

Statement of Priorities (DSP Focus) - Budget 2025

There are over 516,000¹ family carers in Ireland, providing millions of hours of care and support each day to friends, family members and neighbours across the country. Many of these carers have removed themselves from the paid workforce as the caring responsibilities they have make it almost impossible to balance work and care. More again are doing that balancing act, working in the paid labour force whilst also providing significant levels of care in the evenings and at weekends, and whenever necessary. The contribution that these family carers provide to Irish society – not to mention the economic savings to the Exchequer in terms of replacement care costs – is significant. We acknowledge the sentiments from Government, as outlined in the current Programme for Government that;

Family carers are the backbone of care provision in Ireland.

They deserve support and recognition from Government.

However, this support and recognition must come in the form of actions and not simply in words².

This Care Alliance Ireland Pre-Budget Statement for Budget 2025 summarises three key priorities which, would continue to progress the development of services and supports for Ireland's over 500,000 family carers.

Priority 1: Funded Policy Development

Priority 2: Funding of Services and Supports

Priority 3: Addressing Poverty and Income Inequality

For this submission, we have focussed our attention on the actions and issues most relevant to the remit of the DSP, as requested. We have included our key asks relevant to other Departments as bullet points for brevity but are open to discussing these at any stage with relevant representatives.

This submission should not be seen as the collective views of all Care Alliance Ireland members. We have consulted with our member organisations in preparation for this submission, however we do expect that many of them will make, or have made, their own submissions. We asked our member organisations to identify and rank their key concerns for Budget 2025 and the results are outlined below in ranked order, most important first.

¹ Care Alliance Ireland, 'Family Carers in Ireland - Infographic', 2023.

² Care Alliance Ireland, 'Family Carers and Being a "Hero"' (Care Alliance Ireland, 2022).

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The percentage of respondents who identified the issue within their top 3 priorities is in column three.

Priority rank	Item	% of respondents who identified issue within top 3
=1	Scrapping of the Means Test for Carers Allowance	54.4
=1	Introduce funding to address gaps in service provision where individuals experience 'comorbidities' and therefore can effectively slip in between the cracks	54.4
=2	Investment into respite services to increase availability of short term and emergency respite places	45.5
=2	Increasing the number of hours a family carer can work/study/volunteer and still be eligible for Carers Allowance/ Carers Benefit (currently set at 18.5hrs per week)	45.5
=3	Increases in rates of payments to family carers and those the care for and support	36.4
=3	A new, updated National Carers Strategy with associated ringfenced funding	36.4
4	Increases to the Carer Support Grant	27.4
=5	Extend GP Card Eligibility to those in receipt of the Carer Support Grant	9.1
=5	Introduce the Transport Support Scheme announced in 2014 as a replacement for the Mobility Allowance and Motorised Transport Grant	9.1

Priority 1: Funded Policy Development

Key Ask:

- **Development of a new National Carers Strategy with dedicated ringfenced funding, per the Programme for Government.**

Priority 2: Funding of Services and Supports

Key Asks:

- **Funding of programmes to address the specific needs of family carers from minority populations.**
- **Extend GP Visit Card eligibility to those in receipt of the Carer Support Grant, as committed to in the Programme for Government.**
- **Increased funding to specifically address service gaps for those with intersectional support needs (e.g. those who are intellectually disabled AND over 65 AND with mental health concerns).**
- **Multi-year funding to enable Care Alliance Ireland, and our member organisations, to continue to support family carers on a sustained basis.**

Priority 3: Addressing poverty and income inequality

It has been shown that there is an economic cost to having, or caring for someone who has, a disability or long-term health condition (be that physical or mental health)³. Income support is vital for many full-time family carers in Ireland today. Due to the all-encompassing nature of a great deal of the care provided, many family carers have taken an extended break from their paid employment in order to care for their loved ones. This means that they are generally dependent on income support to manage their day-to-day finances. Research from 2022, from Family Carers Ireland found that 68% of family carers experience financial distress, with 13% in arrears with their rent or mortgage (in contrast to 7% of the general population)⁴. It is clear, therefore, that protecting and expanding

