



Family
Carers
Ireland
Fairness for Carers

Family Carers Ireland Pre-budget Submission
Budget 2019



CARERS IN CRISIS

Working to create an Ireland where carers are properly recognised, supported and empowered.

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Family Carers Ireland is working with Government to create an Ireland where carers are properly recognised, supported and empowered; where they are enabled to maintain their own health and wellbeing; to care with confidence; and can participate as fully as possible in economic and social life (National Carers' Strategy, 2012. Vision Statement P.2). Significant policy reforms are needed to make this vision a reality.

The priorities set out in this submission reflect the voices of carers from across Ireland who have shared their stories of crisis and told us what they expect Government to deliver for them in Budget 2019.

Carers in Crisis

Carers are reaching breaking point, overwhelmed by the isolation, ill-health, exhaustion and financial strain that caring can bring. In 2018, Family Carers Ireland invited carers to share their story. Their experiences show that the failure to provide adequate supports, including home care and respite, is leaving carers burnt out, isolated and unable to look after their own health.

Family Carers Ireland has heard from carers who are housebound due to a lack of support, as well as carers who have collapsed due to exhaustion, or who have had to refuse essential medical treatment for themselves because they can't find replacement care to look after their loved one. Others have been forced to leave their jobs to provide care, having then had to resort to using up their savings, giving up their homes or relying on family to cope financially.

Carers also describe battling against a system that:

- Requires Carer's Allowance recipients to provide fulltime care (minimum 35 hours a week), but pays them just €16 more than basic social welfare rates.
- Prevents recipients of Carer's Allowance, Carer's Benefit or the Carer's Support Grant from working or studying more than 15 hours per week.

- Denies carers the right to a break.
- Penalises long-term, 'lifetime' carers who are unlikely to qualify for a Contributory State Pension¹.
- Excludes Carer's Allowance as a qualifying payment for Fuel Allowance, meaning people who move from other welfare payments to Carer's Allowance lose Fuel Allowance valued at €607p.a.
- Includes Carer's Allowance in the assessment of income for the Working Family Payment, meaning a household where Carer's Allowance is received may lose more in the WFP than they gain in Carer's Allowance.
- Reduces the number of home support hours available to an older person or a person with a disability where there is a family member in receipt of Carer's Allowance.
- Expects carers to carry out essential care tasks single-handed, when health and safety regulations prevent paid care workers from undertaking the same task due to the risk of injury.
- Has failed to replace the Mobility Allowance and Motorised Transport Grant withdrawn in 2013.
- Creates geographic disparities in access to services based on historic funding arrangements.
- Means-tests carers' access to the GP Visit Card by offering it only to carers in receipt of Carer's Allowance, while providing universal, non-means tested access to people aged over 70 years and children under 6years.

Today 1 in 10 people in Ireland is a carer.

By 2030, we will need twice as many carers to meet the needs of our ageing population and the increasing number of people with a disability or chronic condition.

Unless urgent action is taken to better support carers and address years of underspending on home care, respite and carer payments, families will be unwilling to take on a caring role and the pressures on our already overburdened health and social care system will significantly increase.

"Carers are the backbone of care provision in this country.

In 2012, the first ever Carers' Strategy was published. We are committed to implementing it in full.

We wish to see greater involvement of carers in the preparation of care plans, aiding the provision of care, together with more accessible training and respite care, to facilitate full support. We also support an increase in Carer's Allowance and Carer's Benefit as well as improved access to counselling supports for carers". PfcG 2016.

10 Priorities for Budget 2019:

1. Urgently address the home care crisis pending the introduction of a statutory home care scheme.

The Department of Health's plan to establish a statutory home care scheme by 2021 is welcome; however, families cannot wait until then to see services improve. Pending the introduction of the statutory scheme, interim measures are urgently needed to address the home care crisis which is seeing thousands of people stuck in hospitals or forced into residential care when they could return or stay at home if appropriate care was provided.



