



FAMILY CARERS: The Forgotten Frontline

Family Carers Ireland's Proposals for
Budget 2022

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PRIORITIES FOR BUDGET 2022

Many of Ireland's 500,000 family carers feel they have been forgotten by Government throughout the COVID pandemic. As the country begins to emerge from the crisis, **there is now an opportunity for Government to demonstrate that they recognise carers and value their contribution.**

Family Carers Ireland calls on Government to use Budget 2022 to demonstrate their commitment to carers by delivering six priorities.

1

€5m in annual funding to deliver the Carer's Guarantee (Programme for Government - PfG).



2

€68.5m to increase weekly carer payments by €8, Carer's Support Grant to €2,000 and Carer's Allowance income disregards.



3

€3m in annual funding towards a dedicated Carer's Pension for long-term family carers (PfG).



4

€5m to publish a refreshed National Carers' Strategy Action Plan 2021 - 2025 (PfG).



5

Introduce the Statutory Homecare Scheme (PfG) including an annual entitlement to 20 days respite and a Carer Needs Assessment for fulltime carers.

6

Establish a Commission on Care (PfG) to include an examination on the role, reliance and recognition of family carers in long-term care provision.

FOREWORD

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Our definition of work must change, must evolve and widen, to incorporate the important role of caring and carers as essential workers; workers far too long undervalued by society. President Michael D. Higgins, May 1st 2021.

”

Like many of us, family carers began 2021 optimistic that the worst of the COVID pandemic was behind us. With the commencement of the vaccination programme, carers looked forward to the resumption of normal life, albeit a new normal. With the continuance of the pandemic longer than most would have predicted, that unfortunately hasn't happened and any optimism family carers had has been replaced by growing despair, mental and physical exhaustion and frustration that once again they have been forgotten in Government's response to the crisis. Despite the essential care family carers continue to provide throughout the pandemic:

- Family carers are **not provided with PPE** but instead are expected to pay out of their own pocket for gloves, masks and aprons, often at extortionate and inflated prices. Family Carers Ireland had to rely on funding donations in order to source and distribute PPE to family carers.
- While other workers could apply for an enhanced Illness Benefit if they were required to restrict their movements or tested positive for COVID-19, **family carers had to continue to care** and, in some cases, where the carer tested positive for the virus, were forced to pay privately for alternative care for their loved one while they recovered.
- While parents could apply for a Pandemic Unemployment Payment (PUP) if they are unable to work due to childcare issues as a result of school closures, **family carers who had to give up work to provide care** to a disabled, sick or older person 'voluntarily' rather than being made redundant could not.
- In some cases where disability services have resumed, **it's assumed family carers will replace** transport services previously provided or accept a reduced quantum of services.

- While other jurisdictions, including the UK, have rightly prioritised family carers in their vaccine schedules, carers in Ireland were **not mentioned or acknowledged in the vaccination allocation strategy**. Instead, carers have been told to wait their turn and they will be vaccinated along with the general population, forcing thousands of carers to remain in isolation to avoid bringing the virus into their homes and infecting a medically vulnerable household member.

ONE OF THE GREATEST LEARNINGS TO EMERGE FROM THE COVID CRISIS IS THE STATE'S FUNDAMENTAL DEPENDENCE ON THE CARE PROVIDED BY FAMILIES.

Family carers not only stayed at home themselves during the crisis but enabled older people, people with a disability, the sick and terminally ill to stay at home as well. When services shut down, they stepped up, continuing to care round the clock to ensure their loved ones stayed at home and out of hospital. Carers have played a more significant role in suppressing COVID-19 than most and their essential contribution to the national response must be acknowledged.

As we emerge from the crisis, there is now an opportunity for Government to show that they recognise and value carers' contribution. Family Carers Ireland calls on Government to use Budget 2022 to demonstrate their commitment to carers by delivering six policy proposals¹.

¹ Other policy issues such as housing, transport and access to therapies are being pursued outside the budget process.

WHO CARES?

