

***Pre-Budget Submission for Budget 2016 to  
The Department of Social Protection***

**Recognising and Respecting Family Carers in Ireland as Key Partners in  
Care**

***June 2015***

**Background**

**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 achieve this by supporting our 100+ member organisations in their direct work with Family Carers through the provision of information, developing research and policy, sharing resources, and instigating opportunities for collaboration.

There are approximately 274,000 Family Carers in the Republic of Ireland<sup>1</sup>. 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.

Our legitimacy derives from our membership base which includes all the carer organisations and virtually all the disease/disability-specific organisations currently providing services to Ireland's Family Carers. Our membership is comprised of both large and small, regional and national organisations.

***What we do***

We work with organisations in order that they can enhance the information and supports they provide 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.

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<sup>1</sup> Department of Health, "The National Carers' Strategy" (Department of Health, 2012).

We act as a distribution channel for information on Family Carer issues, with a quarterly Newsletter, *Care Alliance Ireland Exchange*, which is sent to member organisations and a wide range of stakeholders; and a bi-monthly *Research & Policy E-zine* which is sent to academics, non-profit organisations and other interested individuals. We actively encourage collaboration in all our projects. We provide cohesion to those organisations working to support Family Carers. We commission relevant research that supports focussed and quality interventions in the lives of Family Carers.

By focussing on these discrete functions (research, policy, information, and collaborative ventures), we enable more of our member's funds to go directly to coal face services.

**(Note:** We have consulted our member organisations in preparing this submission; however, the submission is not to be seen as the collective views of Care Alliance members. We expect that many of our member organisations will make, or have made, their own submissions.)

## **Context**

The need for Family Carers to provide support to people in the home is growing both in Ireland and internationally, and will continue to increase over the coming years<sup>2</sup>. A number of significant factors are at play including an aging population, increased life expectancy, increasing rates of women's labour market participation and a decline in family size. Indeed, Census 2011 results point to a significant increase in the numbers of those providing unpaid care in the home<sup>3</sup>. In particular the number of older carers has increased significantly. Care Alliance Ireland is specifically concerned at the growing numbers of 'hidden carers', namely Male Carers and individuals under the age of 18 providing care in the home.

We understand that formal state provision will never be able to meet care needs in full and that Family Carers will continue to provide the majority of such care

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<sup>2</sup> Maev-Ann Wren et al., "Towards the Development of a Predictive Model of Long-Term Care Demand for Northern Ireland and the Republic of Ireland" (Centre for Health Policy and Management, Trinity College Dublin, 2012).

<sup>3</sup> Central Statistics Office, "Profile 8: Our Bill of Health (Census 2011)" (Dublin, 2012), <http://www.cso.ie/en/census/census2011reports/census2011profile8ourbillofhealth-healthdisabilityandcarersinireland/>.

well into the future, as the cost of the State providing the same level of care as Family Carers is estimated between €2.5- €4 billion annually<sup>4</sup>. Indeed, as the focus of Government policy on community based care and support intensifies (for example, as evident in the most recent National Service Plan<sup>5</sup>), so too does the requirement for Family Carers to provide care to relatives in the home. Without adequate support for Family Carers and the continued further development of community-based services, such continued high reliance on family care may be unsustainable in the longer term.

Providing care can be both enriching and rewarding where expectations placed on Family Carers are reasonable and adequate supports are provided. Evidence from research undertaken by Care Alliance Ireland<sup>6</sup> identified the satisfaction that Family Carers may feel in being able to support people that they care about. It is, however, crucial that they are given adequate assistance to sustain them in their role. Caring can also be a source of burden and stress<sup>7</sup>. While providing care to a loved one may be willingly given, there may be costs to many aspects of the Family Carers’ life – these costs can be emotional, physical, social and financial<sup>8</sup>.

The 2012 publication of the first ever National Carers Strategy in Ireland was significant. The Strategy sets out a future roadmap for better recognition and supports for Family Carers across Ireland into the future. We appreciate the considerable work undertaken by various officials in the Department in engaging with carers organisations in our joint pursuit of progressing the strategy’s implementation.