- Home Support Hours² should be increased by at least 25 percent from 17.094m hours provided to 50,500 people in 2018 to 21.4m hours delivered to 53,500 people. (Cost €102m).
- Publish the HSE's Audit of Respite Provision commenced in 2016 and enshrine within the statutory home care scheme an annual entitlement to at least 20 days respite in line with the statutory leave available to paid workers.
- All carers receiving the Carer's Support Grant should be granted a Medical Card. (Cost €64m)³.
- Plan for the future care and housing needs of people with disabilities, and invest in a range of independent living and community-based

residential centres so people with a disability can live with dignity and independence and their parents have peace of mind knowing that their child will be looked after when they are no longer able to provide care.

- Address the shortage of home care workers by reforming social welfare rules and incentivising employment in the sector.

2. Increase carer payments by €20 per week and the Carer's Support Grant to €2,000.

Carers are the only social welfare recipients required to work fulltime as a condition of payment (minimum 35 hours per week), but receive just €16 more than basic social welfare rates. The requirement that they provide fulltime care as a condition of payment means that carers are unique within the social welfare system and should be treated as such.

The current rate of Carer's Allowance of €214 is €6.50 less than it was in 2009, despite a 5.6 percent increase in the Consumer Price Index (CPI) during this period⁴. This means that the equivalised value of Carer's Allowance in 2009 of €220.50 is €233 in 2018, with Carer's Benefit in 2009 of €221.20 equal to €233.65 in 2018.

For the 28,903⁵ fulltime carers who do not qualify for Carer's Allowance, the only recognition of their caring role is the annual Carer's Support Grant of €1,700 - less than €33 per week.

- Recognise the fulltime care required of Carer's Allowance recipients and increase the rate by €20 from €214 to €234 (Cost €79m).
- Increase Carer's Benefit by €20 from €215 to €235 per week (€2.8m).
- Increase the annual Carer's Support Grant from €1,700 to €2,000 (€34m)⁶.
- The Domiciliary Care Allowance, which has not increased in almost 10 years, should be increased from €309.50 to €330 per month (€8.3m)⁷.
- In line with Government's Roadmap for Pension Reform,⁸ increase the hours a carer can work or study while receiving Carer's Allowance, Carer's Benefit or the Carer's Support Grant from 15 to 18.5hrs per week.

² Home Support Hours refers to the combined Home Help and Home Care Package hours.

³ Based on the annual cost of Medical Card of €1,217 (HSE, 2017) and assuming half of all recipients of the Carer Support Grant already have a Medical Card, in line with the general population.

⁴ Based on the percentage change in the CPI from July 2009 to May 2018.

⁵ Approx. 105,000 carers received Carer Support Grant in 2017. Less 76,097 carers who receive Carer's Allowance is 28,903.

⁶ Expenditure on the Carer's Support Grant scheme for 2017 was €192.93m.

⁷ In January 2018 34,000 children received DCA.

⁸ Strand 6: Supporting Fuller Working Lives.

10 Priorities for Budget 2019:

3. Increase the income disregard for Carer's Allowance from €332.50 (single)/€665 (couple) to €450/€900 respectively and extend allowable deductions.



Only **one in five** of Ireland's 355,000 carers receive Carer's Allowance due to the strict eligibility criteria attached to the payment. Given that some 105,000 carers were eligible for the Carer's Support Grant in 2017, it is reasonable to assume that 28,900⁹ carers don't qualify for Carer's Allowance solely due to their means.

Because the financial assessment is applied to gross rather than net income, and does not take into account mortgage repayments, dependent children, college fees, Fair Deal contributions, medical costs etc., the assessment does not reflect the reality faced by many caring families, who may appear financially comfortable based on gross income, but are struggling to make ends meet when normal living and caring expenses are accounted for.

