

Pre-Budget Submission for Budget 2017

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

Care Alliance Ireland

July 2016

1) Introduction

The need for Family Carers to provide support to people in the home is continuing to grow both in Ireland and internationally, and will continue to do so over the coming years. A number of factors are at play, including increasing life expectancy, an ageing population, declining family size and higher rates of women's labour market participation. Census 2011 data point to a significant increase in the number of those providing unpaid care in the home, with a particular growth in the number of older carers. We eagerly await Census 2016 figures to see how these trends are unfolding.

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 well into the future. The cost of the state providing the same level of care as family carers is estimated to be between €2.5 billion and €4 billion annually (Care Alliance Ireland, 2015). As government policy on community-based care intensifies, so too does the requirement for family carers to provide care to relatives in the home. In addition, it is clear that the primary desire by people who need extra support and care is to receive that care in their own home and in their own community (Donnelly, O'Brien, Begley & Brennan, 2016).

However, it could be strongly argued that various governmental policies are in direct conflict with each other. On the one hand, the focus has been on developing supports for Family Carers with respect to the actions contained within the National Carers' Strategy (Department of Health, 2012) and the Programme for Government (Government of Ireland, 2016). Yet on the other hand, there has been a clear priority to increase the availability of, and funding for, residential care via the Fair Deal

scheme, corresponding with the decreasing availability of home care supports (when accounting for demographic changes) (Care Alliance Ireland, 2016; Donnelly et al., 2016).

Providing care can be both enriching and rewarding where expectations placed on Family Carers are reasonable and adequate supports are provided. Research evidence has identified the satisfaction that Family Carers may feel in being able to support the people that they care about (Brand, Barry & Gallagher, 2016; Stokes, 2010). 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. Whilst care to a loved one may be willingly given, there may be costs to many aspects of the Family Carer’s life: emotional, physical, social and financial.

The following sections focus on what our member organisations have identified over the past year as the critical issues facing the Family Carers that they support, namely:

- 1) Direct income supports
- 2) Allied benefits
- 3) Home Care Packages etc.
- 4) Service improvements

(Note: we consulted our member organisations in preparing this submission. However, the submission should not to 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.)

2) Direct income supports

Income support is a lynchpin for many family carers in Ireland today. Due to the all-encompassing nature of a great deal of the care provided, many Family Carers have taken a break from their paid employment in order to care for their loved ones. This means that they are dependent on income support to manage their day-to-day

finances. Family carers, in general, are at higher risk of poverty than non-carers (OECD, 2011), with research in the UK finding that 72% of family carers were worse off as a consequence of their caring role (Carers UK, 2007). A similar study in Ireland found that over two-thirds of family carers found it difficult to make ends meet (O'Shea, 2000), with a 2014 study by the Neurological Alliance of Ireland finding that 45% of Family Carers of people with a neurological condition had been impacted by the economic impact of caring and the condition on daily life (Neurological Alliance of Ireland, 2014). It is clear, therefore, that protecting and expanding income support schemes is vital for ensuring that Family Carers can continue to perform their roles, which provide the bedrock of care in Ireland.

2.1) Carer's Support Grant

We acknowledge the action in Budget 2016 that restored the Respite Care Grant, (now renamed as the Carer's Support Grant). This has been a request of all Family Carer support organisations since the 19% cut to the grant in 2013, and is a welcome action that will have a meaningful impact on the lives of a great number of Family Carers across the country.

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 those who have applied for the grant in isolation). It is paid, arguably arbitrarily, to those on a list of beneficiaries on a single date in June. 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 occurrences are characterised by bereavement and high levels of stress, and indeed 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.

The renaming of the grant in Budget 2016 acknowledges that its purpose is to support family carers in whatever manner they see fit. We strongly suggest that the Carer's Support Grant should be administered on a pro-rata basis, which would lessen both

carer stress and income in equality, and would speak to a number of actions at the core of the National Carers' Strategy (Crowley, 2015).

2.2) Cessation of payments

We acknowledge the action in Budget 2016 to increase the time which a Family Carer can continue to avail of their Carer's Allowance payment from six to 12 weeks after the death of the person they care for. This is a welcome development. However, it fails to acknowledge the full impact of the cessation of caring for those in receipt of Carer's Benefit or those whose loved ones entered full-time care. In particular, those who have been caring for a sustained period of time (3 or more years) may find it difficult to return immediately to the workforce. Indeed, anecdotal evidence suggests that recipients of Carer's Allowance and Benefit frequently move to another form of social protection payment. The net cost of extending the time of eligibility would therefore be minimal, but would allow for stress and worry about financial security to be minimised.