However, in many of the sections of the Strategy, progress has been slow or non-existent, and in some cases, the situation has regressed for family carers. This is evidenced in the “Family Carers’ Scorecard<sup>9</sup>”, recently published by the

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<sup>4</sup> Care Alliance Ireland, “Family Caring in Ireland,” 2015.

<sup>5</sup> Health Service Executive, “National Service Plan 2015” (HSE, 2014).

<sup>6</sup> Ann Stokes, “The Caring Reality of Family Carers: An Exploration of the Health Status of Family Carers of People with Parkinson’s Disease.,” 2010, <http://www.carealliance.ie/userfiles/file/FullReportFinal.pdf>.

<sup>7</sup> Care Alliance Ireland, “Family Caring in Ireland”; Care Alliance Ireland, “Literature Review on the Relationship between Family Carers and Home Care Support Workers,” 2014.

<sup>8</sup> Care Alliance Ireland, “Family Caring in Ireland.”

<sup>9</sup> Carers Association Ireland, “Family Carers’ Scorecard: What Has the National Carers Strategy Achieved? An Assessment of Progress from the Perspective of Family Carers.,” 2015,

Carers Association, and written in consultation with the National Carers Strategy Monitoring Group, which Care Alliance was a member of. Much of this submission is guided by these actions, and the progress (or lack thereof) made since the inception of the Strategy, and the last Budget.

The priority policy areas of our Pre-Budget Submission are supported by the four national goals set out in the National Carers Strategy. We are also guided by the mission statement of the National Carers Strategy which says:

*'Carers will be recognised and respected as key care partners. They will be supported to maintain their own health and well-being and to care with confidence. They will be empowered to participate as fully as possible in economic and social life'.*

## **Income Support**

There is no doubt that income support is critical for the majority of full-time Family Carers<sup>10</sup>, and the maintenance of same must be considered a priority by the Department of Social Protection. While the National Carers Strategy recognises the importance of supporting Family Carers, it fails to guarantee to fully protect current income supports. At the same time, we note the five specific action points identified in the area of income support, and welcome the responsibility the Department of Social Protection has taken on in this regard. The action points are in the area of information, timely access to income supports, reduction in waiting times, highlighting the potential to share an allowance, and a review of transition arrangements post-caring.

We acknowledge the progress made to date in some of these areas, but again highlight our concern that although progress is being made, that progress in many areas was delayed and/ or is progressing at a slow pace.

We again offer to support the Department in putting together specific protocols to keep applicants informed of progress in their application for Carers Allowance

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[http://www.carersireland.com/userfiles/file/Family%20Carers%20Scorecard%20Full%20Report\(3\).pdf](http://www.carersireland.com/userfiles/file/Family%20Carers%20Scorecard%20Full%20Report(3).pdf)

<sup>10</sup> Care Alliance Ireland and Neurological Association of Ireland, "Nationwide Survey of Neurological Carers Highlights Impact of Budget Cuts," 2014, <http://www.carealliance.ie/userfiles/file/National%20Survey%20Highlights%20Impact%20of%20Cutbacks%20on%20Family%20Carers%20Final%20120314.pdf>.

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and Benefit, also noting that the progress made to date is good, and is positively impacting Family Carers<sup>11</sup>.

Regarding the cessation of Carers Allowance post-caring (whether due to bereavement or due to the caree's admission into full-time nursing home care), to reduce anxiety of such carers we again suggest a 6 month period of withdrawal of payment for carers who have been providing full time care for in excess of 3 years. The net cost would be minimal as most traditionally move onto another social welfare payment. We wish to formally request that the Department undertakes a small piece of quantitative research that would establish the exact figures in this matter. We offer our support as appropriate. This will provide an evidence base for consideration of any future change in policy as well as support with workforce planning for former carers, as per The National Carers Strategy (Objectives 4.2., 4.2.4, 4.2.5).

The evidence is that the longer caring continues, the more difficulty former carers have in successfully re-entering the paid workforce. Collaborative research undertaken by Care Alliance Ireland and The School of Nursing and Midwifery, Trinity College Dublin in 2011 on the area of post-caring points to the need for a formalised system of support that addresses the potential poverty trap and the risk of long-term unemployment as a consequence of opportunities lost during full-time caring. We recommend the extension of the recently introduced Back to Work Family Dividend supporting families to include Family Carers, to aid the transition from Family Caring to employment once caring ends.