Despite increasing steadily during the period 2000 to 2008, the income disregard for Carer's Allowance has stagnated for the last 10 years. Neither has government honoured the commitment set out in Towards 2016 to expand the income disregards for Carer's Allowance so that all those on average industrial incomes can qualify (p55).

- Increase the income disregard for Carer's Allowance from €332.50 (single) and €665 (couple) to €450 (single) and €900 (couple).
- Extend the allowable deductions in the assessment of means for Carer's Allowance to include dependent children, rent/mortgage payments, medical costs and Fair Deal contributions.
- The formula for assessing means from capital (savings, shares and property) for Carer's Allowance should be increased in line with the Disability Allowance, where the first €50,000 in capital is disregarded rather than €20,000 allowed for Carer's Allowance applicants, reflecting the desire of carers to provide financially for their loved ones after their death.
- The financial assessment for Carer's Allowance should be based on net, not gross, income, in line with the assessment of earnings under Carer's Benefit¹⁰.
- Carer's Allowance should not be subject to tax.
- Disregard the Half-Rate Carer's Allowance in the assessment of means for Fuel Allowance.
- Disregard Carer's Allowance and Carer's Benefit in the assessment of income for the Working Family Payment.



Changes in Carer's Allowance Income Disregard 2000 - 2018

Budget	2000	2001	2002	2003	2004	2005	2006	2006	2007	2008	2008/2017
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%

⁹ 105,000 recipients of the Carer's Support Grant less the 76,097 carer in receipt of Carer's Allowance.

¹⁰ With Carer's Benefit the maximum amount a carer can earn if the work 15 hours is €332.50 per week. (€332.50 is the net income after you have deducted income tax and Universal Social Charge, PRSI, superannuation, pension levy, union dues, subscriptions to Friendly Societies and any health insurance contract premium from your total wage.)

10 Priorities for Budget 2019:

“Joan entered employment at the age of 16 in 1965. In 1974 her first child Mark was born with a disability. Joan was unable to return to work and devoted her life to caring for Mark.

She reached age 66 in 2015 however as she had only 460 paid contributions and 62 credited contributions she did not qualify for the State Pension (Contributory). Because Joan’s husband was employed as a Civil Servant and paid a Class B stamp (pre 1995), his civil service pension was fully assessable in the means test of the State Pension (Non-Contributory) and so Joan didn’t qualify for the State Pension (Non-Contributory) or an Increase for a Qualified Adult (IQA), nor could she make voluntary contributions. Therefore, despite caring fulltime for Mark for 43 years (saving the State €1.2m¹¹) without ever receiving Carer’s Allowance, Joan has no entitlement to any State Pension and is financially reliant on her husband.”

4. Address the anomaly affecting carers who have no State Pension entitlement.

The introduction of a Total Contribution Approach and a homemaking credit of up to 20 years as set out in a ‘Roadmap for Pension Reform’ will help address anomalies in the current yearly averaging system. However, there remains a relatively small number of long-term carers who qualify for neither a State Pension (Contributory), State Pension (Non-contributory) or Increase for a Qualified Adult (IQA), due to their caring responsibilities and the assets of their partner. They therefore receive no acknowledgement from the state of their years of care, and the enormous contribution they make.



- Introduce a ‘carer pension’ that recognises the contribution of lifetime carers who have cared in excess of 20 years but don’t qualify for a State Pension.
- Overhaul the Homemaker’s Scheme to offer more practical interventions for carers such as making voluntary contributions on their behalf; offering generous tax relief on voluntary contributions paid by partners; or abolishing the 2-year rule¹² and awarding carer credits to all carers.

5. Extend eligibility for Carer’s Benefit to include the self-employed.

Carer’s Benefit is an import scheme for supporting working carers who need to leave employment temporarily to provide fulltime care for a loved one, and is attached to one of the most generous Carer’s Leave arrangements internationally.

