

Making the Respite Care Grant a pro rata payment

by

Caroline Crowley, PhD

crowleyresearch@gmail.com

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Objective of this paper

To argue for the need to make the Respite Care Grant a pro rata payment in Budget 2016.

What is the Respite Care Grant?

The Respite Care Grant is an **annual** payment made to full-time carers, regardless of their means, by the Department of Social Protection. Carers are those who look after certain people in need of full-time care and attention. Carers can use the grant in whatever way they wish including, but not limited to, respite care.

Who is eligible for the Respite Care Grant?

This is a grant given to people in receipt of the Carer's Allowance (including the half-rate payment), Carer's Benefit, Domiciliary Care Allowance (including the half-rate payment) and the Prescribed Relative's Allowance (which preceded the introduction of the Carer's Allowance in 1990) **who is caring for someone on one particular day of the year, generally the first Thursday of June.**

Why is the Respite Care Grant important?

As outlined in previous pre-budget submissions from the West Cork Carers Support Group:

"respite is critical in supporting carers to take a break from their caring role. Carers often cannot find time to address their own health and social needs and without regular breaks there is undoubtedly an increased risk of carers being unable to cope and continue providing care. [...] The Respite Care Grant is the only direct financial support that many carers can receive and is an important way of recognising their value and contribution."

Why is making the Respite Care Grant pro rata important?

If a carer becomes ineligible for the Respite Care Grant before the first Thursday of June, it is because they have either lost their loved one during the previous 12 months through bereavement or due to health deterioration necessitating a transition to long-term nursing home care. Either of these occurrences is likely to have been preceded by a period characterised by medical emergencies, having to navigate unfamiliar medical and social service administration, and increased personal costs and stress. In other words, this is likely to have been one of the most challenging periods in the carer's care-giving experience. This is the year that they most need the Respite Care Grant. Yet, even if they have provided care for eleven and a half months but cease caring before the first Thursday in June for any reason, they are not eligible for the grant. This paper argues for making the Respite Care Grant a pro rata payment to redress this injustice and allow carers to claim a proportion of the grant if their caring ceases before the first week in June.

A carer's story

"My husband and I have lived with and provided full-time care for mam and dad since November 2011 when they were in their early 80s. By spring 2012, I realised that I could not hold down a full-time job and adequately meet this caring role so I finally listened to advice from the Public Health Nurse, applied for the Carer's Allowance and settled into my new full-time care role. The arrival of the Respite Care Grant each June since then has become a key support. By the fourth year of caring in 2015, we were actively looking forward to and planning for it.

After Christmas 2014, dad's health went into chronic decline and the level of care he needed rose significantly. He now needed help with toileting, an emotional transition for all concerned to honour the gentleman that he remained his entire life. Throughout the night, he needed care as he did not have the cognitive ability to understand that he could no longer walk and toilet safely by himself or to call for help. Following weeks of little sleep, we found a laser beam and bleeper system to alert us when he was rising during the night so that we could reach him in time to help. Now we could look forward to some sleep, however interrupted. Throughout the day, he was a fall risk so we invested in a baby monitor to have him in sight no matter where we were in the home and to alert us when he was trying to leave his safe chair.

With little notice, preparation or training, we had entered a period of 24-hour intensive care-giving and reached out to professionals and family alike as we struggled to adjust to an ever-changing and deteriorating situation. We were overwhelmed and utterly dependent on support from anyone able to give it. We arranged for a private care giver for dad to help us get a few nights of undisturbed sleep. Family members helped out when and where they could. We called on all services for advice, travelled back and forth to appointments, and bought and tried out new gadgets to help us care for dad. Meanwhile, we continued to care for mam whose already poor health was, along with our own, being negatively affected by the stressful situation. It was the toughest period of care-giving to date.

Then, in May 2015, dad had a seizure at home and required emergency hospitalisation. He lost his mobility entirely and this, combined with his rapidly declining cognitive condition, meant that home was no longer the safest and most comfortable place for dad. As we reviewed local nursing homes, discussed the choices with family members and continued to care for mam, another dark cloud hung over us. We knew that if dad entered long-term nursing home care before the rapidly approaching first Thursday of June, we would be ineligible for the Respite Care Grant for dad; and how we needed that grant this year. What then were our possible choices?