- **13 per cent** of the Irish population aged over 15 years provide care (Irish Health Survey 2019).
- Extrapolation to the national population means Ireland has some **499,904 family carers**.
- Family carers provide an average of **38.7 hours of care each week** (Census 2016) which means that collectively, carers provide **19m hours of unpaid care each week**.
- The **annual replacement cost of the care provided by family carers is approximately €20bn**.
- HBSC study found 13.3 per cent of children aged 10-17 years provide care. Extrapolation to the national population means there could be as many as **67,000 young carers** in this age cohort.

CARERS IN RECEIPT OF SOCIAL WELFARE:

- 116,838 recipients of the annual Carer's Support Grant.
- 89,549 carers receive Carer's Allowance (caring for 99,505 care recipients).
- 3,427 carers receive Carer's Benefit (caring for 4,043 care recipients).

Almost **one million** additional people in Ireland provided some form of unpaid care as a result of the pandemic². This is on top of the **500,000** unpaid carers who were already caring before the outbreak, bringing the total to **over 1.4 million**.

More than a quarter of the Irish population.

PROPOSALS FOR BUDGET 2022:

- 1** €5m in annual funding to deliver the Carer's Guarantee (Programme for Government - PfG).
- 2** €68.5m to increase weekly carer payments by €8, Carer's Support Grant to €2,000 and Carer's Allowance income disregards.
- 3** €3m in annual funding towards a dedicated Carer's Pension for long-term family carers (PfG).
- 4** €5m to publish a refreshed National Carers' Strategy Action Plan 2021 - 2025 (PfG).
- 5** Introduce the Statutory Homecare Scheme (PfG) including an annual entitlement to 20 days respite and a Carer Needs Assessment for fulltime carers.
- 6** Establish a Commission on Care (PfG) to include an examination on the role, reliance and recognition of family carers in long-term care provision.

² Behaviour and Attitudes Survey 2020.



€5m in annual funding to deliver the Carer's Guarantee.



We will deliver a Carers Guarantee proposal that will provide a core basket of services to carers across the country, regardless of where they live.

(PFG p.50, p76).

In 2019, Family Carers Ireland developed a 'Carer's Guarantee' proposal, setting out how, with additional annual funding, the organisation could ensure the uniform delivery of a core basket of services to family carers across the country, regardless of where they live, thus helping to eliminate the 'postcode lottery' that has long characterised carers' access to services. These core services include (i) access to emergency respite; (ii) intensive one-to-one support for carers in crisis; (iii) training programmes ranging from basic care skills workshops to QQI accredited 'Caring with Confidence' training; (iv) targeted support groups and carer networks and (v) access to information and advocacy clinics in local communities, primary care centres and hospitals.

In the period since the Carer's Guarantee was presented to Government, the outbreak of COVID-19 fundamentally changed the landscape within which we operate and has had a significant impact on how the services named in the guarantee are delivered. The pandemic has also brought about a substantial increase in the number of family carers seeking help, with many families now in need of intensive one to one support. Consequently, the Carer's Guarantee has been updated to take account of these new circumstances and will now require €5m in annual funding to deliver.

While Family Carers Ireland acknowledges the €2m committed to the Carer's Guarantee in Budget 2021, we ask that the following factors be considered in the context of Budget 2022:

- The €2m allocation announced in Budget 2021 falls far short of what is required to deliver the Carer's Guarantee. The inadequacy of the funding means that only some of the core services identified as necessary will be available, and so will do little to address the geographic disparity in services across the country.
- Rather than be allocated to Family Carers Ireland, who developed the Carer's Guarantee based on our organisational infrastructure and geographical reach, the €2m was directed through the HSE Service Plan with no reference to how the guarantee would be delivered or how the sector would be involved. Family Carers Ireland acknowledges subsequent positive engagement with the HSE with regard to the €2m allocation, however, we would like to be involved from the outset.
- The language regarding the €2m allocation is ambiguous and confusing, with the department referring to the funding as towards ending the postcode lottery, i.e. the Carer's Guarantee, while the HSE Service Plan specifies that the €2m is towards the National Carers' Strategy.