It is therefore concerning that take up remains relatively low, with just 2,763 people in receipt of Carer’s Benefit in May 2018¹³. Family Carers Ireland believes more should be done to promote Carer’s Benefit and Carer’s Leave amongst working carers, and that the scheme should be extended to include people who are self-employed in line with commitments made in the Programme for Partnership Government.

- Extend eligibility for the Carer’s Benefit scheme to include people who are self-employed (paying a Class S stamp).

6. Extend the Free Travel Scheme to children in receipt of Domiciliary Care Allowance.

Children in receipt of Domiciliary Care Allowance (DCA) are the only recipients of a ‘disability’-related welfare payment that are excluded from the Free Travel Scheme. This anomaly leads to the situation where parents travelling with a child in receipt of DCA have access to free travel if they receive Carer’s Allowance, but the child for whom they care must pay.

- Children in receipt of DCA should have an automatic entitlement to the Free Travel Scheme.

¹¹ Based on CSOs Irish Health Surveys average weekly care of 45 hours x €12 p/h over 43 years.

¹² Carer Credits are only awarded to carers who receive Carer’s Allowance within two years of their last paid contribution.

¹³ Caring for 3,178 people.

7. Replace the Mobility Allowance and Motorised Transport Grant withdrawn in 2013.

The failure to replace the Mobility Allowance and Motorised Transport Schemes, withdrawn in 2013 on the grounds of age discrimination, has led to the illogical situation whereby those who received a Mobility Allowance prior to 2013 have been allowed to keep it while others now equally in need are locked out. It also means that the only transport support available is the Disabled Drivers and Passengers Scheme, which is targeted only at those with severe physical disabilities, with no support available to those with an intellectual disability.

This prioritises the needs of people with physical disabilities over those with an intellectual disability and is subject to legal challenge.

- Immediately introduce the Transport Support Scheme committed to in 2014 as a replacement for the Mobility Allowance and Motorised Transport Grant.
- Extend eligibility for the Disabled Driver and Disabled Passengers Scheme to all people with a disability, not only those with a physical impairment

8. Disregard Carer's Benefit and Fair Deal contributions in the assessment of SUSI Grants.

While Carer's Allowance is disregarded in the assessment of means for SUSI grants Carer's Benefit is not, meaning third-level students may not be eligible for a SUSI grant, or receive a reduced grant if either parent receives Carer's Benefit.

Another anomaly in the financial assessment of SUSI grants is the failure to disregard Fair Deal contributions being paid in respect of a parent. In one instance a student was unable to attend college as she was refused a grant based on the income of her parents. However, the assessment by SUSI did not allow the deduction of the €600 weekly contribution being paid in respect of her father's nursing home care as he had early-onset dementia.

- Disregard Carer's Benefit and Fair Deal Contributions in the assessment of SUSI grants.



9. Reduce processing times for Carer's Allowance and establish a centralised Medical Assessment Unit.

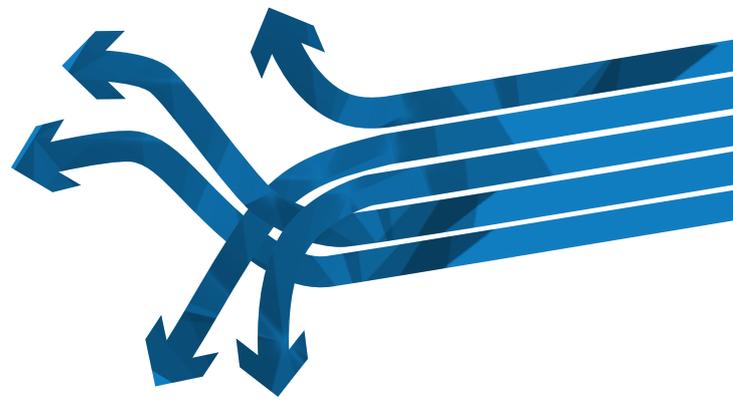
Processing times for Carer's Allowance applications now range between 15-18 weeks, with similar delays in the processing of the Domiciliary Care Allowance and Disability Allowance, with some applicants facing significant financial hardship pending approval of their payment.

