

Protecting Ireland's Invisible Workforce



SUBMISSION TO THE GOVERNMENT OF IRELAND
BUDGET 2011





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WHY SUPPORT FAMILY CARERS IN BUDGET 2011?



Because it makes economic sense and will save taxpayer money in the long run:

- Ireland's 160,917 Family Carers provide 3.7 million hours of care each week which equates to a **saving of €2.5 billion each year**. This means that the average fulltime Carer **contributes €40,500 of caring work each year**.
- There are 40,883 fulltime Carers in Ireland, more than the 39,000 nurses employed by the HSE. These Carers alone **work 2.5 million hours each week and contribute €1.6 billion** to the Irish economy each year.
- In 2010 the CSO estimated that Ireland could now have as many as 274,000 Family Carers and 57,550 fulltime Family Carers.¹

- If just **one in ten fulltime Carers in Ireland decided they were unable to continue to provide care, replacement care would cost Government €165 million** each year.

To protect the quality of life of Family Carers and those for whom they care:

- If left unsupported Carers can experience real **physical, financial and emotional hardship**. As a result it is more likely that the cared-for person will be admitted to hospital and the Carer's own health deteriorate.
- Family Carers are already **propping up Ireland's fragile health system**, yet announcements by the HSE point to the expanding role they will play in its future, with fewer patients in our hospitals, shorter hospital stays and an increasing focus on community care. As such, Carers will play a key role in relieving our already overburdened health service, all while enabling our older and vulnerable adults and children to be cared for within their own homes and communities.

To ensure Family Carers will be available in the future to meet Ireland's growing care needs:

- As more people become aware of the hardships that accompany being a Carer, many may choose not to become a Carer. Consequently the **full cost of that social care will fall on society and the Government**.
- **Population ageing** is one of the greatest challenges facing Irish society and our economy. Unless we take action now, we will be condemning older and vulnerable people and their Carers to lives of poverty and ill-health. Reform of the care and support system is an economic necessity.

¹ Quarterly National Household Survey: Caring Module. Quarter 3, 2009.

'Hands Off' the Half Rate Carers Allowance and the Respite Care Grant

- Government must not remove the Half Rate Carers Allowance or reduce its current rate of €106 per week.
- Retain the annual non means-tested Respite Care Grant at the current rate of €1,700.
- In cases where the cared for person has passed away six months prior to June when the payment is made, a half rate Respite Care Grant should be paid.

Protect Carers Allowance and Carers Benefit and Address Anomalies in Qualifying Criteria

- Protect Carers from further cuts in Carers Allowance or Carers Benefit.
- Waive the HRC for persons returning home from abroad to provide full-time care.
- Means testing for the self-employed should be treated in the same way as other claimants and should consider their current circumstances rather than the previous year's earnings.
- Applicants for Carers Allowance caring for someone with a mental illness must be treated in the same way as those caring for someone with a physical disability.
- Promote that the Carers Allowance can be shared by two Carers providing care on a part time basis.
- Carers whose caring comes to an end after they reach age 60 should be offered an early retirement option rather than being directed to a Jobseekers payment.
- Ensure that the Department of Social Protection's Appeals Office is adequately resourced to address current backlogs and ensure waiting periods are reduced to 12 weeks.

SUMMARY OF PRIORITY ISSUES FOR BUDGET 2011

The Carers Association welcomes the opportunity to provide an input into the 2011 Budget considerations. At a time when Ireland is learning from our past mistakes and starting to build for the future this submission provides Government with responsible, cost effective measures to better support Irelands 161,000 Family Carers who will play a vital role in building a sustainable health and community care sector. While The Carers Association acknowledge the significant pressures on public finances at present, Government simply cannot afford to ignore the income and support needs of Family Carers. In that context, The Carers Association have identified the five priority issues Family Carers must see delivered in Budget 2011:



Enhance and Support Carers Health and Wellbeing

- The Carers Association calls on Government to provide a non-means tested medical card and annual health check to all full-time Carers.
- No further increases should be levied in relation to A&E and drug scheme charges.
- The 50 cent prescription charge should be abolished.