The Programme for Government commits specifically to the delivery of the Carer's Guarantee which implies that it will be delivered in the format proposed by Family Carers Ireland. Should Government continue to implement the guarantee as it has done heretofore, with minimal funding and through the HSE Service Plan, then Family Carers Ireland fears that the ambition of the guarantee will have been misinterpreted and the opportunity to finally end the postcode lottery for family carers will be lost.



€68.5m to increase weekly carer payments by €8, the Carer's Support Grant to €2,000 and Carer's Allowance income disregards.

2

RECOMMENDATION OF THE CITIZENS' ASSEMBLY 2021:

Reform Carer's Allowance by

- (a) Increasing the level of the income disregard
- (b) Reimbursing the costs associated with caring
- (c) Increasing the ceiling on the number of hours in paid work outside the home
- (d) Providing access to State employment and training programmes
- (e) Increase the level of the Carers' Support Grant in the next Budget and keeping it under review to ensure it keeps pace with other increases in social protection payments



Increase Carer's Allowance and Carer's Benefit by €8 per week:

Cost estimated to be €30m.

The establishment of the Pandemic Unemployment Payment (PUP) at €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. In fact, of the 89,000 carers receiving Carer's Allowance, half receive a reduced rate due to other means and are therefore likely to receive even less than the basic social welfare rate⁴. Family Carers Ireland is currently working with the Vincentian Partnership for Social Justice to establish a Minimal Essential Standard of Living (MESL) for households where fulltime care is provided. Pending the completion of this research, and in line with the recommendations made by the Vincentian Partnership⁵, Family Carers Ireland is calling for Carer's Allowance and Carer's Benefit to be increased by €8 per week to begin to bridge the gap between the rate of Carer's Allowance/Carer's Benefit and the real costs facing caring households⁶.

The rates of Carer's Allowance and Carer's Benefit are less in 2021 than they were in 2009, meaning they have never been restored to their pre-austerity levels more than a decade ago.

³ €30m is based on an €8 increase to the 92,976 recipients of CA and CB, however reflects that 40,447 of these receive Half Rate Carer's Allowance and so would receive €4 or less. Estimation does not reflect that 50% of CA recipients receive a reduced rate and therefore won't receive the full €8.

⁴ Department of Employment Affairs and Social Protection (2019) Policy Review of Carer's Allowance.

⁵ Vincentian Partnership (2020) https://www.budgeting.ie/download/pdf/vpsj_mesl_pre-budget_submission_2021.pdf

⁶ Increasing Carer's Allowance from €219 to €227 would be the first annual step in reaching income adequacy during the lifetime of this Government based on the Minimum Essential Standard of Living (MESL). See www.budgeting.ie.

Increase the Carer's Support Grant from €1,850 to €2,000: Cost €19.5m.

The annual Carer's Support Grant is an important payment that recognises the unique contribution of family carers. While the grant can be used as the carer chooses, for many it goes towards the cost associated with caring or towards paying household bills. For some 24,234⁷ fulltime carers of people who are medically assessed as in need of fulltime care, the grant is the only financial recognition of the care they provide. Family Carers Ireland is calling for the grant to be increased to €2,000 in Budget 2022 in line with recommendation made by the Citizens' Assembly.

Begin the gradual increase of Carer's Allowance income disregards towards average weekly earnings during the lifetime of the Government by providing a €35 increase in the income disregard for Carer's Allowance (couples) and €17.50 (single) in Budget 2022, with annual increases thereafter: Cost est. €14m⁸.