While Family Carers Ireland acknowledges the significant increase in the number of applications received by the Department in recent years and the efforts of staff to deal with the backlogs, we believe that a reform of internal systems is required to address the ongoing issue of delays. Family Carers Ireland recommends the creation of a cross-departmental, centralised Medical Assessment Unit which would manage the medical assessments of all social welfare and health supports.

Such a unit would provide a single, uniform system for medical assessment and reviews, replacing the different systems currently operated across departments, help streamline work processes resulting in more efficient processing, reduce the number of Medical Assessors required, improve customer services and help to ensure a more accountable and better managed medical assessment process. Pending the success of the centralisation of a Medical Assessment Unit, a similar approach could be extended to include a centralised financial assessment unit.

- Allocate additional staff to the Carer's Allowance, Domiciliary Care Allowance and Disability Allowance sections to address backlogs in claims processing.
- Establish a centralised Medical Assessment unit to manage the medical assessments of all social welfare and health supports.
- Recipients of the Carer's Support Grant who then apply for Carer's Allowance should not be required to complete the medical report section of the CR1 form, similar to the arrangement in place for carers of children in receipt of DCA.

10 Priorities for Budget 2019:



10. Publish a refreshed and funded National Carers' Strategy (2018-2023).

Ireland's first National Carers' Strategy (NCS), published in 2012, signalled the State's commitment to respecting carers as key partners in care and responding to their needs across a number of policy areas. At the time of its publication, while the country was in the midst of the financial crisis, Government warned of the limited resources available and emphasised that actions could only be implemented on a cost-neutral basis. This warning was however accompanied by a commitment that as Ireland's economy recovered, Departments would be given the opportunity to revisit the Strategy and propose additional actions (NCS, page 3).

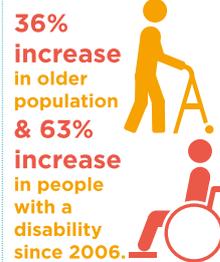
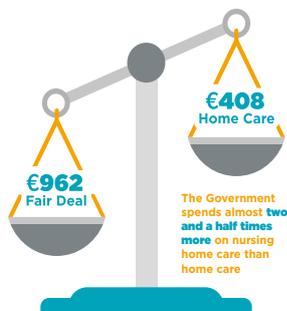
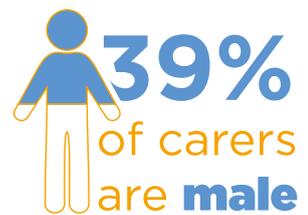
The intention to review the Strategy was also agreed in advance of its publication, with a pledge to build in periodic reviews to ensure the Strategy remained relevant and fit for purpose (NCS, page 19).

In addition, Family Carers Ireland received a written commitment from each political party in advance of Election 2016 that, if elected, they would publish a refreshed NCS backed by dedicated funding.

The refreshed Strategy must include a dedicated budget for implementation and offer carers a more ambitious set of actions, framed by the outcomes that matter most to carers and which are lacking in the original strategy (i.e. flexible respite, access to quality homecare, financial support, involvement in care planning, transport, support for working carers, housing grants etc.).

It must also reflect the significant departmental changes that have taken place since 2012, alongside the establishment of new agencies who now also have a role in supporting carers.

- Ring-fence funding for phase two of the National Carers' Strategy 2018-2022.
- Remedy the postcode lottery experienced by carers and support the move to primary care by increasing section 39 funding to Family Carers Ireland to allow us to deliver a package of supports, including respite to carers in each of the 9 CHO regions.



