdown

**On Tuesday June 29th 2021**, family carers from across Ireland joined *Family Carers Ireland* for an online discussion about their experience of caring through the COVID crisis, the challenges they face now as we begin to emerge from the pandemic and their hopes and priorities for the future as we look forward to life after lockdown. We thank the carers who contributed to the discussion, including our three panel speakers, for their openness and honesty. The feedback raised during the meeting will inform *Family Carers Ireland*'s policy, research and lobbying efforts as well as helping direct our carer supports and services. The information has also been shared with members of the newly established All Party Oireachtas Interest Group on Family Carers who are currently developing their work programme. The following paper provides a summary of the points raised by family carers during the meeting.

### *Reflections from the pandemic*

#### ***Fear of hospital***

- Many carers described feeling immense ***fear and anxiety about visiting hospital*** during the pandemic due to the perceived risk of infection. While one carer described how she and her husband only attended hospital after the Chief Medical Officer assured the public that hospitals were safe and had a relatively positive experience, the remaining carers who spoke described their experience of a hospital or Emergency Department visit during the pandemic as 'horrific', 'terrifying' and 'horrendous'.
- Carers described being ***prevented from accompanying their loved one into the hospital***, despite the cared for person being frail or unable to speak for themselves. This caused both the family carer and cared for person immense stress. There also appeared to be a lack of consistency across hospitals with regard to the implementation of policies relating to family members accompanying patients, with some hospitals facilitating carers attendance while others wouldn't allow it. One carer explained '*my husband was incredibly stressed going to hospital and his mental state affects me.'*
- One carer described how she felt ***pressure from medical staff*** to bring her father to his routine hospital appointments as normal despite both of them being 'terrified to go'. Another carer described Emergency Department staff as 'on the defensive' and discussed a 'horrific' experience in the ED during COVID due to poor communication from staff.
- Another carer described the trauma she and her mother experienced when her dad was in hospital, and ***due to COVID restrictions his family weren't allowed to visit him***. The gentleman was old and unable to use technology so could only communicate with his family via loud speaker on the phone. However, the family couldn't get through to the hospital ward by phone so weren't able to speak with him. The hospital staff arranged for him to have a Zoom call with his family each morning however this caused more distress for the family as they could see he wasn't able to use the iPad given to him. The carer stated '*they'd plonk the iPad in front of him and leave the room. Needless to say it was very upsetting for my mum of 84 years'.*
- One carer described the difficulty her dad experienced while in hospital during COVID, which was made worse as he isn't proficient in English as so ***struggled to communicate*** with medical staff.

*'Paediatric care in general has an attitude of the parent/family are responsible for care. The services are lacking and unsupportive'* (Carer in chat box).

### ***An insight into carers' lives***

- A number of carers referred to how the pandemic created a ***'more level playing field'*** between carers and the rest of society, in the sense that others got to experience some degree of the isolation and social restrictions carers feel in normal times and not just during the pandemic.
- One carer compared this experience to the song Common People by Jarvis Cocker, where people who are not family carers, got to experience ***what normal life is like for carers*** during lockdown. He felt that COVID -19 has given others an insight into the realities faced by many family carers, however feared this empathy wouldn't be long-lasting and family carers would be forgotten about again.
- One family carer spoke about the ***difficulties accessing vital equipment/aids/creams*** for her son who has a very rare chronic skin condition and how the health services have labelled these as 'cosmetic' and therefore 'not essential' meaning the family have to pay privately.

### ***The forgotten frontline***

- ***Carers described feeling forgotten about 'again'*** and isolated during the pandemic. Services were shut down to protect service users and staff, schools were closed to protect pupils and teachers and shops were closed to protect workers and customers – however no one was concerned about family carers who were left to pick up the pieces and carry on throughout lockdown, often alone and without the support of family and friends.