1. Accept the fact that in spite of caring for dad for some 360 days in the previous 12-month period, including the most demanding period of care to date, we would be ineligible for the Respite Care Grant?
2. Keep dad in hospital as a 'bed blocker' until we got past the first Thursday in June?
3. Bring dad home although it was no longer a safe option for him or us and struggle to care for him until after the first Thursday in June?

We accepted the first choice and then fate intervened. Dad had been scheduled for respite during the same week that he was in hospital. As a respite bed was available the following week, dad was discharged from the hospital ward and admitted to the respite unit in the same hospital so that the physiotherapy staff could continue to work with him to help him walk again. He never did regain mobility. Dad entered long-term nursing home care after that week of respite, on the Monday just following the first Thursday of June. We received the Respite Care Grant for both mam and dad.

Dad passed away three weeks later. We continue to care for mam at home."

Government strategy for carer respite

The National Carer's Strategy (Department of Health, 2012¹) sets out the government's plan of action for improving the lives of Irish carers into the future and includes not only carers in receipt of a social welfare payment but informal and family carers across the community. Carer respite is highlighted in the strategy as a 'priority area for action' (p.6), one of nine listed. Out of the four national goals identified to progress the strategy, goal 4 aims to 'empower carers to participate as fully as possible in economic and social life' and the first of the goal's two objectives states its intent to '4.1 Enable carers to have access to respite breaks' (p.11).

Specifically the strategy explains:

"Respite care enables carers to take up or maintain work, education, leisure and training opportunities. Very importantly, a break from caring can **lessen the psychological and emotional stress** experienced by many carers and can help carers to continue to provide the support that they give.

Both full time carers and carers that combine caring with working outside the home need access to a range of **flexible** (in relation to **timing and type**) and responsive respite care services, including in-home, residential and emergency respite" (p.18).

Therefore, the government's national strategy fully recognises the psychological and emotional **stress** experienced by carers and the need for **flexible services** in relation to both type and **timing**. In its roadmap for implementation, the strategy sets out three actions to achieve objective 4.1 (table 1).

Table 1: Actions for objective 4.1 in the National Carer's Strategy, 2012.

Action	Responsibility	Indicative timeframe
4.1.1 Promote a better awareness of the respite care grant	DSP	2012/2013
4.1.2 <i>Promote a range of person-centred and flexible respite options</i>	HSE	2012/2013
4.1.3 Identify gaps in existing services and establish performance indicators for the provision of respite services	HSE	2013/2014

The aim of the second action, 'promote a range of person-centred and flexible respite options', also lies at the core of this paper. Responsibility for this action in the national strategy has been given to the HSE. This paper argues that the Department of Social Protection (DSP) also has a very important contribution to make to realising the action in full. The DSP will contribute significantly to realising the intent of action 4.1.2 by changing the annual Respite Care Grant from one paid only to carers who are caring for their loved one(s) on the first Thursday of June each year to one that is paid on a pro rata basis. Making the respite care grant a pro rata payment will convert it from the admin-centred and inflexible respite option it is currently to one that is person-centred and flexible, in line with objective 4.1. As the government department with lead responsibility for the development of the National Carer's Strategy, the DSP is ideally placed to set an example here.

¹ Department of Health (2012). The National Carer's Strategy: Recognised, Supported, Empowered.

Rationale for making the respite care grant a pro rata payment

Carers work seven days a week, 365 days per year, without entitlement to breaks or holidays. In light of this care-giving reality, making the Respite Care Grant a pro rata payment will help to alleviate two of the greatest challenges facing carers: (1) high levels of stress and (2) low levels of income.