Provide Comprehensive Supports for Family Carers including Young Carers

- Funding for home care services should be increased to ensure that Carers and older people can receive them at adequate levels.
- Increase the provision of respite services including emergency, residential and in-home respite care.
- Increase funding towards the provision of suitable respite care for children with autism, special needs or mental health issues.

- Government must immediately address the issue of families in receipt of Carers Allowance or Carers Benefit being excluded from receiving home care supports.
- Introduce a legal right to a comprehensive Needs Assessment for Carers to include health and social issues.
- Introduce a specific budget to advance the recommendations emerging from the Office of the Minister for Children and Youth Affairs Young Carers study.

Publish the National Carers Strategy

- The Carers Association calls on Government to publish the National Carers Strategy, setting out their commitments in relation to income supports, healthcare, training, the labour market, transport, housing and information services with implementation of the Strategy's recommendations to take place when economic, social and political indicators allow.

ANALYSIS OF PRIORITY ISSUES:

DEPARTMENT OF SOCIAL PROTECTION

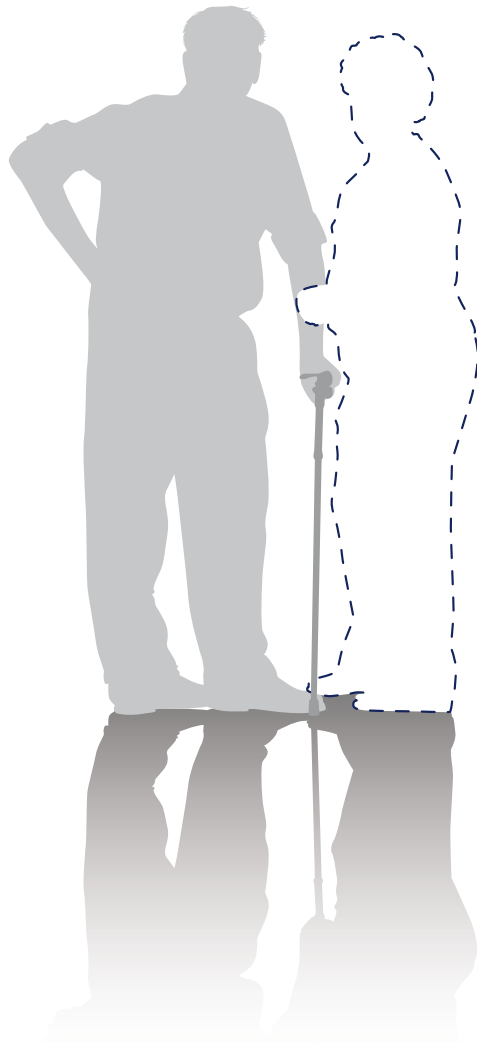
'HANDS OFF' THE HALF RATE CARERS ALLOWANCE AND THE RESPITE CARE GRANT

Half Rate Carers Allowance

The Half Rate Carers Allowance, paid at a maximum rate of €106 p.w., is an essential part of a Carers limited income and often goes towards subsidising the costs associated with providing care. Proposals by An Bord Snip Nua to eliminate dual payments would mean that many of the 19,134 Carers in receipt of the Half Rate would face a potential 30% reduction in their incomes. Such a move would make no economic sense;



- If sourced privately, €106 would provide only 5 hours of home care each week. However, Carers in receipt of the Half Rate must be providing fulltime care. A review undertaken by Care Alliance Ireland suggests that fulltime Carers provide an average of 110 hours of care each week². In this case, these Carers are working for less than 96 cent per hour.
- For people with a high level of disability, the *lowest* figure that international studies have put on their extra cost of living was €40 per week³.
- Over half of all Half Rate recipients are older persons in receipt of a pension or qualified adults on a pension payment.
- Ireland's older population is set to increase to 1.4 million by 2041 (CSO). The elimination of the Half Rate Carers Allowance will mean that less people will be able to afford to provide care for our ageing population.
- The Allowance enables 19,134 dependent people to be cared for at home. By comparison the estimated cost of nursing home care is €800-€1,000 p.w, whilst the cost of hospital care is in the region of €5,000 p.w.