While the Programme for Government contains a number of ambitious commitments for family carers, it falls silent on the one issue consistently identified by family carers as most important to them – the Carer's Allowance means test. While the majority of family carers believe strongly that the means test should be abolished – a call echoed by a number of political parties – Family Carers Ireland has taken a more modest approach, by calling for the disregard to be gradually increased year on year during the lifetime of this Government until it is in line with average weekly earnings, which in Q4 2020 were €826 per week. This commitment was previously set out in the policy document Towards 2016⁹ however, for the past 13 Budget cycles there has been no increase in the Carer's Allowance disregard, despite it having increased by 350 per cent in the years between 2000 to 2008 (Table 1).

Because of the means test, genuine fulltime family carers continue to be denied Carer's Allowance. These are by no means wealthy families. 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 are¹⁰. These are families who typically have higher than average household costs due to caring and where often one member of the household has had to give up work to provide care.

TABLE 1: CARER'S ALLOWANCE INCOME DISREGARD 2000 – 2021

Budget	2000	2001	2002	2003	2004	2005	2006	2006	2007	2007	2008/2021
Income Disregard											
Single	€95	€158	€191	€210	€250	€270	€270	€290	€320	€332.50	No change
Couple	€190	€317	€382	€420	€500	€540	€540	€580	€640	€665	
Increase	+ 350%										0%

⁷ 116,838 carers received Carer's Support Grant in 2020. A total of 92,604 carers receive the Grant automatically because they receive Carer's Allowance or Carer's Benefit. Means approximately 24,234 carers receive the Grant as a stand-alone payment. Note, may be some duplication as 43,500 recipients of DCA also receive the Grant.

⁸ DEASP 'Review of Carer's Allowance 2019' (p.33) estimated a cost of €55m for increasing the Carer's Allowance income disregard to the level of average industrial earnings. The costing of €14m is based on a €35 increase, moving gradually towards the income disregard meeting average weekly earnings.

⁹ Average earnings in Q4, 2020 were €826 while the income disregard for Carer's Allowance is €332.50/€665 (couple).

¹⁰ A household with a gross income of €61,000 will receive a weekly Carer's Allowance of €4.

Living Wage

The Programme for Government commits to progressing to a 'living wage' (€12.30 per hour) over the lifetime of this Government. While the calculation of the Living Wage is based on a single adult household, the Living Wage Technical Group recognises that households with children experience additional costs and as such have calculated a range of Family Living Income needs. Given that under the existing Carer's Allowance means test only households with a gross income of less than €37,500 are eligible for the maximum rate of Carer's Allowance (€219), and those with a gross income of up to €62,000 receive a greatly reduced rate, then four of the six family types identified by the Technical Group would be ineligible for Carer's Allowance (where both parents work) or receive only a reduced rate of Carer's Allowance. The exclusion of families living on a Living Wage further emphasises the extent to which the commitment to ensure the Carer's Allowance income disregard kept pace with Average Weekly Earnings (Towards 2016) has not been achieved.

TABLE 2: FAMILY LIVING INCOMES - ANNUAL GROSS SALARY PER ADULT, 2020 € PER ADULT¹¹

Family Type	From €	To €
Two parents and one child (infant)	20,540	26,230
Two parents and two children (one in pre-school and one in primary)	21,150	30,095
Two parents and three children (one infant, one pre-school, one in primary)	24,605	43,315
Two parents and four children (two in primary and two in secondary school)	32,740	42,500
One parent and one child (in primary school)	20,540	39,855
One parent and two children (one in pre-school and one in primary school)	39,855	56,325

Increase the €20,000 disregard to €50,000 in the Capital Formula:

Cost est. €5m

Because the State makes no provision for the future care of children and adults with care needs, families must do so. It's not uncommon for carers, particularly the parents of a child with a disability, to go without in order to save money towards their child's future care. In doing so, these carers are penalised by virtue of the capital formula applied to their savings and assets in the means assessment for Carer's Allowance. Family Carers Ireland is calling for the capital formula - which has not changed since 2005 - to be increased from €20,000 to €50,000 in line with the Disability Allowance. We are also calling for the maximum assessment rate to be reduced from €4 to €3 in every thousand euro assessed.

