

PRE-BUDGET SUBMISSION TO THE GOVERNMENT OF IRELAND

BUDGET 2010

**Equality and Justice
for Family Carers
*Can we Afford Them?***



Who are Family Carers?

Family Carers are relatives, friends or neighbours who provide *unpaid* care for people with a disability, mental illness, chronic condition or frail older people. Because Carers must be constantly available due to the heavy demands and responsibilities of caring many are unable to take up employment and so are reliant on Government supports. In addition, there are significant financial costs associated with caring such as extra heating costs, special dietary requirements, transport and medical expenses which very often must be met by the Family Carer.

In recent years Government have recognized Family Carers as a unique group because of the unstinting level of care they provide and their enormous financial contribution to the Irish health and social economy.

"The reforming of the system and the abolishing of the old rule that you cannot get two welfare payments means that for the first time people who are caring can have some real recognition of their caring duties. Introducing the new dual payment system means we will be starting to recognise the Carers Allowance less as a welfare income payment & more as a direct support for caring duties and responsibilities."

**The late Minister for Social and Family Affairs
Mr. Seamus Brennan, 2006.**

Carers Contribution to the Irish Economy

- According to the Census of Population 2006, there are 160,917 Family Carers in Ireland providing 3.7 million hours of unpaid care each week and contributing more than €2.5 billion to the Irish economy each year.
- 40,883 of these Carers provide fulltime care (more than the 39,000 nurses employed by the HSE) and contribute €1.6 billion to the economy.
- This means that the average full-time Carer in Ireland saves the State more than €40,000 each year.

Martin Cullen

Martin Cullen has been caring for his 86 year old mother Margaret for over 8 years. He gave up work in 2001 to provide high dependency care for his mum when she suffered a stroke. Margaret also suffers from stroke related Parkinson's, incontinence and is partially bed bound. Two years ago, following years of lobbying, Martin finally received a Half Rate Carers Allowance of €110 per week in recognition of his caring role. If the proposal by An Bord Snip to phase out the Half Rate Carers Allowance is implemented, Martin will face a potential 30% reduction in his income. Martin is pleading with Government, on behalf of all Carers, not to abolish the Half Rate Carers Allowance. *"Carers cannot be seen as a soft target for Government cuts. We can't be asked to pay for other people's mistakes."*



Protecting Carers at a Time of Economic Uncertainty

2009 has been a difficult year for Ireland's 160,917 Family Carers. In March, the Government announced that they would not publish the National Carers Strategy and more recently the report of the Special Group on Public Service Numbers and Expenditure Programmes (An Bord Snip Nua) and the Commission on Taxation have set out numerous recommendations which, if implemented, would be detrimental to Carers. These recommendations include phasing out the Half Rate Carers Allowance, the reduction of all Welfare payments by 3 to 5%, means testing Home Care Packages, the taxation of Social Welfare payments including Carers Allowance and the suspension of tax relief on long-term care.

A significant weakness of the reports of An Bord Snip Nua and the Commission on Taxation is their lack of consideration for the cumulative effect of cuts on individuals when taken across all Government Departments and the need for a detailed social analysis of their potential impact on vulnerable groups. In fact the report of An Bord Snip warns that *"care will need to be taken to avoid the inadvertent accumulation of measures in individual cases"* (p.190).



This accumulation of measures is clearly visible in the case of Carers, where they will be affected by proposed cutbacks across Departments:

- Department of Social and Family Affairs - including the suspension of Christmas bonus payments, a 3-5% reduction in welfare payments and a potential 30% decrease in income if proposed cuts to the Half Rate Carers Allowances are implemented;
- Department of Health and Children – including reductions in the provision of frontline services, home help hours and home care packages and a reduction in spending on disability services provided by voluntary organizations by €50 million;
- Department of Community, Rural and Gaeltacht Affairs – including the withdrawal of Scheme of Community Supports for Older People and a reduction in the allocation for community and voluntary sector supports;
- Department of Transport – including the proposed withdrawal of the Rural Transport Programme;
- Department of Education - including a €60 million reduction in funding for Special Needs Assistants.

In times of recession the Government must prioritize areas for spending and investment. The Carers Association call on Government to recognize Carers as one of Ireland's greatest resources who must be developed and supported if they are to be able to continue to save the State billions of Euros each year.



PRIORITY ISSUES TO BE ADDRESSED IN BUDGET 2010

Arising from extensive consultations with Family Carers undertaken during July and August 2009, this submission sets out areas to be prioritised for Government action and spending in Budget 2010.