Respite Care Grant

The Respite Care Grant paid annually to 71,000 Family Carers is of enormous importance in allowing Carers to take a break and in supporting their overall health and wellbeing. The grant is the only recognition or recompense given to 23,000 Family Carers who do not qualify for any other payment despite providing fulltime care for a loved one. Any reduction in the Respite Care Grant would be a serious retrenchment by Government in recognising the contribution of Family Carers in Irish society, and completely at odds with Government policy to support the provision of home care.

Priorities for Budget 2011

- The Carers Association calls on Government not to remove the Half Rate Carers Allowance and to retain the payment at its current rate of €106 per week.
- Retain the annual non means-tested Respite Care Grant at the current rate of €1,700.
- In cases where the cared for person has passed away six months prior to June when the payment is made, a half rate Respite Care Grant should be paid to the Carer.

PROTECT CARERS ALLOWANCE AND CARERS BENEFIT AND ADDRESS ANOMALIES IN QUALIFYING CRITERIA

An Irish study undertaken by O'Shea in 2000 found that *'over two-thirds of Carers expressed difficulty in making ends meet and were likely to have suffered financial strain as a result of their caring responsibilities'*⁴. Research published in the UK in 2007 found that 72% of Carers are financially worse off as a consequence of caring and many are forced to sell their homes, cut back on food, heating and clothes, give up their jobs, and sacrifice pensions and savings in order to make ends meet⁵.

Cutbacks imposed on Carers Allowance, Carers Benefit, and the Half Rate Carers Allowance in Budget 2010 as well as the removal of the Christmas bonus announced in April 2009, have meant that Carers have seen their incomes fall by over 5% while also struggling with the additional costs associated with caring. In fact, despite an overall reduction in consumer prices, many essential goods and services, especially health related services, have seen price inflation in recent years, e.g., GP and prescription charges and private health insurance. As such, Carers dependent on social welfare have to spend a greater proportion of their income on basic necessities than those on higher incomes or those not providing care.

Qualifying criteria for care related payments have caused great difficulty and financial hardship for Carers, especially the self employed and those returning home from abroad to provide care. Caring is not a role that is chosen voluntarily by families but is one that falls on them, often without warning. Therefore, assessing an applicant's eligibility

for a welfare payment based on their habitual residency is unfair. So too is assessing the means of a self employed person based on their previous years income, or assessing their means differently from that of an employed person. In both cases what should be assessed is their present role, the sacrifice they have made and the enormous contribution they make to the Irish economy and to the lives of those for whom they care.

Priorities for Budget 2011

- Protect Carers from further cuts in Carers Allowance or Carers Benefit.
- Waive the HRC for persons returning home from abroad to provide full-time care.
- Means testing for the self-employed should be treated in the same way as other claimants and should take into consideration their current circumstances rather than the previous year's earnings.
- Applicants applying for Carers Allowance for someone with mental health issues must be treated in the same manner as those caring for someone with a physical disability.
- Promote that the Carers Allowance can be shared by two carers providing care on a part time basis.
- Carers whose caring comes to an end after they reach age 60 should be offered an early retirement option rather than being directed to a Jobseekers payment.
- Ensure that the Department of Social Protections Appeals Office is adequately resourced to address current backlogs and ensure waiting periods are reduced to 12 weeks.

² Analysis of raw data from Pilot Survey on Census 2011. See www.carealliance.ie/publications.php

³ NDA (2004) Disability and the Cost of Living

⁴ O'Shea, E. (2000) The Costs of Caring for People with Dementia and Related Cognitive Impairments, Dublin: National Council for the Aged. P 18

⁵ Carers UK (2007) Real Change not short change: time to deliver for Carers.

ANALYSIS OF PRIORITY ISSUES:

DEPARTMENT OF HEALTH AND CHILDREN

ENHANCE AND SUPPORT THE HEALTH AND WELLBEING OF CARERS

Since Budget 2009 health charges have increased substantially. A&E charges have increased to €100, or €125 without a GP referral, the threshold for the Drug Payment Scheme has increased to €120, prescription charges have been introduced and the over 70s now face a means test when applying for a medical card. The cost of health insurance is also increasing and the Health Insurance Authority now report that some 800 people per week are forced to cancel their private health insurance.