TABLE 3: CAPITAL FORMULA

Carer's Allowance (Current)		Carer's Allowance (Proposed - same as DA)	
Capital	Weekly means	Capital	Weekly means
First €20,000	Nil	First €50,000	Nil
Next €10,000	€1 per €1,000	Next €10,000	€1 per €1,000
Next €10,000	€2 per €1,000	Next €10,000	€2 per v1,000
Balance (over €40K)	€4 per €1,000	Balance (over €70K)	€3 per €1,000 ¹²

¹¹ https://www.livingwage.ie/download/pdf/living_wage_2020_4_page_annual_paper.pdf

¹² FCI are calling for this to be reduced to €3 in every thousand euro.



€3m in annual funding towards a dedicated Carer's Pension for long-term family carers (PfG).

3

We will develop a pension solution for family carers that recognises their important work (PfG p76).

It's long been 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. The number of carers affected by this anomaly is relatively small. However, for those who have devoted their lives to caring, but are told at pension age that their years of hard work and personal sacrifice is not enough to warrant a State Pension, the hurt and insult is immense.

While the Total Contributions Approach (TCA) to the calculation of the State Pension Contributory includes 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 partner's income or assets owned.

The State should develop an individualised pension solution for carers to ensure they have an adequate income once they reach retirement age (Citizen's Assembly 2021).

For many years, Family Carers Ireland has lobbied for an equitable State Pension that recognises rather than penalises family carers and values the 'contribution' they make through their years of caregiving, in the same way we value social insurance 'contributions' paid through PRSI. Family Carers Ireland is therefore heartened by the Programme for Government commitment to address the long-standing pension anomaly affecting family carers (p.76) and we welcome the constructive engagement we have had to date with the Pensions Commission. In summary, Family Carers Ireland:

- acknowledges that the introduction of a **TCA** for those who have spent time outside the paid workplace to provide care has addressed a significant number of the legacy issues attached to the Yearly Average Approach. The TCA does not however address all issues. For this reason, we recommend the introduction of a non-means-tested **Lifetime Carer Pension scheme** to ensure no carer is denied a pension or receives a reduced pension due to significant periods spent caregiving.
- defines a lifetime carer as a family carer who has **provided fulltime care (at least 35 hours per week) to someone in need of care for 20 years or more**. The duration of their caring role places them beyond the protections afforded by the Homemakers Scheme and the Home Caring Period.
- recommends the broad **introduction of the TCA including the Home Caring Period Scheme**, as proposed by the National Pensions Framework, to improve pension provision for family carers who have cared for less than 20 years.
- recommends that supports for carers who wish to remain in employment are in place and should include flexible work arrangements, including the transposition of the **EU Directive on Work Life Balance for Parents and Carers**, more generous tax credits and reliefs and better access to respite and replacement care to enable the carer to engage in work.

Publish a refreshed National Carer's Strategy Action Plan 2021 - 2025 with ringfenced funding (PfG).



The National Carers' Strategy presents in a single document all the actions that will be undertaken by Government, across relevant departments, to improve the lives of family carers. These actions span the range of needs family carers and those for whom they care have, including recognition, access to homecare and respite, financial supports, transport, information, advocacy, housing, training, employment and the right to a life of their own away from their caring role. The importance of having an up to date National Carers' Strategy cannot therefore be overstated.

The actions contained within Ireland's first National Carers' Strategy, published in 2012, have been exhausted, however Government has renewed its commitment to review and update the strategy during the term of this Government (PfG, p.76). Family Carers Ireland has engaged closely with the Department of Health and has made a written submission outlining the actions we believe the refreshed National Carers' Strategy should contain, all of which are based on the commitments already set out in the Programme for Government. We have received assurances from the department that the refreshed strategy is a priority and will be published in 2021. Given the period of significant health reform that we are now in the midst of, including the implementation of Sláintecare and the creation of a statutory homecare scheme (both of which are predicated on the provision of care in the home) as well as the changes that have been brought about by the COVID pandemic, it is critical that a refreshed National Carers' Strategy and action plan for the period 2021 - 2025 is developed alongside ringfenced funding for its delivery. While it is difficult to estimate how much the National Carers' Strategy is likely to cost until the final action plan is agreed, the €5m estimate assumes that actions contained in the refreshed strategy that are already committed to, such as the creation of a Statutory Homecare Scheme, will have secured funding in their own right and therefore the €5m relates to the funding of new actions. As with all costings included in this submission, figures should be confirmed by the Parliamentary Budget Office (PBO).