Department of Social and Family Affairs

Half Rate Carers Allowance

The introduction of the Half Rate Carers Allowance in 2007 was recognition from Government that Family Carers are a unique group because of their work and contribution to the health sector and social economy. The Carers Association believe that the payment, which is worth up to €110 per week and received by approximately 18,500 Carers, offers excellent value:

- If sourced privately €110 would provide only 5 hours of home care each week. However, Carers in receipt of the payment must be providing fulltime high dependency care, which experience has shown is often in excess of 60 hours each week.
- Half Rate Carers Allowance enables 18,500 dependent people to be cared for at home. By comparison the estimated cost of nursing home care per patient is in the region of €800-€1,000 per week, whilst the cost of acute hospital care is in the region of €5,000 per week.
- The Half Rate Carers Allowance is used by Carers to cover the day to day cost of living including the hidden costs of caring.
- If implemented, the proposal set out by An Bord Snip Nua to eliminate dual payments would mean that Carers in receipt of the Half Rate Carers Allowance would face a potential 30% reduction in their incomes – a cut which no other vulnerable group is being expected to accept.
- Demographic predictions undertaken by the CSO suggest that Ireland's older population will increase from its 2006 level of 462,000 to approximately 1.4 million by 2041. In this context, it is imperative that provisions are made to support the care of older people in their own homes. The elimination of the Half Rate Carers Allowance for new applicants will mean that less people will be able to afford to provide care for our ageing population.

» **The Carers Association call on Government to retain the current eligibility criteria and payment rates for the Half Rate Carers Allowance.**

Safeguard Family Carers from Proposed Social Welfare Cuts

Proposals to cut social welfare payments by 3-5% would be detrimental to Carers who are already struggling to cope on limited incomes and who have already taken a 2% cut in income through the suspension of the Christmas bonus. Due to the demanding nature of caring and the fact that qualifying criteria for these payments state that Carers must be providing full-time care, many Carers are unable take up paid employment and so are reliant on welfare support. While arguments have been made that the cost of living has decreased, experience has shown that often income received through welfare payments is used by Carers to cover the additional costs associated with caring such as heating costs, special dietary requirements and medical expenses.

» **The Carers Association call on Government to protect Family Carers from any cuts in social welfare payments and for the reinstatement of the Christmas Bonus.**

National Carers Strategy

Despite Government stating that the National Carers Strategy could not be published due to the current economic situation, resources have been made available for the publication of the National Drugs Strategy and the National Positive Ageing Strategy when economic, social and political indicators dictate. Family Carers are already denied many basic supports and the National Carers Strategy, committed to in Towards 2016 and the programme for Government, held a glimmer of hope that once and for all Government would acknowledge the enormous contribution Carers make to the Irish economy and provide them with the supports and services which are vital to enable them to continue in their caring role.

» **The Carers Association call on Government to acknowledge the contribution made by Family Carers and to publish the National Carers Strategy**

Household Benefits Package

The Household Benefits Package plays an important role in tackling social exclusion and allowing people to live independently in their own homes through the provision of allowance towards electricity, telephone and television costs. However recent proposals have recommended that the Package be treated as taxable income.

» **The Carers Association call on Government not to treat the Household Benefits Package as taxable income.**



Remuneration of Carers

Family Carers significantly reduce the strain on Ireland's healthcare system while also providing quality care that greatly benefits the person receiving care. When appropriate financial and ancillary support is provided to the Carer by the State, caring can be shared fairly. However, when there is not a fair shouldering of responsibility by the State, caring often comes with an extremely high personal cost for the Carer in terms of lost income and employment opportunities, while struggling to meet increased living expenses and extra medical costs.

» **The Carers Association call on Government to apply the means test for Carers Allowance only to the income of the Carer and not on household income, and move towards;**

› **increasing the rate of Carers Allowance to €338 per week (equal to the minimum wage for the standard working week);**

› **with the eventual introduction of a payment for full-time Carers, linking the payment level to labour market equivalent.**

» **Allow Carers to receive the full rate of Carers Allowance for each person they care for.**

» **PRSI contributions should be awarded to Carers on the same basis as paid contributions. In addition ensure Carers are not caught by the changing criteria for the retirement pension (i.e. 520 paid contributions needed from year 2012 to qualify for old age contributory pension compared to 260 at present).**

» **Government must immediately put in place sufficient resources to ensure that the Carers Allowance section of the Department is adequately resourced to deal with the volume of applications.**

» **Award Family Carers the Fuel Allowance as a non means tested payment.**

Carers and Work

There are 90,544 Working Carers in Ireland representing 56% of all Family Carers (CSO, 2006). Of these 14,068 (16%) are providing full-time care to a loved one.

» *The Carers Association call on Government to increase the number of hours a Carer is permitted to work from 15 to 19.5 hours, to allow Carers to be eligible for the Community Employment Scheme.*

» *Family Carers who are in seasonal employment or work on a week-on week-off basis should be allowed to average their total work hours over a 52 week period and if under an average of 15 hours per week still be eligible for Carers Allowance.*

Habitual Residency Clause

In 2008, 54 people were refused Carers Allowance because they had not been resident in Ireland for 2 years prior to making their application.