³ Carers UK, 'The Cost of Caring: How Money Worries Are Pushing Carers to Breaking Point' (Carers UK, 2011); John Cullinan, 'The Economic Costs of Disability for Families', *Frontline: The Irish Voice of Intellectual Disability*, no. 97 (2015); John Cullinan and Sean Lyons, 'The Private Economic Costs of Adult Disability' (Disability through the Lifecourse: ESRI Research Conference, Economic and Social Research Institute, 2014); Bernadette MacMahon, Hannah Boylan, and Robert Thornton, 'Care at Home: Costs of Care Arising from Disability' (Family Carers Ireland, 2022); Alzheimer Society of Ireland and Family Carers Ireland, 'The Cost of Living While Caring: A Brief Report on the Financial Situation of Family Carers of People with Dementia in Ireland', 2023.

⁴ Family Carers Ireland, 'The State of Caring 2022' (Family Carers Ireland, 2022).

income support schemes are vital for ensuring that family carers can continue to perform their roles with some level of financial security.

In light of the success of the Basic Income for the Arts (BIA) pilot scheme which provides a payment of €325 per week to artists, there is an opportunity to rethink how financial supports are provided to those caring for friends and family at home. Additionally, in 2020 the National and Social Economic Council (NESC) recommended the development of a ‘participation income’ to recognise the contribution of those who are not currently working in the economy, but who are making a contribution to society in some other way – for example by caring for family or friends, or undertaking significant volunteer work⁵.

Many family carers see the various income supports for family carers (i.e. the Carer Support Grant, Carers Benefit and Domiciliary Care Allowance) as a payment for the work they do, as opposed to a payment to keep them out of poverty. For this reason, the means test for Carers Allowance in particular can be very distressing, as can reviews of their means as a household. For them, the care needs of those they support are unlikely to have changed – and if they have, their caring is more likely to have increased in intensity over time. If the Government is truly seeking to acknowledge the considerable work that family carers undertake on a daily basis, and to show appreciation for that contribution, significant enhancements to the income supports schemes available to family carers are an appropriate place to begin.

In our Pre-Budget Submission to the Department for Budget 2024, we welcomed the commitment of the Department to a review of means testing across government departments and were pleased to be in discussions with the relevant policy makers throughout the past 12 months in this regard. We also called for a specific review of the means test as it applies to family carers. Whilst we appreciate it is an ambitious ask, we have called for a review and a fundamental shift in thinking of how both Carers Allowance and Carers Benefit are thought of within the welfare system as part of our input to the Joint Oireachtas Committee on Disability Matters (May 2023)⁶ and more recently the Joint Oireachtas Committee on Social Protection, Community and Rural Development and the islands on the specific topic of means testing on Carers Allowance (May 2024)⁷. We prepared both an opening statement⁸ and briefing document⁹ for that Committee, which should be read in conjunction with this submission.

⁵ National Economic and Social Council (NESC), ‘The Future of the Irish Social Welfare System: Participation and Protection’ (National Economic and Social Council, 2020).

⁶ https://www.oireachtas.ie/en/debates/debate/joint_committee_on_disability_matters/2023-05-11/

⁷ https://www.oireachtas.ie/en/debates/debate/joint_committee_on_social_protection_community_and_rural_development_and_the_islands/2024-05-29/

⁸ https://www.carealliance.ie/userfiles/files/CAI_JOC_MeansTesting_May2024_Statement.pdf

⁹ https://www.carealliance.ie/userfiles/files/CAI_JOC_MeansTesting_May2024_BriefingDoc.pdf

Family carers remain the only customers of the Department of Social Protection who are effectively required to work full time to receive an income support. This already positions family care very differently to other schemes within the department and should be treated accordingly.