Introduce a Statutory Homecare Scheme (PfG) including an annual entitlement to 20 days respite and a Carer Needs Assessment for fulltime carers.

5

Government's commitment to the creation of a statutory homecare scheme is well established and set out in a raft of policy documents, including Sláintecare, the Programme for Government and the COVID-19 Nursing Home Expert Panel report. While the importance of the scheme has been amplified by the COVID pandemic, the crisis has also caused its delay, with the scheme's pilot postponed until 2021 rather than 2020 as originally planned. While this delay is understandable, Family Carers Ireland is calling for the establishment of the scheme to be given utmost priority, with appropriate funding made available in Budget 2022 to meet the demand implications of introducing a statutory homecare scheme. The ESRI predict that following the creation of the scheme, the number of hours provided through publicly funded home support could increase from 18.56 million hours pre-COVID in 2019, to almost 42 million hours - a 126 per cent increase¹³. It is important to note, these projections are based only on the demand generated by older people aged over 65 and do not include demand from younger adults with care needs who will also be provided for under the scheme¹⁴.

Provide an annual entitlement to 20 days respite for fulltime family carers:

Cost to be estimated by Parliamentary Budget Office.

Respite (time away from caregiving responsibilities) has been identified as one of the most necessary and effective strategies to preserve and improve the well-being and quality of life of family carers. Respite is necessary to give carers the freedom they need to look after their own health and wellbeing, enjoy social and family relationships and other aspects of their lives that may have been neglected due to their caregiving responsibilities. Respite is also internationally accepted as a critical component to addressing the long-term care crisis and improve the sustainability of informal care.¹⁵

It is therefore deeply concerning that family carers, on whom the health system is so reliant, have no entitlement to any time away from their caring role. While labour laws rightly stipulate a basic annual leave entitlement of 4 weeks for paid employees, family carers are not entitled to a single day's respite. The impact of this is clear from research repeated by Family Carers Ireland in 2019, but first undertaken in 2009, which shows that the situation of family carers has gotten worse during this ten-year period. Carers' health, both physical and mental, has deteriorated as has their access to vital supports and services including respite. Carers reported in 2009 and again in 2019 that they need more respite and homecare hours to support them to be healthy. Despite these calls, in the last decade there has been a 70 per cent increase in the number of carers diagnosed with depression; a 24 per cent increase in carers reporting poor health; a 30 per cent increase in those experiencing anxiety and a 65 per cent increase in the number of carers who have no access to respite. In 2019, 83 per cent of carers stated that they didn't have access to appropriate respite¹⁶.

¹³ ESRI (2021) 'Demand for the Statutory Homecare Scheme'.

¹⁴ HSE Winter Plan 2020/2021 and Service Plan 2021 collectively provide for 23.7m home support hours, with funding of €619m . Allowing for a modest increase of 10m additional home support hours in 2022 aligned with the introduction of the statutory homecare scheme, and factoring in the accepted 2 per cent increase needed to keep pace with population ageing and growth, would require additional home support funding of €265m in Budget 2022 to bring the total budget to €884m.

¹⁵ Lund DA, Utz R, Caserta MS, Wright SD. Examining what caregivers do during respite time to make respite more effective. *Journal of Applied Gerontology*. 2009;28(1):109–131. doi: 10.1177/0733464808323448. [Google Scholar].