» *Abolish the Habitual Residency Clause for people returning to Ireland to provide care.*

Respite Care Grant

In the programme for Government, Government committed to increasing the Respite Care Grant to €3000 for each person cared for by 2012.

» *The Carers Association call on Government to increase the Respite Care Grant to €3,000, to allow Carers to take their statutory holiday entitlement of 20 days per year.*

Information

In Towards 2016 Government committed to continue to support information and awareness campaigns for Family Carers.

» *The Carers Association call on Government to allocate funding towards an extensive information campaign to ensure that Carers receive support and advice regarding welfare rights, entitlements, supports and health services.*

» *If implemented the proposal by An Bord Snip to end dual welfare payments will mean that organizations that support Carers will lose many of their front line Community Employment staff who have been trained to provide information. Government should not proceed with the proposal to eliminate dual welfare payments.*

Department of Health and Children

Respite Care Services

Since the publication of The Years Ahead: A Policy for the Elderly in 1988, it has been Government policy to favour home and community care over long term residential care. However, in practice, Government cutbacks in service provision and funding have contradicted this policy and stood in the way of its implementation.

» *The Carers Association call on Government to introduce a specific budget for the provision of in-home respite for all full time Carers to allow them to take at least a six hour break from their caring duties per week.*

» *Increase the provision of residential respite care services including emergency and after hours respite care.*

» *Increase funding towards the provision of suitable respite care for children with autism, special needs or mental health issues.*

» *Funding for Home Help services should be increased to ensure that Carers and older people requiring these services can receive them at adequate levels.*

Home Care Packages

Figures from the HSE Performance Monitoring Report (2009) have shown that 8,867 people are in receipt of a Home Care Package. Home Care Packages are a valuable resource for Family Carers and care recipients, providing them with the core services and supports needed to enable them to continue living in their own homes.

» *The Carers Association call on Government to increase funding towards Home Care Package and not introduce a means test.*

Needs Assessment for Carers

» *Introduce a legal right to a comprehensive Needs Assessment for Family Carers, to include health and social issues.*



Medical Cards

Access to health and personal care services is crucial for Carers and those for whom they provide care. Proposed changes in the eligibility criteria for the medical card will mean that less Carers will qualify and so will find it increasingly difficult to afford healthcare services and medication. Research undertaken by The Carers Association and The Royal College of Psychiatrists in 2009 show that Carers health and wellbeing is already adversely affected by their caring role with Carers frequently ignoring their own health needs in favour of those to whom they provide care. Any increase in medical or drug costs will further exacerbate this problem.

» *The Carers Association call on Government to provide a non-means tested medical card and annual health check to all full time Carers.*

» *Renewal of prescriptions should be extended from a three month to a six month period.*

Young Carers

In Towards 2016 Government committed to commission a study on the extent to which young people undertake inappropriate caring roles and to establish a programme of in-home supports to alleviate the specific issues identified.

» *Following the publication of the report on Young Carers commissioned by the Office of the Minister for Children, The Carers Association call on Government to introduce a budget of €5 million to advance the recommendations emerging from the research.*

Core Grant Funding

Ireland's ageing population represents a critical challenge to the development of appropriate health and social service provision, both for Carers and those requiring care.

» *The Carers Association call on Government to increase core grant funding for voluntary organizations operating in the older person and Carer sector. This funding should span all services provided by individual organizations and is a vital requirement for ensuring the sustainability and progress of the sector in meeting the growing demands of our ageing population.*



Department of Environment, Heritage and Local Government

Housing Adaptation Grant Scheme

Making homes accessible, for example, making them wheelchair-friendly, extensions to create more space, adding a ground floor bathroom or toilet or stair-lifts, are vital if older people, people with disabilities and those requiring care are to remain living independently in their own homes and communities. However current waiting periods for processing Housing Adaptation Grant applications and inadequate funding is leaving vulnerable people living in unsuitable accommodation for extended periods of time and is adding significant additional burden to their Carers.

» *Funding for the Housing Adaptation Grant Scheme must be increased to allow older people, people with disabilities and those requiring care to remain living independently in their own homes and communities.*

Department of Community, Rural and Gaeltacht Affairs

Scheme of Community Supports for Older People

Government's decision to suspend the Scheme has had a significant impact on vulnerable older people. The provision of security measures including personal alarm pendants, window and door locks, sensor lights etc had been hugely beneficial in giving independence to older people, especially those living in rural areas. It is essential that older people have a sense of security which substantially contributes to their quality of life.