*'Because of the lack of services, we're on the verge of homelessness and losing everything that we had worked for, when we could work. When you are a carer or have a condition, you are viewed in general as being obsolete or irrelevant'.* (Carer in chat box)

## ***The current landscape***

### ***The paucity of respite***

- The ***lack of respite*** was a recurring theme throughout the meeting. Carers described doing their utmost to keep their loved one at home and out of a nursing home however they cannot access the respite they need to sustain their caregiving efforts. One carer described contacting seven centres in an effort to book respite for his 92-year-old father in law for October only to be told to 'call them closer to the time' or 'we don't have anything'. When he did find a suitable respite facility, he was told that the costs would not be covered (under the Health Charges for In-Patient Services Regulations 2005 which provides for free inpatient care in a public facility for up to 30 days in a 12 month period), because the facility was located outside his HSE region.
- Another carer who had a relatively good respite service prior to the pandemic has now been told that that level of ***respite provision will not return after COVID*** due to funding. He recounted how families were previously told that if they looked for more respite then they were denying another family respite, as there were finite resources available. He called for an explanation from the HSE as to why respite isn't or can't be provided at the same level as before and emphasised the need for transparency.
- Other carers stated that they ***never had respite***, even before the pandemic.

*'Respite should be available to everybody as a right, not least for our 'children' who should be entitled to be with their own age cohort, not stuck at home with old parents'. (Carer in chat box).*

## ***The resumption of services***

- Some carers described how services were completely withdrawn during the first phase of lockdown, however as services resumed in late 2020/2021 the services they availed of before COVID simply didn't return or are now ***provided on a significantly reduced scale***. One carer explained that her son, who had been receiving 30 hours of support per week prior to COVID, has now had his service reduced to 10-12 hours. She also explained that service-users are being assigned a 'priority rating' based on their needs to determine the level, type and quantum of service they will receive (See Appendix 1 HSE Resumption of Adulty Disability Services).
- Other carers emphasised the importance of services for the cared for persons' ***mental health and wellbeing.*** One carer described how difficult it was to watch their loved one go into a type of depression during lockdown because they missed their friends and the routine of going to the day service. When the service resumed, they slowly returned to their normal self.

## ***Failure to provide for children/adults with mental health difficulties***

- One carer spoke passionately about the failure of the State to meet the needs of her daughter who has an eating disorder. She expressed her deep concern about the lack of specialist in-patient beds available nationally and highlighted the failure of the CAMHS team to meet her daughter's needs. While a National Clinical Care Programme for Eating Disorders has been promised by Government it has yet to be delivered meaning people with an eating disorder continue to be ignored leaving them and their families in crisis and for those living with an eating disorder, at serious risk of death.

*'The children and adult mental health system is broken/not working, the HSE is resigned to its ineffective state. I was repeatedly asked by all levels of HSE if I had private health cover. When services were unavailable or inadequate the option was put that you can go privately - it was used in a threatening way when they rejected criticism despite knowing full well that private care is prohibitively expensive and often not covered by those who do have private health care'.* (Family carer in chatbox)

## ***Education provision***

- One carer described her ***struggle to secure a school place*** for her daughter. While her older son was not expected to undertake a psychological assessment when he began school, her daughter, who has complex care needs, had to and as a result has been refused a school place which the carer finds discriminatory. The carer has successfully fought to have a special place provided in her local school for her daughter so she has the 'luxury' of having both her children attend the same school.
- Another carer described how school is her son's only social outlet and while schools were closed this had a profound ***impact on his mental wellbeing as he missed his friends and the social interaction school gave him***.

*'Why, why, why, is it always a battle'* (Carer in chatbox).