High levels of stress

The second progress report of the National Carer's Strategy² offers insights into the need for changing the Respite Care Grant. Primary care social work assessments often point to **carer stress** as a key concern that **requires a range of responses**, including respite to give the main carer a break, and respite services are recognised for helping the **carer's emotional well-being**. Furthermore, progress reported by the HSE for action 4.1.2 highlighted above, acknowledged that it recognises:

1. 'the importance of **flexible responsive respite services** as part of the overall care package for individuals/carers.'
2. That respite service needs are addressed on an **individual case by case basis** encompassing both planned and emergency options.

The need for flexible, responsive respite services addressed on an individual case by case basis is clearly recognised in the National Carer's Strategy and is being addressed; but it appears that it is only been done so from a medical services' perspective. This paper calls for that progress to be complemented and supported from a government services' perspective too by making the Respite Care Grant a pro rata payment.

Low levels of income (and the effects of caring on carer employment prospects)

According to the 2011 Census of Population, 187,112 Irish residents identified themselves as carers that year, 61 per cent of them female. Figures 1 and 2 show the hours of care carried out by carers each week in Ireland. Almost one-fifth of males (13,375 carers) and one-quarter of females (26,607 carers) spend more than 43 hours per week on their caring role. In other words, almost 40,000 people in Ireland (39,982) work the equivalent (and more) of a full-time job in their caring role. When those giving 29 to 42 hours of care per week are included, the numbers increase to one-quarter of male carers and almost one-third of female carers totalling 54,121 workers. This level of caring commitment either precludes any possibility of employment or severely constrains the opportunity for over 54,000 carers to supplement their limited social welfare incomes.

Income prospects of the 15% of males and 16% of females numbering 29,255 workers who provide 15 to 28 hours care per week (~2-4 hours per day) are also restricted by their caring role because as anyone with experience of caring knows, the carer's daily, weekly and monthly routine is ever-changing and unpredictable, dependent as it is on the progress of the physical and/or mental health condition(s) of the person(s) receiving care. Such realities of carers' lives are incompatible with regular, secure employment.

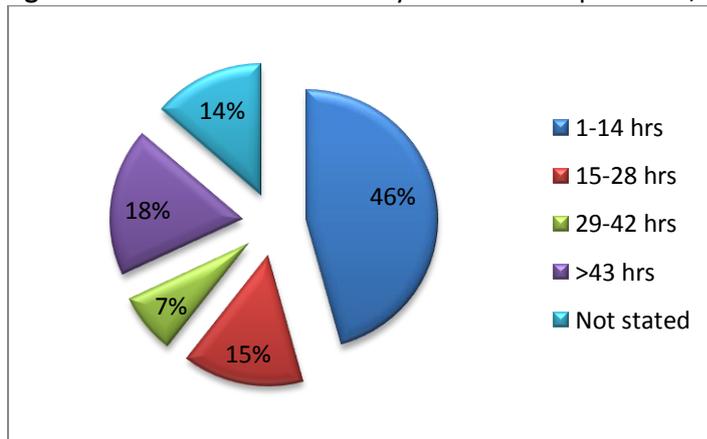
Finally, for the remaining 46% of male and 42% of female carers totalling 80,891 workers who provide up to two hours of care per day, a regular full-time job is more realisable but those carers are likely to suffer from different employment limitations. For example, daily caring responsibilities limit job opportunities by precluding workers from jobs that would necessitate a long commute³ while unscheduled illnesses and emergencies among those being cared for necessitate having to

² Department of Health (No date). The National Carer's Strategy: Recognised, Supported, Empowered. Second Progress Report, September 2013 – September 2014.

³ A cost that is potentially greater for rural residents the further they live from cities or large towns as the highest paid jobs tend to be concentrated in urban areas.

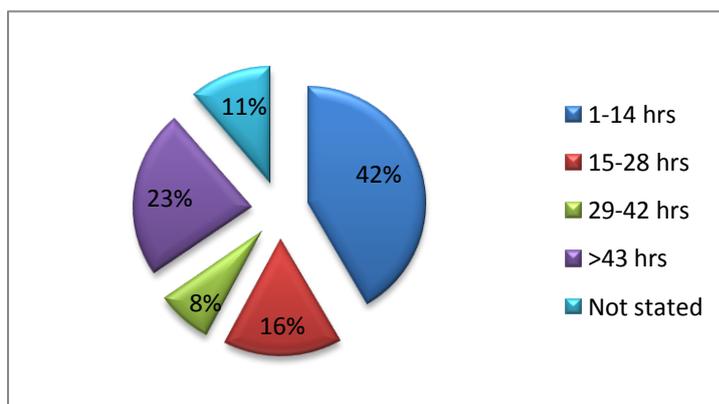
take unpaid leave or to use up holiday hours, incurring both economic and social costs. In other words, every carer pays a price for taking on the caring role.