Carers Support Grant

We acknowledge that the Carer Support Grant is a considerable and welcome economic boost for family carers (in particular for those who may not qualify for other financial supports). However, this grant is a once-off payment which is distributed once each year to those in receipt of Carer's Allowance/Benefit (along with others who have applied for the grant in its own right). It is paid on a single date in June. Therefore, those who may have been caring for a loved one for 11 out of the preceding 12 months do not receive the payment.

In general, there are two reasons for a family carer to no longer be in receipt of Carer's Allowance or Benefit: the death of the person they care for; or their entry into long-term care. Both of these significant life events are characterised by bereavement and high levels of stress, and sometimes quite considerable financial outlay. If the person they cared for at home has moved to residential care, in many cases the family carer continues to provide a significant level of care, with regular - often daily - visits.

In addition, there are many family carers whose caring responsibilities are episodic and unpredictable in nature, for example those family carers supporting a person with a chronic condition (who may experience periods of wellness and illness), and those supporting loved ones with mental health conditions which are often cyclical in nature. The arbitrary timing of this payment means that these family carers may miss out on the payment which they are entitled to in all other ways, but whose administration is not flexible enough to take note of this cyclical nature to their caring role. In addition, we have recently received some evidence that those caring for a child who has recently turned 16, and therefore is changing from being in receipt of Domiciliary Care Allowance to Disability Allowance have had difficulties receiving their annual Grant.

The renaming of the grant in Budget 2016 acknowledged that its purpose is to support family carers in whatever manner they see fit. To compliment this, we strongly suggest that the Carer's Support Grant should have an option for recipients to choose to be administered on a pro-rata basis – perhaps in two six-monthly instalments. This would lessen both carer stress and income inequality, and would speak to a number of actions at the core of the National Carers' Strategy¹⁰.

¹⁰ Caroline Crowley, 'Making the Respite Care Grant a pro Rata Payment', 2015.

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We acknowledge and welcome the increase in Budget 2021 of the rate of the payment to €1,850, to take account of the increased financial pressure family carers experienced during the Covid19 pandemic. We suggest continuing this to increase the payment to €2,000 per annum (or 8%) to account for these pressures continuing into the future, in particular in light of the significant increases in inflation and the increased cost of living over the past three years. We also recommend ensuring that those carers who are caring for a child turning 16 are not disadvantaged by this change in circumstance, as discussed above, come the time of the payment.

Key asks:

- **Increase Carer Support Grant to €2,000 per annum**
- **Facilitate the payment of the Carer Support Grant on a pro-rata basis**

Adaptation grants

Reported difficulties in accessing and availing of different adaptation grants schemes such as those for home adaptations and transport has led to significant distress for many people with disabilities and long-term conditions, and their family carers. Our member organisations repeatedly raise the issue of the lack of availability and transparency of the Housing Adaptation Grants in particular. Concerns have been raised recently that the upper level of payment for the Housing Adaptation Grant, capped at €30,000 is simply not adequate for the work needed in many cases to adapt a home for a person with a disability¹¹. This is especially true in light of even further recent increases in the costs of material and labour. The rates and limits for this scheme have not changed since it first came onto the Statute books in 2007¹². This makes an increase in the rates and limits even more important to ensure that those who need to avail of the Grant to remain living in their communities can do so.

In addition, the repeated lack of introduction to an alternative scheme to the Motorised Transport Grant (closed to new applicants since 2013) continues to be disappointing. This particularly affects rural and isolated family carers who did not apply for the scheme before it was closed eleven years ago. Many of our member groups are supporting individual family carers and family groups who remain considerably isolated because of the combined lack of a replacement scheme, and the lack of adequate accessible public transport in rural locations. This continues to be an issue raised by our member organisations for those they represent and support.