We thus ask that the eligibility for continuance of payment of Carer's Allowance be extended to 12 weeks post-cessation of caring where this is due to either to death of the person being cared-for or admittance to long-term care.

2.3) Half-rate Carer's Allowance

The current rate of payment of the full Carer's Allowance is set at a little above that of the Supplementary Welfare Allowance. For many Family Carers, Carer's Allowance may be their only source of income. Both full- and half-rate Carer's 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 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 Carer's Allowance, a substantial proportion of whom are aged over 66 years and already living on a low income. It is vital that this basic support measure is continued to be recognised as a core payment. We believe strongly 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.

3) Allied benefits

3.1) Bereavement Grant

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, 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.

3.2 Telephone Allowance

Along with direct income supports, allied benefits such as the Household Benefits Package are crucial to enable family carers to continue caring for their loved ones. The cutting of the Telephone Allowance (to the value of €9.50 per month) was a significant loss to older people and their Family Carers. Isolation is a key issue which Family Carers and those they care for experience on an ongoing basis, and the Telephone Allowance went some way to combatting this. In addition, a landline phone is often a requirement of personal alarms and assisted living devices, which are crucial in allowing many older people to remain living well in their community, supported by Family Carers. Access to these personal alarms and safety devices in turn provides confidence and reassurance to Family Carers that their loved ones are safe and well when they themselves are outside the home attending to other matters. Without these supports, the safety of older people and their ability to remain living at home can be thrown into doubt, once again exacerbating the disparity between official policy (Department of Health, 2012 & 2014) and the actual lived experience of families in Ireland today. We thus recommend that the Telephone Allowance is reintroduced in full.

3.3) Housing Adaptation Grant for People with a Disability

This grant has seen cuts of 56% since 2010 (Disable Inequality, 2016). If government is true to its commitment in multiple policies to ensure that people can continue living in their own homes and in their own communities, then funding for, and access to, the Housing Adaptation Grant for People with a Disability scheme must be increased. In addition, elements of the scheme must be revised to take into account changing demographics (for example, exclude the income of adult children living in the household from the assessment of means).

4) Home Care Packages etc.

4.1) Funding levels

A number of recent studies have highlighted the critical underfunding of the home care sector, in particular when compared with the residential sector. At its most basic level, the HSE spent 3% less on home care in 2015 (€320 million) than it did in 2008 (€331 million), despite a 25% increase in the population aged over 65 years over the same period (Donnelly et al., 2016). In the most recent Budget, the Nursing Home Support Scheme was set to increase by €35 million between 2015 and 2016, but there was a planned reduction of almost €10 million for older people's services (Care Alliance Ireland, 2016).

We acknowledge the recent (June 2016) announcement of additional funds for the health and social care budget, in particular the €40 million additional funds for home care. However, it is unclear where this money will be spent, and the impact it will have given the increasing demographic pressures. There is some evidence that the actual number of hours of home help per client has reduced materially over the years. In 2000, the figure was estimated at eight hours per client per week (Mercer Ireland, 2002); the 2016 HSE targets suggest a figure of a little over four hours per client per week (Care Alliance Ireland, 2016). Looking at delivery from a utilisation and accessibility perspective, increases in service delivery since 2013 will merely have **partially** restored the actual percentage of the 65+ group who are in receipt of services to the level that existed in 2008. As highlighted in the recent report on

provision of home care (Donnelly et al., 2016), people are finding it increasingly difficult to access appropriate Home Care Packages for their loved ones, and there is wide disparity as to their availability at local level. This is forcing people out of their homes and communities, making it very difficult for Family Carers to have any form of respite, even to undertake daily tasks such as shopping or banking.

We therefore call for an increase in the funding levels available for Home Care Packages in Budget 2017. We recommend that the HSE sets a 2016 goal of reaching the 2011 target level of public provision of home care per person aged 65+. Our figures suggest that this will require additional resourcing of €31m in 2016 equating to an additional 1.55m home care hours over and above current published targets. This will also require the collection of data at a national level that details actual hours of home care delivered through Home Care Packages.

In the medium term, we recommend that the HSE sets a goal of reaching the 2008 level of public provision of home care per person aged 65+. Our figures suggest that this would require additional resourcing of €72m in 2016, rising to €116m in 2019 (Care Alliance Ireland, 2016). We also support our member organisation, the Alzheimer Society of Ireland's call for an investment of €67 million for home care supports for people with dementia (Alzheimer Society of Ireland, 2016).