Figure 1: Male carers classified by hours of care per week, 2011.



Source data: Census of Population, 2011.

Figure 2: Female carers classified by hours of care per week, 2011.



Source data: Census of Population, 2011.

Costing a pro rata Respite Care Grant

Is the cost of making the Respite Care Grant pro rata affordable? What about the administrative burden?

Additional financial cost

The most recent comprehensive data on numbers in receipt of, and expenditure on, care-giving payments from the Irish social welfare system come from 2013 (Department of Social Protection, no date⁴). These data are used here to estimate the cost of implementing a pro rate change to the grant.

The Department of Social Protection pays the respite care grant automatically to carers in receipt of Carer's Allowance, Carer's Benefit, Domiciliary Care Allowance or Prescribed Relative's Allowance. Only one Respite Care Grant can be paid for each person getting care. Table 2 lists the number of recipients of these carer payments in 2013.

⁴ Department of Social Protection (No date) 'Statistical information on social welfare services, 2013.'

Table 2: Number of recipients of carer payments, 2013

Payment type	Number
Carer's Allowance recipients ⁵	57,136
Carer's Benefit recipients	1,598
Families in receipt of the Domiciliary Care Allowance ⁶	25,510
<i>Subtotal - estimate of carers eligible for Respite Care Grant⁷</i>	<i>84,244</i>
Subtract - number of recipients of Respite Care Grant in June 2013⁸	72,721
Estimate of carers in 2013 who did not receive Respite Care Grant	11,523

Data source: Dept of Social Protection (No date) 'Statistical information on social welfare services, 2013.'

These rough calculations estimate that approximately 11,500 carers were negatively impacted in 2013 by the fact that the Respite Care Grant is not a pro rata payment. What would it have cost the exchequer if a pro rata payment was in operation in 2013? For simplicity, table 3 uses a rounded-up estimate of 12,000 carers to calculate the additional cost for that year.

Table 3: Estimated exchequer cost in 2013 for making the respite care grant a pro rata payment.

	Jun	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Total
Number⁹	1,000	1,000	1,000	1,000	1,000	1,000	1,000	1,000	1,000	1,000	1,000	1,000	12,000
Cost (€000s)¹⁰	115	230	345	460	575	690	805	920	1,035	1,150	1,265	1,380	8,970

While acknowledging the caveats listed in the footnotes, this simple exercise suggests that at the highest end of the range, it would have cost an additional €9m in payments annually if the respite care grant was pro rata. This €9m represents just 0.26% of the entire expenditure on social welfare and 7.5% of total spend on the respite care grant in 2013.

Overall in 2013, a total of almost €3,405m (€3,404,962,000) was spent on social welfare payments, of which just under €120m (€119,945,000) or 3.5% went on respite care grants. Using the reckoning above, if there had been a pro rata Respite Care Grant in place that year, it would have increased the total cost of the grant from 3.5% to 3.7% of the entire social welfare payment budget.

There will also be increased administration costs associated with a pro rata Respite Care Grant, e.g. processing an extra 11,500 respite care grant applications in the 2013 example above. This is why making the application process as clear, simple and short as possible will be essential in order to optimise administrative efficiency and minimise these costs.

⁵ Includes recipients of half rate Carer's Allowance.

⁶ Includes 1,716 families with two or more child beneficiaries of the domiciliary care allowance giving a total of 27,363 child beneficiaries.