## ***Juggling employment and care***

- A number of carers juggle ***paid employment with caring responsibilities and described the challenges involved*** and the importance of having supportive employers and initiatives such as *Family Carers Ireland's* Caring Employers, which assists employers to build a supportive and inclusive workplace for staff who are, or will become, carers.
- One carer described the military type planning that goes into running their household to ensure both she and her husband can work while ensuring their son receives the care he needs. She noted that as her son is now approaching adulthood and his care needs are increasing, both she and her

husband are ***facing difficult decisions in relation to their future careers***. While both want to continue to work and are successful in their respective careers, the demands of caring and ensuring her son continues to receive the support he needs means this is unlikely.
- Discussions with regard to working carers emphasised the need for ***targeted initiatives*** including the transposition of the EU Directive on Work Life Balance for Parents and Carers, the overhaul of tax incentives and reliefs available to families to support them to remain in the workforce and better alternative care packages that will support the cared for person while they are in work. One carer spoke about the value of Family Carers Ireland's Caring Employers programme and how her own employer has recently signed up for same stressing the importance of a supportive employer.

***Being forced to leave the workforce to provide care***

- A number of carers have had to leave work or take early retirement in order to provide care. This has had significant consequences on the family's income, particularly during COVID. One carer who took early retirement is now on a Jobseekers Allowance, despite sharing fulltime care of their daughter with his wife. Another carer described leaving a well-paid, successful career to care for her daughter and now ***struggles on an income that's 80% less than before***. This carer emphasized that while she's grateful for Carer's Benefit, it's not nearly enough to meet her daughter's needs and normal household running costs.

***Homecare***

- While Government invested additional funding into homecare during 2020/2021, practical issues remain in its delivery. A shortage of appropriately trained homecare workers is an increasing problem not only in rural areas, but also in towns and cities. It is particularly difficult to ***access male homecare workers*** which is the preference of many older men receiving care at home.
- While homecare overall was not noted as problematic, ***access to night time care is virtually non-existent.*** For family carers who care for someone who wakes or wanders during the night, this is a significant issue. The consistent deprivation of sleep has a profound impact on the carer's health and ability to continue to provide care. As such, the provision of night time home support hours should be considered a normal part of the HSE home support provision for families that need it.
- Issues were raised with regard to a family carer being expected to ***become an employer*** should they receive direct funding from the HSE. This imposes significant responsibility on the family and leaves them vulnerable to issues arising from employment legislation or personal injury claims as well as the extensive practical responsibilities that come with being an employer.

## *Moving forward*

***Extending access to Carer's Allowance and other carer supports***

- A consistent theme was carers' immense frustration with the ***means test imposed on Carer's Allowance and how this locks genuine family carers out of the scheme.*** This is made even more frustrating for carers who don't qualify, as Carer's Allowance is a passport payment – meaning your receipt of it opens up automatic entitlement to a number of additional supports, including the annual Carer's Support Grant, Carer GP Visit Card, Free Travel, Household Benefits Package and allows recipients to apply for the Better Energy Warmer Homes scheme. The majority of family carers believe Carer's Allowance should not be means tested while others accept the more modest approach of increasing the income disregard which has been FCI's position heretofore.
- There was also anger with the ***rate of Carer's Allowance and Carer's Benefit*** which are just €16/€17 respectively more than basic social welfare rates. A number of carers who receive Carer's Allowance referred to the fact they receive a greatly reduced amount due to other means in the household. One carer asked 'what's Carers Allowance for' pointing to that fact that its

inadequate to cover the costs of caring households, particularly given situations where the loss of income from employment is exacerbated by higher household costs due to caring.

- Reference was made to the ***Pandemic Unemployment Payment (PUP) initially being paid at a rate of €350*** per week, validated the inadequacy of existing social welfare rates. The expectation that family carers will provide fulltime care – at least 35 hours each week to those medically assessed as in need of fulltime care - for just €219, €16 more than basic social welfare rates is untenable.
- While not specifically mentioned by carers, their deep concerns with regard to the means test for Carer's Allowance implies the need for ongoing lobbying efforts by FCI for a fundamental ***reform to the Carer's Allowance disregard and capital formula*** to ensure more full-time family carers are eligible.

*'If we didn't have savings we couldn't have managed during my husband's cancer'*. (Carer in chat box).