Access to healthcare services and medication is crucial for Family Carers, who because of the nature of their caring role are disproportionately affected by these increases resulting in even greater financial hardship and the risk of discouraging Carers from seeking medical help. Research undertaken by The Carers Association and the Royal College of Psychiatrists shows that Carers health is already adversely affected by their caring role with over 50% stating that they had been diagnosed with a mental health problem. The report also showed that Carers frequently ignore their own health needs in favour of those for whom they care⁶.

The Carers Association is concerned that Carers and those with a disability or illness will incur these increased charges to a greater extent than individuals in good health and thus the increase represents an additional and unfair financial burden on Family Carers.

Priorities for Budget 2011

- The Carers Association call on Government to provide a non-means tested medical card and annual health check to all full-time Carers.
- No further increases should be levied in relation to A&E and drug scheme charges.
- The 50 cent prescription charge should be abolished.

PROVIDE COMPREHENSIVE SUPPORTS FOR FAMILY CARERS INCLUDING YOUNG CARERS

Respite Services

Respite is regarded as one of the key support interventions to alleviate the stress of caring and to support the health and wellbeing of the Carer. The Family Carers Health survey found that while 63% of Carers report being emotionally drained and 56% physically drained by their caring role, only 55% access respite services. Forty per cent of respondents stated that they believe additional respite services would help improve their health.

Despite the importance of respite care, The Carers Association has witnessed significant reductions in the allocation and availability of Home Help hours, Home Care Packages and respite care services. In fact, the HSEs Performance and Financial Management Report published in June 2010 highlighted: *"...anecdotal concerns in relation to a possible contraction in levels of home care being provided in 2010. This is concerning given the fact that the planned service levels have actually been increased in this years Service Plan on foot of additional resource allocated in Budget 2010"*.

Since it was established in 2005 the HSE has focused on shifting as much care as possible from acute hospitals to community based facilities. Despite this, the HSE Performance Monitoring Report for December 2009 showed:

- Only 31 more Home Care Packages were delivered in 2009 than in 2008.
- The number of people receiving Home Help was 53,791 in 2009, 1.3% below the projected target and 1,575 less than the number of recipients in 2008.
- Home Help provision fell short of its target for 2009 by 9,677 hours. However this was actually 661,279 hours less than what was delivered during the same period in 2008.

At a time when the HSE have publicly stated their intention to move towards a community care model, and funding allocations in these areas should have been increased, these figures are particularly alarming.

Table 1:
Home Care Package and Home Help Hours
as at December 2007 - 2009

Support	2007	2008	2009
Home Care Packages	8,035	8,990	8,959
Home Help Recipients	54,736	55,366	53,791
Home Help Hours	12,351,087	12,631,602	11,970,323

⁶ Family Carers' Health Survey: The Carers Association and the Royal College of Psychiatrists. (2009)

Home Help Provision for Families in Receipt of Carers Allowance

An issue of serious concern is the HSEs policy not to provide home care services to families in receipt of Carers Allowance or Carers Benefit. While this policy is not documented by the HSE, it is raised consistently by Carers during Support Group meetings, through the National Care Line and by our local Centre Managers. In these cases, the Carers Allowance or Benefit is regarded by the HSE as a payment for work undertaken by the Carer and not as an income supplement as has been stated by Government. This is an issue of grave concern as it discriminates against and exploits Family Carers and removes any acknowledgement of the health and social supports needed to help them continue in their caring role. Such actions by the HSE mean that Family Carers would be treated more favorably if they were on a Jobseekers Allowance.

Young Carers

In 2009 the Office of the Minister for Children commissioned a study on the experience and issues affecting Young Carers in Ireland. The study identified a continuum of caring whereby some caring experiences amongst young people has a largely positive impact while for others the role involves a level of physical or emotional caring that impairs the child's health, development or welfare. Specific negative impacts identified in the research include absence from school, social isolation, physical illness, worry and resentment and the loss of normal childhood activities and experiences.

In 2010 it was estimated that Ireland could have as many as 28,000 Young Carers aged under 18 years and 52,700 aged under 25 years⁷. Despite this, there is no single dedicated Young Carer support group or service in the country. By comparison Scotland has a Young Carer Strategy and 48 services working directly with over 3,300 Young Carers. The City of Glasgow alone has seven dedicated Young Carer projects.