Employment & Social Protection

- Address the shortage of homecare workers by reforming social welfare rules and incentivising employment in the sector.
- Recognise the fulltime care required of Carer's Allowance recipients and increase the rate by €20 from €214 to €234 (Cost €79m).
- Increase Carer's Benefit by €20 from €215 to €235 per week.
- Increase the annual Carer's Support Grant from €1,700 to €2,000 (€34m)
- In line with Government's Roadmap for Pension Reform increase the hours a carer can work or study while receiving Carer's Allowance, Carer's Benefit or the Carer's Support Grant from 15 to 18.5hrs per week.
- Increase the income disregard for Carer's Allowance to €450 (single) and €900 (couple).
- Extend the allowable deductions in the assessment of means for Carer's Allowance to include number of dependents, rent/mortgage payments, medical costs and Fair Deal contributions.
- The formula for assessing means from capital (savings, shares and property) for Carer's Allowance should be increased in line with the Disability Allowance, where the first €50,000 in capital is disregarded rather than €20,000 allowed for Carer's Allowance applicants, reflecting the desire of carers to provide for their loved ones after their death.
- The financial assessment for Carer's Allowance should be based on net, not gross, income, in line with the assessment of earnings under Carer's Benefit.
- Disregard the Half-Rate Carer's Allowance in the assessment of means for Fuel Allowance.
- Disregard Carer's Allowance and Carer's Benefit in the assessment of income for the Working Family Payment.
- Introduce a 'carer pension' that recognises the contribution of lifetime carers who have cared in excess of 20 years but don't qualify for a State Pension.
- Overhaul the Homemaker's Scheme to offer more practical interventions for carers such as making voluntary contributions on their behalf; offering generous tax reliefs on voluntary contributions paid by partners; abolishing the 2-year credit rule and awarding credits to all carers.
- Extend eligibility for the Carer's Benefit scheme to include people who are self-employed (paying a Class S stamp).
- Children in receipt of DCA should have an automatic entitlement to the Free Travel Scheme.
- The Domiciliary Care Allowance which has not increased in almost 10 years should be increased from €309.50 to €330 per month (€8.3m).
- Allocate additional staff to the Carer's Allowance, Domiciliary Care Allowance and Disability Allowance sections to address backlogs in claims processing.
- Recipients of the Carer's Support Grant who then apply for Carer's Allowance should not be required to complete the medical report section of the CR1 form, similar to the arrangement in place for carers of children in receipt of DCA.

DEPARTMENT

Summary of Priorities

Health/ HSE

- Home Support Hours should be increased by at least 25 percent from 17.094m hours provided to 50,500 people in 2018 (average 6.5 hours per week) to 21.4m hours delivered to 51,500 people (average 8 hours per week). (Cost €102m).
- Publish the HSE's Audit of Respite Provision commenced in 2016 and enshrine within the statutory home care scheme an annual entitlement to at least 20 days respite in line with the statutory leave available to paid workers.
- All carers receiving the Carer's Support Grant should be granted a Medical Card. (Cost €64m).
- Plan for the future care and housing needs of people with disabilities, and invest in a range of independent living and community-based residential centres so people with a disability can live with dignity and independence and their parents have peace of mind knowing that their child will be looked after when they are no longer able to provide care.
- Immediately introduce the Transport Support Scheme committed to in 2014 as a replacement for the Mobility Allowance and Motorised Transport Grant.
- Ring-fence funding for phase two of the National Carers' Strategy 2018-2022 (DPER).
- Remedy the postcode lottery experienced by carers and support the move to primary care by increasing section 39 funding to Family Carers Ireland to allow us to deliver a package of supports, including respite to carers in each of the 9 CHO regions.

Education & Skills

- Disregard Carer's Benefit and Fair Deal Contributions in SUSI grant assessments.

Finance

- Carer's Allowance should not be subject to tax.

Expenditure & Reform

- Establish a centralised Medical Assessment unit to manage the medical assessments of all social welfare and health supports.
- Ring-fence funding for phase two of the National Carers' Strategy 2018-2022.