## ***Supporting the mental health and wellbeing of family carers***

- The COVID-19 pandemic has caused fear, anxiety and worry amongst us all. However, it has most acutely been 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 commensurate increases in people's experience of loneliness and depression. Carers' concerns with regard to health and wellbeing are two-fold. Firstly, they are concerned about the impact the pandemic has had on the wellbeing of the person they care for, and secondly with how the COVID crisis has affected their own health and wellbeing, with many now physically and emotionally drained. As we emerge from the pandemic and look forward to the return of a new normal, ***priority must be given to supporting the mental health and wellbeing of those most affected by COVID-19, including carers and those for whom they care***. One carer described this best, stating *'If you don't protect your wellness you'll be forced to live with an illness'.*
- ***A fear of the future*** was highlighted for ageing parents of adults with intellectual disability. What will happen when they can no longer care? Where will their son/daughter live? There are currently no suitable settings for many young people or adults with long-term care needs.
- ***Acknowledgement was given to the supports provided by FCI*** during the crisis, particularly the emotional support, Crisis Fund and the introduction of the Emergency card scheme as well as the general day to day support offered by FCI staff. It's essential that these supports continue after the crisis.

## ***Full resumption of services and respite***

- While carers are mindful of the long-term costs that will be incurred by the State in covering the enormous expenses associated with the pandemic, these ***costs cannot be borne yet again by Irelands most vulnerable citizens – those who need care and the family carers*** providing it.
- Carers are deeply concerned that inferences to a need to reduce services or respite due to a lack of funding are already being made. While some carers stated that services must resume at the same level as before the pandemic, this was challenged with a person stating that this wouldn't be good enough and in fact services should increase post COVID given what we have learned from the experience of caring through COVID and the ***State's absolute reliance on family carers***.
- Many carers referred to the ***post code lottery*** of supports and services that exist for family carers across the country again highlighting that where you live determines what supports you will or will not receive – this is particularly so for respite.

***Learning from the positives of COVID***

- While some carers described positive experiences from the pandemic, one carer in particular explained how the COVID pandemic has brought their lives forward by some 10-15 years due to the widespread adoption of remote working and virtual engagement. She described this as '***virtual inclusion'*** which has given her son a greater sense of belonging within the world.
- Another carer described how COVID has forced us all to slow down and reassess the values we place on material things. For some the pandemic has given the ***opportunity to reassess their future goals and priorities***.

Family Carers Ireland believes *no one should have to care alone* and offers a vast range of supports and services for family carers nationwide.

**Please see below some quick links to the services and supports offered by FCI.**

→ Learn who FCI is as an organisation

→ Learn about the supports that are available for family carers including free counselling, family carer events, young carer support etc.

→ Learn about your Rights & Entitlements incl. Carers Leave & Carers Benefit, Grants available etc.

→ Access free interactive e-learning modules, created with experts to help you in your caring role

→ Join our FREE Emergency Scheme, which helps you, the family carer plan in the event of an emergency, such as contracting Covid-19

→ Enquire about the provision of professional in-home care support in your area

→ Freephone our Careline on 1800 24 07 24. We are always here to lend an ear, as ***we believe no one should have to care alone.***

→ Join a community of family carers by becoming a member for €20 per year. Read about the benefits of having an FCI card here.

→ Join other family carers in our safe and secure online forum sharing tips, information and ask questions.

→ Get in touch. We have excellent Carer Support Managers who will guide and assist you locally. Find your nearest Carer Support Centre here. Please note our Centres are still closed due to Government guidelines but all Managers are still contactable.

## Take part in future research:

Family Carers Ireland is dedicated to developing and supporting research that has relevance and meaning for family carers, research that influences social policy and enhances the quality of life of family carers and the people they care for. If you would like to take part in future research projects, we would be delighted to add you to our family carer directory. Please email us with your consent to be contacted at **ndunne@fmailycarers.ie**. Your contact details will be kept private and confidential.

www.familycarers.ie

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