In addition, the removal of the Bereavement Grant has had a large knock-on effect on the transition to post-caring, which has been visible since it's discontinuation in January 2014. We would suggest that the Grant be reintroduced for the families of those in receipt of Disability Allowance, Carers Allowance, and Half-Rate Carers Allowance.

We note that the status of the action point in the NCS regarding transition arrangements post-caring has regressed since the inception of the Strategy.

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<sup>11</sup> Carers Association Ireland, "Family Carers' Scorecard: What Has the National Carers Strategy Achieved? An Assessment of Progress from the Perspective of Family Carers."

We acknowledge the positive strides in the reduction of waiting list times for the processing of applications for Carers Allowance. We would encourage the department to ensure that this level of resourcing is sustained to maintain this progress. It is also vital that these waiting times are not dependent on the location of Family Carers, but are standard across locations.

### **Half-Rate Carers Allowance**

The current rate of payment of the full Carers Allowance is set at a rate a little above that of the supplementary allowance. For many Family Carers, Carers Allowance may be their only source of income. Both the full rate Carers Allowance and half-rate Carers Allowance are means-tested, meaning they only go to Family Carers on low to moderate household incomes. Many Family Carers have seen a reduction in their overall income due to a number of cutbacks since 2009. At the same time, many Family Carers are faced with severe financial strain as a result of having caring responsibilities and inadequate income supports. Approximately 25,000 Family Carers receive the half rate Carers Allowance. In addition, many of those in receipt of the means-tested half-rate Carers Allowance are aged over 66 years and are already living on a low income. It is vital that this basic support measure is recognised as a core payment.

We believe that the total paid in this scheme is a very small sum when compared with the enormous contribution made by these Family Carers to Irish society. To remove or reduce this payment to such valuable people in our community risks undermining their availability or inclination to provide Family Care, and is likely to place considerable additional pressures on state funded home care and residential care, all at considerable financial cost to the exchequer. In addition, there is some evidence that social welfare payments are spent predominantly in the local economy, with positive immediate economic impacts.

### **Respite Care Grant**

The 19% cut to the Respite Care grant in 2013 was harsh. Notwithstanding this, the Respite Care Grant remains an important source of income to full-time Family Carers. Many thousands of full-time Family Carers, primarily due to means testing, do not receive the Carers Allowance. The Respite Care Grant for them is the only direct financial support they can receive from the state for

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caring for their dependent family member. Ultimately, this payment is an important way of recognising the value and contribution of Family Carers.

Periods of rest and time to oneself are a rare occurrence for many Family Carers. They are also difficult to plan in advance. Respite is essential for many Family Carers, maintaining their health and well-being and thus enabling them to continue in their role of providing care to a loved one in the home<sup>12</sup>. One of the key goals of the National Carers Strategy is to support Family Carers to manage their physical, mental and emotional health and wellbeing, and appropriate access to respite can be a key support in this regard.

Care Alliance Ireland is therefore asking that over a 2 year period, the level of the Respite Care Grant is restored to the €1,700 level it had been.

## **Conclusion**

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.

While the income supports available to Family Carers through the Department of Social Protection go some way towards assisting them in their role, major gaps for Family Carers in Ireland persist. Care Alliance Ireland believes strongly in the value of the state in providing a comprehensive suite of supports for Family Carers, across a number of Departments. Key among these must be a comprehensive assessment of the needs of a Family Carer in their own right. We welcome the progress the HSE is making in the development of a single assessment tool and the inclusion of a Carer Needs Assessment in this process. We encourage the Department of Social Protection to work in collaboration with other government departments and agencies in supporting the implementation of the National Carers Strategy.

By considering our recommendations for Budget 2016, we believe that the Government will go some way to recognising and respecting Family Carers as key partners in care.

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<sup>12</sup> Stokes, “The Caring Reality of Family Carers: An Exploration of the Health Status of Family Carers of People with Parkinson’s Disease.”; Care Alliance Ireland, “Family Caring in Ireland.”

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