¹¹ See for example <https://www.limerickpost.ie/2022/04/04/call-to-raise-limit-on-housing-adaptation-grants/>

¹² <https://www.irishstatutebook.ie/eli/2007/si/670/made/en/print>

Key asks:

- **Increase the upper level of payment for the Housing Adaptation Grant to €50,000, in particular in recognition of the increased costs of living and economic pressures families continue to experience. This would also help to account for the fact the Grant limits and rates have not been changed since the inception of the Scheme in 2007**
- **Introduce the Transport Support Scheme announced in 2014 as a replacement for the Mobility Allowance and Motorised Transport Grant as a matter of urgency**

Bereavement costs

In previous years we have advocated for the reintroduction of the Bereavement Grant as a means to assist with the significant costs incurred when navigating the death of a loved one. These costs add additional stress and worry to family carers who may already have been experiencing significant financial difficulties due to their time spent caring for the deceased until their death.

However, our colleagues in member organisation of Care Alliance Ireland, The Irish Hospice Foundation, published their report '*The Real Financial Impact of Bereavement*' in May 2023¹³. Following this report, it was clear that the Additional Needs Payment (ANP) is more appropriate in terms of meeting the financial needs people may have following a bereavement. However, further work by the Irish Hospice Foundation found that very few people are aware of the payment, and in addition the administrative burden of application is extremely heavy at a time when they are stressed and potentially very vulnerable.

We therefore support the Budget 2025 asks of the Irish Hospice Foundation in this regard, through a call to review of the knowledge and communication about the Additional Needs Payment, whereby the following options may be explored¹⁴;

- a) There would be a distinct payment within the suite of Supplementary Welfare Allowances (where the ANP currently sits) that uses the word bereavement, as opposed to only addressing the cost of funeral expenses. It was noted in the study that funeral expenses are just one element of the costs associated, others include loss of income or legacy debt, which people may need support to pay for following a bereavement. We recognise and acknowledge that the Community Welfare Services will take all the

¹³ <https://hospicefoundation.ie/our-supports-services/advocacy-research/research/the-real-financial-impact-of-bereavement/>

¹⁴ Note, these following points have been supplied and used verbatim from our colleagues in the Irish Hospice Foundation. Please refer to their Pre-Budget Submission for more detail on this particular topic.

circumstances of an individual case into account and payments in these areas are not restricted to funerals but we would like this to be acknowledged in the language used.

b) The process of applying for the ANP is simplified. Aligned to this there is more targeted publicity about the availability of the payment so that there is more awareness about it. The awareness campaign would put particular emphasis on the availability of bereavement supports such as those outlined on the Government website. Awareness is particularly needed among certain groups such as family carers or bereaved parents with young children that were identified in the qualitative part of the study as being more vulnerable to the economic impacts of bereavement.

- **Key Ask: Review of the knowledge and communication about the Additional Needs Payment in particular for those with additional costs related to bereavement.**

Carers Allowance & Benefit

We acknowledge the measures that were taken in Budget 2024 to widen the eligibility net for those in receipt of Carers Allowance by increasing the weekly income disregards and the increase in the weekly rate of pay in Budget 2024.

Carers Allowance and Benefit remain the sole state income support for which the recipient must record evidence of caring/working full-time (at least 35 hours per week) in order to qualify. This also does not take into consideration that many family carers in receipt of Carers Allowance or Benefit provide far more than 35 hours of care per week – with research indicating that 82% of family carers care for more than 50 hours per week¹⁵.

In addition, Carers Allowance remains a taxable source of income, something which our members have highlighted as inappropriate given the extra costs of caring. In addition, the Department themselves recognise that given the means of those who qualify for the Allowance the likely tax liability is small, and so in practice this simply places an unnecessary administrative burden on family carers, as well as causing significant worry and distress.

However, our key ask in this regard follows our work, and the work of our colleagues in Family Carers Ireland in calling for the abolition of the means test for Carers Allowance, and the creation of a Universal or Participation Income for Family Carers.

We acknowledge the costing analysis for the abolition of the means test for family carers as published by the Parliamentary Budget Office which identifies a cost of between

¹⁵ Family Carers Ireland, College of Psychiatrists of Ireland, and UCD (2019), 'Paying the Price: The Physical, Mental and Psychological Impact of Caring'.