Priorities for Budget 2011

- Funding for Home Care services should be increased to ensure that Carers and older people can receive them at adequate levels.
- Increase the provision of respite services including emergency, residential and in-home respite care.
- Increase funding towards the provision of suitable respite care for children with autism, special needs or mental health issues.
- Government must immediately address the issue of families in receipt of Carers Allowance or Carers Benefit being excluded from receiving home care supports.
- Introduce a legal right to a comprehensive Needs Assessment for Carers to include health and social issues.
- Introduce a specific budget to advance the recommendations emerging from the Office of the Minister for Children and Youth Affairs' Young Carers study.

⁷ Research undertaken by Professor Saul Becker from the University of Nottingham.

ANALYSIS OF PRIORITY ISSUES:

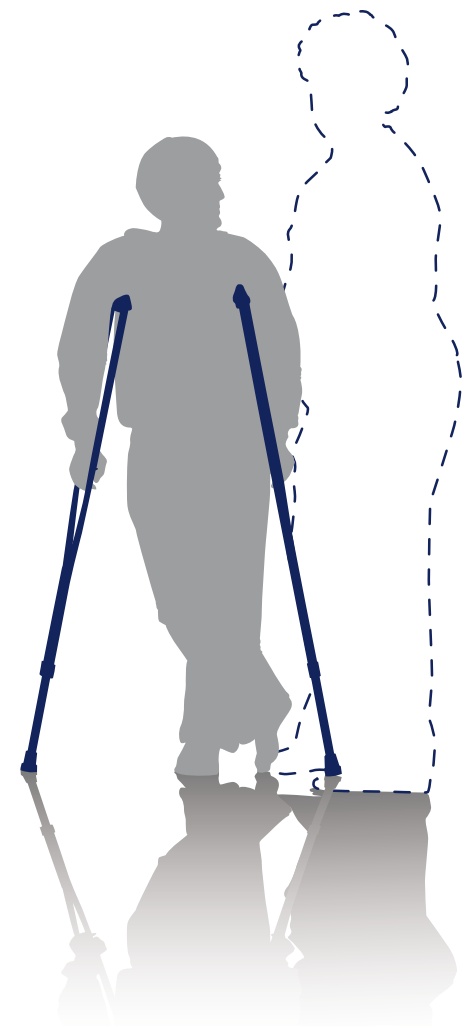
DEPARTMENT OF COMMUNITY, EQUALITY AND GAELTACHT AFFAIRS

PUBLISH THE NATIONAL CARERS STRATEGY

Despite Government stating that the National Carers Strategy could not be published due to the current economic crisis, resources have been made available for the publication of the National Drugs Strategy, National Strategy on Domestic, Sexual and Gender-based Violence and a National Positive Ageing Strategy. 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 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.

Priorities for Budget 2011

- The Carers Association calls on Government to publish the National Carers Strategy, setting out their commitments in relation to income supports, healthcare, training, the labour market, transport, housing and information services with implementation of the Strategy's recommendations to take place when economic, social and political indicators allow.



CARERS IN IRELAND – AN ECONOMIC ANALYSIS

The willingness of family members to provide care can mean that Government may treat family care as a 'free resource'. However, caring can entail significant economic costs for individuals. The following cases illustrate the tremendous economic cost that Carers in Ireland bear and the budgetary challenges they face.

Case 1: Fulltime Family Carer for a child with autism receiving Carers Allowance

Catherine cares for her eight year old son who has autism. Because he is in mainstream education and not affiliated with any service the family must pay privately for all assessments and supports. Catherine's husband has been reduced to a 2-day week so he is now claiming partial Jobseekers Benefit. A total of €228.70 is spent by the family on medical costs each week, more than Catherine's Carers Allowance and three times the

weekly Domiciliary Care Allowance rate. There is currently an income shortfall of €5.43 per week which is being subsidised by a small amount of savings that the family had put aside while Catherine's husband was in fulltime employment. These savings are now almost gone. It's a constant struggle for the family to manage their limited income while ensuring that their son has access to the supports and services he needs.