⁷ The total is (1) inflated by double-counting where those in receipt of the domiciliary care allowance may also qualify for carer's allowance or carer's benefit, (2) underestimated by the number of recipients in receipt of Prescribed Relative's Allowance (predecessor to Carer's Allowance) who are eligible for the respite care grant but for whom no published data are available, and covers the period Jan-Dec 2013 while the respite care grant covers the period June 2012 to May 2013.

⁸ Based on a total 2013 spend of €119,945,000 on the respite care grant and a grant award of €1,375 for each person being cared for, a total of some 87,233 respite care grants were dispensed among 72,721 grant recipients (because some carers look after more than one person, e.g. elderly parents, or several children).

⁹ Number of those being cared for who either enter long-term nursing home care or die in that month.

¹⁰ The additional cumulative cost of pro rata respite care grant in June 2013 if paid in respect of those who enter long-term nursing home care or die during any month in the previous 12 month period (assuming the full monthly amount is paid regardless of the date of nursing home entry or death) based on €1,375 respite care grant divided by 12 months (€114.58) and rounded to €115. In month 1, this gives an additional cost of 1 month x 1,000 people x €115 = €115,000, in month 2, 2 months x 1,000 people x €115 = €230,000, and so on.

Additional administrative burden

Thus, key to the success of implementing the proposal in this paper is to ensure it is straightforward to administer. Currently, those already in receipt of care-giving payments automatically receive the respite care grant. Others complete an application for same. The following recommendations outline what additional administration is required to make the Respite Care Grant a pro rata payment and reveal that the administrative burden is not prohibitive.

Recommendations

New 'short' Respite Care Grant application form

Recommendation 1: introduce a new 'short' Respite Care Grant application form for carers in receipt of DSP care-giving payments, who automatically receive the Respite Care Grant, whose care-giving ended during the previous 12-months. This form will require the carer to confirm the date on which caring ceased e.g. person being cared for entered long-term nursing home care¹¹ or died¹².

Recommendation 2: use weeks of care to calculate the value of Respite Care Grant for each applicant. If caring ceased during week 4, the carer receives 4 week's worth of the annual Respite Care Grant; if caring ceased during week 51, the carer receives 51 week's worth, etc. There are two justifications for using the week during which care-giving ceased:

- in the latter stages of care-giving, which tend to be short-lived, intense, stressful crisis periods brought on by emergencies, weeks are a fairer measure than months;
- Using the week during which caring ceased puts the emphasis on the carer and should include weeks when even one day of care was given. This is to recognise the value of the carer's role right to the end of their care-giving¹³.

Change to current Respite Care Grant application form

Recommendation 3: For those carers not in receipt of weekly care-giving payments from the DSP but who meet the other rules of eligibility for the annual Respite Care Grant, change the eligibility wording *from* 'the 6-month period of care includes the first Thursday of June' *to* 'the 6-month period of care occurs or concludes within the previous 12-month period'. There are two justifications for making this change. It will ensure that:

- carers who satisfy the minimum requirement of fulfilling a 6-month period of care, but one that does not include the first Thursday of June, can avail of the Respite Care Grant. This removes the injustice of an arbitrary date in the year determining eligibility rather than the legitimate period of care-giving itself.
- carers who satisfy the minimum requirement of a 6-month period of care but whose qualifying period of care happens to fall across two years on the DSP administrative calendar, can avail of the Respite Care Grant in the second year (during which that period of care concluded). This removes the injustice of the DSP administrative calendar determining eligibility rather than the legitimate period of care-giving itself.

Conclusion

Considering:

1. the government's recognition of the importance of respite services for helping carers' emotional well-being,

¹¹ Proof of same by supplied document from nursing home confirming date of entry and resident ID.

¹² Proof of same by death certificate.

¹³ It will also address bed blocking.

2. its acknowledgement of the importance of flexible and responsive respite services in the National Carer's Strategy,
3. repeated calls from all Irish carer groups to make the Respite Care Grant pro rata on the grounds of social justice, and
4. the affordability and administrative feasibility of making the Respite Care Grant pro rata,

this paper concludes that the time has come for the government to, in its own words, 'recognise, support and empower' carers by making the Respite Care Grant a pro rata payment in Budget 2016.