¹⁶ Family Carers Ireland, College of Psychiatrists of Ireland & University College Dublin (2019) *Paying the Price: The Hidden Impacts of Caring*, Dublin: Family Carers Ireland. <https://familycarers.ie/wp-content/uploads/2019/10/Paying-the-Price-The-Hidden-Impacts-of-Caring.pdf>



Family Carers Ireland are calling on the Department of Health to use Budget 2022 and the institution of a statutory home care scheme as an opportunity to legislate for an annual respite entitlement of 20 days. This is in line with the statutory entitlement provided for paid workers and could operate in a similar way to the 30 days free public in-patient care provided for under the HSE's Long-stay Contributions¹⁷.

Provide access to a Carer Needs Assessment to fulltime family carers in crisis or at risk of crisis: *Cost to be estimated by PBO.*

Family Carers Ireland welcomes the HSE's pilot of the Carer Needs Assessment being rolled-out in CHO 2 which aims to assess the impact of the Carer Needs Assessment tool co-designed by the HSE, interRAI and carer representatives. Pending the completion of the pilot and the incorporation of its findings, Family Carers Ireland is calling for access to a Carer Needs Assessment to be enshrined within the statutory home care scheme and made available to fulltime family carers who are in crisis or at risk of crisis across all CHOs.

¹⁷ See: Residential Support Services Maintenance and Accommodation Contributions.

Establish a Commission on Care (PfG) to include an examination of the role, reliance and recognition of family carers in long-term care provision.



The fracture lines of society have been exposed by COVID-19, with older people, adults and children with a disability, those in the poorest health and the people who care for them hardest hit. This has accelerated the need for a renewed focus on our health and social care systems, and has given us an opportunity to reassess the value we place on informal care – which is timely given the significant long-term care challenges that lie ahead due to population ageing. Family Carers Ireland fundamentally believes that this ‘great reset’ must involve recalibrating the relationship Government and society has with family carers and the value placed on their immense contribution. Family carers, many of whom care round the clock behind closed doors, need to know that Government recognises and values them and will give them support, if and when they need it. Given the very significant lessons that have emerged from family carers’ experience of caring through COVID, alongside monumental changes in how and where care is delivered, Family Carers Ireland believes it is imperative that the Commission on Care is established and its terms of reference include the following practical considerations:

- Family Carers Ireland believes that rather than focus only on the care and support of older people, the commission’s focus should include the **care of adults of all ages**. A failure to do so would seem illogical given confirmation that the statutory homecare scheme will extend to adults of all ages.
- It is increasingly clear that the classification of Carer’s Allowance as a ‘social assistance’ payment does not recognise the uniqueness of family carers within the social welfare system and as such is hampering efforts to make the scheme accessible to genuine fulltime carers who we believe should qualify. While the Review of Carer’s Allowance 2019 refers to the Carer’s Allowance means test being the most generous in the social welfare system, this presupposes that it should only be benchmarked against income supports for people of working age which is arguably not the correct categorisation or comparison. Family Carers Ireland is calling for the commission to **review Carer’s Allowance’s classification as a social assistance payment** in the context of the State’s increasing dependence on family carers and the growing responsibilities placed on their shoulders.
- The sustainability of home support and the effectiveness of the statutory homecare scheme is entirely dependent upon securing an adequate **supply of homecare workers** with the skills required to meet the diverse and increasingly complex needs of homecare clients. Indeed, homecare providers agree that the recruitment and retention of homecare workers is **‘undoubtedly the single biggest challenge they face’**¹⁸. It is clear that significant increases in homecare demand as a consequence of the introduction of the statutory homecare scheme will require a commensurate increase in the supply of appropriately trained and vetted homecare workers. As such, we believe the commission should consider how the homecare sector can attract workers by improving working conditions and terms and conditions. Efforts should also be made to consider extending eligibility for work permits for domestic/care work by the Department of Enterprise, Trade and Employment and providing opportunities for undocumented care workers to legitimise their employment through the pending regularisation scheme currently underway within the Department of Justice.
- Respite remains one of the most important interventions to support the sustainability of informal care and as such should be an important consideration in the work of the commission. While Family Carers Ireland’s call to enshrine a right to 20 days respite each year for fulltime carers is ambitious, we believe the commission has an important role to play in taking the first steps towards its realisation. Currently, there is no data on how many respite places or ‘beds’ exist in Ireland, whether for older people, children with life-limiting conditions of adults with care needs. In order for alternative models of care to be considered and presented by the commission, it will be necessary to undertake an **audit of respite provision** which will inform the creation of additional respite supports, both in-home and residential, across the country.

