

Statement of Priorities (DSP Focus) - Budget 2024

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. To this end, Budget 2024 presents the last full calendar year in which the sentiments and actions within the current Programme for Government can be acted upon.

We come to this budget deep into a 'cost of living crisis'; recent research from the Vincentian MESL³ Research Centre⁴ points to a 10.6% inflation rate in the core MESL basket to reach a minimum essential standard of living⁵, over the period March 2022-March 2023. In addition, the MESL food basket price for all household types has increased by an average of 20.8% in the year to March 2023⁶. The general increase in the Consumer Price Index (CPI) in Ireland as of March 2023 was 6.6%, which marks the twentieth straight month where the annual increase in the CPI has been at least 5.0%. This lengthy sustained high inflation rate, although dropping overall, is causing significant stress on the financial burden of society at large, not taking into account the additional costs of disability and caring.

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

² Care Alliance Ireland, 'Family Carers and Being a "Hero"' (Care Alliance Ireland, 2022), https://www.carealliance.ie/userfiles/files/CAI_DiscussionPaper12_FamilyCarersAsHeroes.pdf.

³MESL = Minimum Essential Standard of Living

⁴ Vincentian MESL Research Centre, 'MESL Centre Annual Update 2023', 2023

⁵ The MESL basket is more sensitive to food and energy price changes, given the focus on meeting a minimum essential standard of living.

⁶ The MESL food basket is more sensitive to changes in price of staple foods such as milk, bread and butter, which have all increased significantly in price over the time.

This Care Alliance Ireland Pre-Budget Statement for Budget 2024 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.

(Note: This submission should not be seen as the collective views of all Care Alliance Ireland members. We expect that many of our member organisations will make, or have made, their own submissions.)

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:

- **Continue to address waiting lists for services to children with disabilities**
- **Address silo-ing of services in child and adult disability services, particularly regarding the transition point between leaving school and entering employment/further training for people with disabilities.**
- **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.**
- **Funding of training programmes for family carers caring for a person dying at home**
- **Increased funding for online and blended supports for family carers**

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)⁷. 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)⁸. It is clear, therefore, that protecting and expanding 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 work⁹.

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,

⁷ 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.

⁸ Family Carers Ireland, 'The State of Caring 2022' (Family Carers Ireland, 2022).

⁹ National Economic and Social Council (NESC), 'The Future of the Irish Social Welfare System: Participation and Protection' (National Economic and Social Council, 2020).

significant enhancements to the income supports schemes available to family carers are an appropriate place to begin.

We understand that the Department is committed to a review of means testing in general in 2023, as discussed at the most recent Annual Carers Forum (May 2023). We welcome this, but we also see a need for a specific review of the means tests as it applies to family carers. Whilst we appreciate it is an ambitious ask, we recently 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)¹⁰. Family carers remain the only customers of the Department of Social Protection who are effectively required to work full time in order 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

¹⁰ https://www.oireachtas.ie/en/debates/debate/joint_committee_on_disability_matters/2023-05-11/

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' Strategy¹¹.

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 two 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 adaption 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 disability¹². 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 2007¹³. This makes an increase in the rates and limits

¹¹ Caroline Crowley, 'Making the Respite Care Grant a pro Rata Payment', 2015.

¹² See for example <https://www.limerickpost.ie/2022/04/04/call-to-raise-limit-on-housing-adaptation-grants/>

¹³ <https://www.irishstatutebook.ie/eli/2007/si/670/made/en/print>

even more important to ensure that the 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 effects rural and isolated family carers who did not apply for the scheme before it was closed nine 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.

Many family carers are still wary of the threat of Covid19 for the health and wellbeing of their loved ones, and are unwilling to risk what public transport options there may be in their area. Therefore, access to appropriate private transport remains important. Family carers are relying on private transport more than ever, making this particular point critical – in particular noting the continued lack of publication of a new scheme is at odds with statements made by previous Ministers.

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

The discontinuation of the Bereavement Grant in early 2014 has had a significant knock-on effect on the transition to post-caring. We urge that the Bereavement Grant be reintroduced for the families of those in receipt of Disability Allowance, Carer's Allowance and half-rate Carer's Allowance.

In addition, research on the personal and family costs, including funeral costs, should be undertaken to inform Government policy and foster a cross-departmental strategic approach to issues arising at end of life. Policies on supports available for bereavement and funeral costs should be reviewed to ensure that they are appropriate and accessible to those in most need.

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- **Key Ask: Reintroduce the Bereavement Grant**

Carers Allowance & Benefit

We acknowledge the measures that were taken in Budget 2022 to widen the eligibility net for those in receipt of Carers Allowance by increasing the weekly income and capital disregards, and the increase in the weekly rate of pay in Budget 2023. However, we remain disappointed that the income disregards for a single person is set at less than half that for a couple. This anomaly further penalises single carers and lone parents, and should be equalised 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 week¹⁴.

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.

We reiterate our ask for Budget 2023 last year, which called for a review of the Carers Allowance Scheme in light of recommendations from the National Economic and Social Council research concerning a Participation Income for carers, the commitment to the introduction of a pilot Universal Basic Income scheme in the Programme for Government and the current pilot scheme for a Basic Income for the Arts.

In general Care Alliance Ireland does not advocate specifically for increases in the weekly payment rates of Carers Allowance or Benefit. We reiterate each year that investment in services is key for ensuring that family carers do not reach poverty status, as the additional costs of caring and disability are significant drains on household budgets in this area. However, given the significant rise in the cost of living as outlined in recent research from the Vincentian MESL Research centre, anything less than a €27.50 adjustment in core

¹⁴ Family Carers Ireland, College of Psychiatrists of Ireland, and UCD (2019), 'Paying the Price: The Physical, Mental and Psychological Impact of Caring'.

social welfare rates will be a reduction in real terms¹⁵. This is the absolute minimum required to prevent individuals and families being pulled deeper into poverty. Therefore we are calling for such an increase to the Carers Allowance and Carers Benefit weekly rates of payment.

Key asks:

- **Remove Carers Allowance as a taxable source of income**
- **Review the Carers Allowance scheme as a whole**
- **In the interim, equalise the income disregards for the Carers Allowance means test to €325 for a single person and €750 for a couple**
- **Increase the weekly Carers allowance and Carers Benefit payments by a minimum of €27.50, per data from the Vincentian MESL Research Centre**

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' Strategy¹⁶, 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.

¹⁵ Data from the Vincentian MESL Research Centre shows that an adjustment of €27.50 would be needed to restore the real value of core working age payments to 2020 levels but may need to rise to €31 at the end of 2024 depending on forecast inflation. The cost of the basket of goods needed to ensure Minimum Essential Standard of Living has risen by 18.9% since 2020. See Vincentian MESL Research Centre, 'MESL Centre Annual Update 2023', 2023.

¹⁶ 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>

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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