4.2) Age limits

Whilst there are some instances of individuals under the age of 65 accessing Home Care Packages, in general the scheme targets those over retirement age (Care Alliance Ireland, 2016), which we judge to be unfair and which results in a number of unfavourable secondary consequences. To illustrate with just one example from the disability and chronic illness sector, our member organisation MS Ireland is aware of individuals with MS who are unable to be discharged from acute settings due to the lack of Home Care Packages to support family carers to continue to care for these individuals at home. Likewise, a 2010 study by the Economic and Social Research Institute and Royal College of Surgeons in Ireland found that up to €414 million per year is spent by the state on nursing home care for stroke survivors, with less than €7 million spent on community rehabilitation services that can keep people living in their homes. Obviously, this has massive implications for the acute hospital sector,

which could be relieved with adequate funding for Home Care Packages to those under 65.

However, home care should not simply be viewed as a solution to the ongoing hospital crisis. By increasing funding and access to home care, fundamental change can be achieved, which would truly give expression to the ambitions evident in multiple governmental strategies (including: Department of Health, 2012 & 2014; Department of Justice, Equality & Law Reform, 2004).

4.3) Placing community care on a statutory footing

As alluded to above, it is crucial for community care not to be seen as a stop-gap on the way to residential care, nor as a safety valve to ease pressure in the acute hospital sector. Investment in community care may increase costs in the short-term, but in long-term the cost-benefit is very clear. The cost per week of long-term residential or hospital care is significantly higher per person; almost double in some instances (Wubker et al., 2014).

The Nursing Home Support Scheme (Fair Deal) affords a statutory right to residential care to every person in the country. Residential care is meant to be seen as a last measure for support and care. Yet, having this statutory footing has led to a massive increase in demand for residential services, with many individuals entering full-time residential care inappropriately, because with the correct community supports (such as the timely provision of a comprehensive Home Care Package), they could remain living in their community with the support of their family (Donnelly et al., 2016). Currently, however, 60% of the budget for older persons care supports funds long-term, residential care (Department of Health, 2015).

We are calling for the development of a statutory-based scheme to guarantee access to community-based care. We echo the call from Family Carers Ireland for a roadmap to be published which indicates the timeline for such a move (Family Carers Ireland, 2016).

5) Service improvements

5.1) Respite care

Respite care is regarded as a key support for the health and wellbeing of Family Carers, and is often cited by them as vital to their ability to continue to provide care to their loved ones. However, the availability of respite care on the ground is decreasing, clearly demonstrable when listening to family carers speaking about their challenges¹. Budget 2017 must increase funding for the provision of flexible respite options, including in-home and emergency respite for people of all ages, ensuring equity of access irrespective of where a person lives. It should be demand-led rather than resource-led.

5.2 Disability services

Funding for essential disability services has been cut by €136 million since 2008 (Disable Inequality, 2016). This does not include cuts to vital supports such as Personal Assistance Services, the Mobility Allowance Scheme and the Motorised Transport Grant (Disable Inequality, 2016). This erosion of supports has led to incredibly trying times for Family Carers of people with a disability or extra support need. Funding must be restored to the disability budget to address the serious deficits in disability services that exist and ensure that people with a disability can live with autonomy, dignity and independence.

5.3) General access to health supports

Many of our member organisations are supporting individual Family Carers and their families who are finding it increasingly difficult to access the correct health and support services outside of the voluntary sector. For example, the Irish Heart Foundation/HSE National Stroke Audit 2015 found that within acute stroke services there were therapy staffing deficits of 50% for physiotherapists, 61% for occupational therapists and 31% for speech and language therapists, whilst only 44% of hospitals had any access to medical social workers and a mere 19% had access to a

¹ In 2015, a large survey of Family Carers was conducted by Care Alliance via the National Carers Week Facebook page. A substantial number of respondents highlighted lack of access of respite care as a key barrier to experience

neuropsychologist (McElwaine, McCormack & Harbison, 2015). Further investment into our public healthcare system is desperately needed.

6) 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.

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 encourage all government departments and agencies to work in collaboration in supporting the implementation of the National Carers’ Strategy. Indeed, we call upon government as a whole to prioritise the publication of the second version of the National Carers’ Strategy, 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 approximately 187,000 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 achieve this by supporting our 104 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.

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

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. 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 quality interventions in the lives of family carers.

By focusing on these functions we enable more of our member's resources to go directly to coal face services.

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