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€301.1m to €449.5m per annum for the abolition of the means test¹⁶. We understand this is not an insignificant cost which the government would need to account for. However, with the estimates that family carers in Ireland save the State up to €20billion each year in equivalent formal care costs, the cost of abolishing the means test, even at the maximum rate as defined by the Budgetary Office, is between 1.5 to 2.25%% of this annual saving. Family carers report feelings of deep stress, anxiety and worry regarding the process of the means test and subsequent reviews. In addition, they report feeling like the process of applying for the means test makes them feel worthless, like they are begging, and not at all like valued members of society¹⁷, contrary to the statements made by Government in their own Programme for Government and the National Carers Strategy. In this, there is therefore a balance to be struck between budgetary concerns and taking real steps towards the true acknowledgment of the considerable contributions that family carers make to Irish society.

With regard to the weekly payment rates, following the most recent research from the Vincentian MESL¹⁸ Research Centre, €237 in 2024 has same purchasing power as €203 in 2020. The recommendation from that research is that an increase of €15 per week is required to enable recipients of social welfare payments to sustain a minimum essential standard of living¹⁹. We join with our colleagues across the sector in advocating for an at minimum increase of €15 across all schemes, including Carers Allowance and Benefit.

Key asks:

- **Remove Carers Allowance as a taxable source of income**
- **Review the Carers Allowance scheme as a whole with a view to abolishing the means test over time.**
- **Increase the weekly Carers allowance and Carers Benefit payments by at least €15 per data from the Vincentian MESL Research Centre**

¹⁶ Parliamentary Budget Office, 'Costing Analysis on Abolishing the Carer's Allowance Means-Test' (Houses of the Oireachtas, 2024).

¹⁷ https://www.carealliance.ie/userfiles/files/CAI_JOC_MeansTesting_May2024_BriefingDoc.pdf

¹⁸ MESL- Minimum Essential Standard of Living

¹⁹ Vincentian MESL Research Centre, 2024. MESL 2024: Annual Update. Publication forthcoming:
<https://www.budgeting.ie/publications/mesl-2024/>



Conclusion

As always, it is crucial that the Government is guided in its decisions on family carers by the three key principles laid out in the National Carers' Strategy, namely: recognition, support and empowerment.

Whilst the income supports available to family carers go some way towards assisting them in their role, major gaps persist. Care Alliance Ireland believes strongly in the value of the state providing a comprehensive suite of supports for family carers, across a range of departments and agencies. We call upon Government once again, as a whole, to prioritise the publication of the second version of the National Carers' Strategy²⁰, with ring-fenced funding for the actions contained within it, and a related implementation plan, using the successful National Disability Strategy Implementation Plan (National Disability Strategy Implementation Group, 2013) as a model.

Background Information on Care Alliance Ireland

There are in excess of 516,000 family carers in the Republic of Ireland. Family carer support is provided by a number of organisations, including those dedicated solely to carer support and others who support carers as part of their response to individuals with specific conditions.

Care Alliance Ireland is the National Network of Voluntary Organisations supporting family carers. Our vision is that the role of family carers is fully recognised and valued by society in Ireland. We exist to enhance the quality of life of family carers. We work with organisations to provide better information and supports to family carers. We provide them with opportunities to collaborate on initiatives including National Carers Week, a multi-agency and multi-disciplinary Family Carer Research Group, and joint policy submissions. We deliver a number of online carer specific projects; namely an Online Family Carer Support Project, and a Back to Work Project. We commission relevant research that supports focused and quality interventions in the lives of family carers.

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²⁰ Note that in early 2021 Care Alliance Ireland in partnership with ISS21 in University College Cork undertook research to evaluate the relevance of the 42 actions within the current National Carers Strategy for 2021. This report is available on our website;

<https://www.carealliance.ie/userfiles/files/CarerEngageNCSReport2021.pdf>