» *The Carers Association call on Government to reinstate the Scheme for Community Support for Older People.*

Training

An Bord Snip Nua have recommended that Dormant Accounts, which has been a key source of funding for Carer training under the Training of Carers Measure, be discontinued with any remaining projects being processed to their conclusion and remaining incoming dormant accounts funds be transferred to the Exchequer.

» *The Carers Association call on Government to ensure ongoing support for Carer training which will allow Carers to access accredited training in caring skills, and would be linked to the National Framework for Qualifications.*

» *Fund the development of specific back to work training programs for Carers whose caring role has ceased.*

Department of Transport

Rural Transport Programme

The Rural Transport Programme provides a vital link for the elderly and those living in rural communities in allowing them to access daily services such as shopping, education, employment, banking, health appointments and collecting prescriptions, as well as engaging in civic, social and

recreational activities. However proposals set out by An Bord Snip Nua recommend the abolition of the scheme.

» *The Carers Association call on Government to recognize the importance of the Rural Transport Programme for the elderly, mobility impaired, Carers and those who are rurally isolated and to invest additional resources in maintaining the service.*

Department of Finance

Family Carers continue to experience long delays in accessing essential services, such as occupational therapy, home care equipment or home adaptation grants. However if Carers purchase these products and services privately in advance then any grant will be forfeited.

» *Tax relief should be given to Carers for predetermined categories of expenses associated with their caring commitment (e.g. technical aids, medical care, care products, home renovations and bought-in support care). This tax relief could be offset against their taxable income for the previous year and should be retrospective over 6 years.*

Inter- Departmental Linkage

Many of the initiatives needed to support Carers requires linkage, collaboration and communication across Government Departments. For example, holding elderly patients unnecessarily in hospitals and residential care because of delays in funding applications to convert their homes, could be avoided through better communication and planning between the HSE and Local Authorities.

» *The Carers Association call on Government to ensure effective linkage and co-ordination of Carer related policy at national, regional and local levels and to foster multi-agency, cross-departmental, co-operation.*

Patricia MacGrath



Patricia MacGrath provides constant care for her husband Patrick, who has Parkinson's disease, is a celiac and suffers from a number of heart problems. Patrick is highly dependent on Patricia and needs help with basic tasks such as bathing, shaving, changing clothes, feeding and taking medication. Patricia receives a Half Rate Carers Allowance which in her own words, just about keeps their heads above water. The added costs of dietary and medical expenses and the lack of support services such as respite care make Patricia's life as a Carer all the more difficult. Any cuts in payments in the up-coming budget would prove detrimental to Patricia and Patrick. "I am terrified Government will take away our Half Rate Carers Allowance. We are just about keeping our heads above water as it is but if it's taken away we won't be able to cope. The Government must realize that the Half Rate is not a supplementary payment for Carers. Each and every penny I receive goes towards the care of my husband. The sick, elderly and vulnerable can't be expected to bear anymore Government cuts."

Carers Contribution to the Social Economy

Cities & Counties	No. of Carers (Census '06)	Total Hours worked per week	Value per year at €13 per hour in € millions
Leitrim	1,205	27,344	€18.05
Longford	1,381	34,883	€23.16
Waterford City	1,640	37,883	€25.61
Carlow	1,677	40,739	€27.54
Limerick City	2,074	54,681	€36.96
Monaghan	2,283	54,455	€34.11
Galway	2,409	51,381	€34.73
Waterford County	2,491	53,412	€36.11
Laois	2,472	61,108	€41.31
Roscommon	2,567	62,183	€42.03
Sligo	2,484	58,079	€39.26
Cavan	2,553	62,390	€42.18
Offaly	2,691	65,308	€44.15
Tipperary North	2,705	62,963	€42.56
Westmeath	2,862	66,262	€44.79
Tipperary South	3,263	79,798	€53.94
Kilkenny	3,434	79,736	€53.90
Louth	4,226	98,408	€67.20
Clare	4,507	99,660	€67.37
Wicklow	4,618	103,665	€70.07
Wexford	4,825	123,774	€83.67
Cork City	4,855	114,745	€77.57
Limerick County	5,114	113,510	€76.73
Mayo	5,440	132,873	€89.82
Donegal	5,698	148,288	€100.24
Meath	5,721	126,009	€85.18
Kildare	5,961	140,975	€95.30
Kerry	5,892	142,943	€96.63
Galway County	6,843	164,575	€111.25
Fingal	7,997	166,640	€112.65
Dun Laoghaire - Rathdown	7,544	146,188	€98.82
South Dublin	8,346	188,483	€127.41
Cork County	14,783	329,961	€223.05
Dublin City	18,356	434,749	€293.89
Grand Total	160,917	3,724,434	€2.5+ Billion