¹⁸ National Community Care Network, 2017.



Finally, while we acknowledge that the Commission on Care may not be the most appropriate forum for consideration of the care of children due to the specific expertise required, Family Carers Ireland believes a **commission dedicated to the care of children living with illness or disability** is of equal importance to the Commission on Care.

Internationally, the WHO acknowledges that children with special needs have been impacted more significantly by COVID-19 than any other group. In an Irish context, the Ombudsman for Children has warned that children with disabilities are being left behind by COVID-19' with the pandemic having a disproportionately negative impact for this group.

Before COVID, almost 215,000 children were on a waiting lists for essential health care services including hospital treatment, speech and language, occupational therapy, physiotherapy and psychology with significant variation in waiting times across the country¹⁹. This figure has increased exponentially due to the redeployment of frontline health professionals during the pandemic. The delay in accessing these essential supports mean that many of Ireland's most vulnerable children are being denied the early intervention support that is critical to their development and is placing them at serious risk of regression. Family Carers Ireland urges Government to establish a Commission on the Care of Children Living with Disability or Illness to make recommendations on how we can prioritise the care of children and address the extensive waiting lists that have persisted for many years.

¹⁹ Figures released through a series of Parliamentary Questions raised by Deputy Stephen Donnelly in December 2019.

About Family Carers Ireland

Family Carers Ireland is *the* national charity dedicated to supporting the 500,000 family carers across the country who care for a loved one, including children or adults with physical or intellectual disabilities, frail older people, those with palliative care needs or those living with chronic illnesses, mental ill-health or addiction. Our vision is an Ireland in which family carers are properly recognised, supported and empowered. Established in 2016 through the merger of the Carers Association and Caring for Carers, we provide a range of services and supports for family carers through our network of Support Centres nationwide and advocate on behalf of family carers at local, regional and national level.

How we have supported family carers throughout the COVID pandemic

Before COVID-19, thousands of family carers across Ireland were 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 the crisis by supporting carers in the following ways:

- Collaboration with Government to ensure family carers were recognised as a vulnerable group.
- Secured philanthropic funding to provide practical supports to carers during the pandemic. These donations are used to deliver in-home respite, emergency cover in the event that a carer become unwell or tests positive for COVID, the purchase and distribution of PPE and supporting carers through online forums and communities.
- Intensive Wellbeing Project developed in collaboration with HSE Disability Services which provides intensive supports to the families of people with a disability who are without services and struggling during the pandemic.
- Developed a Family Carer Emergency Scheme which allows the cared for person's information to be recorded so that in the event of an emergency involving the person's carer, the information can be accessed 24/7 and shared to support a safe transition of care.
- Carer identification cards to allow members to prove their caring status during the pandemic.
- Established a weekly virtual coffee club to provide information to family carers on a range of topics.
- New e-learning modules and information guides to provide valuable guidance on topics such as self-care, living with behaviours that challenge, continence care and nutrition.
- Launched a range of psycho-social supports for family carers in distress (in partnership with Mental Health Ireland) coupled with a telephone/online counselling support service for family carers.
- Established a Crisis Fund to provide financial support to families, including support towards food and clothing, unpaid bills, care equipment, emergency respite, home heating, etc.
- Developed a triage system for the prioritisation of and response to carer needs.
- Wellbeing reviews using the Outcome Carers Star examining seven areas of a carer's life - health, finances, emotions, time for self, their caring role, work/education and life at home. Includes targeted action planning and 12 week follow up.



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