Income	€	Expenditure	€	Total €
Jobseekers Benefit	140	Essential Expenditure		
Part-time Employment	294	Mortgage	220	
Carers Allowance	221.9	Groceries	125	467
Domiciliary Care Allow.	77.37	Utilities	60	
Respite Care Grant	32	Transport	40	
		Home Insurance & Maintenance	22	
		Medical Expenditure		
		Health Insurance	38	
		Speech & Language Assessment	9.6	
		Occupational Therapy Assessment	9.6	228.70
		Psychological Assessment	11.5	
		Speech Therapy (1hr wk)	100	
		Occupational Therapy (1hr mth)	30	
		Specialist Medical Treatments	20	
		GP Visits	10	
		Education		
		Training for support child w/ autism	10	
		Tutor for special needs child	20	75
		Back to School/Educational Pension	25	
		Savings		
		Savings	0	0
TOTAL	765.27			770.70
INCOME SHORTFALL				-€5.43

Case 2: Fulltime Family Carer caring for husband and receiving the Half Rate Carers Allowance

Mary has been her husband Michael's primary Carer since he was diagnosed with Parkinson's Disease five years ago. Since then Michael has also been diagnosed with liver and bowel cancer and has undergone surgery and cancer treatment. Because Michael's mobility, speech and general motor skills have been severely impaired, he depends on Mary for every aspect of his daily living, washing, shaving, administering medication, walking, eating etc. This means that Mary's caring role is 24/7; she has no time off and receives no home help or respite services.

Because both Michael and Mary have a medical card most of the couple's expenses relate to the additional costs they incur due to Michael's illnesses. Michael requires a special diet, which means grocery bills are high and is susceptible to the cold so needs the central heating turned on throughout the day. In addition, many of Michael's medical appointments are not along a bus route so they rely on taxi's. During Michael's frequent hospital stays in Dublin, there are additional food, travel and accommodation costs for Mary. The couple have no savings.

Income	€	Expenditure	€	Total €
Pension	230.30	Essential Expenditure		
Qualified Adult	153.50	Mortgage	135	
Half Rate CA	106	Loan- building accessible toilet	50	
Respite Care Grant	32	Groceries	160	502
		Utilities including ESB, Heating & Telephone	80	
		Transport including taxis to medical appointments	50	
		Home Insurance and Maintenance	27	
		Medical Expenditure		
		Expenses Associated with treatments	20	22.50
		Prescription Charges	2.50	
		Savings		
		Pension	0	0
		Savings	0	0
TOTAL	521.80			524.50
INCOME SHORTFALL				-€2.70

Case 3: Fulltime Carer caring for his wife and receiving a Half Rate Carers Allowance

Pat has been providing fulltime care for his wife Margaret for 12 years. Margaret has polio, post polio syndrome, is diabetic and wheelchair bound. Pat himself is unwell, has a heart condition and high blood pressure. He is on Illness Benefit and receives a Half Rate Carers Allowance. Each week the family struggle to make ends meet and often have to go without to ensure that they stay within their weekly budget. The family have no savings or money

left at the end of the week to cover unexpected items, which means they rely on a Credit Union loan to cover these costs. While both Pat and Margaret have a medical card, the card does not cover certain things such as a medical dressings or dietary supplements. Pat is also forced to pay a very high rate of car insurance as his vehicle is modified to provide wheelchair access. Fuel and heating costs are also high as Margaret's polio means that she is extremely sensitive to the cold.

Income	€	Expenditure	€	Total €
Disability Payment	202	Essential Expenditure		
Illness Payment	194	Local Authority Rent	50	
Half Rate CA	106	Heating & Fuel	50	
Respite Care Grant	32	Groceries	120	460
		Utilities	150	
		Transport (Insurance, Tax & Petrol)	90	
		Medical Expenditure		
		Medical Dressings	35	55
		Dietary supplements	20	
		Other		
		Home Maintenance	10	20
		Loan Repayment (Cooker)	10	
		Savings		
		Pension/Savings	0	0
	534			535
INCOME SHORTFALL				-€1.00

Carer's Contribution To The Social Economy County By County

Case 4: Fulltime Family Carer caring for mother and receiving a Half Rate Carers Allowance.

Orla returned from Australia in 2003 to care for her elderly mother who is now 94. She receives a Half Rate Carers Allowance and a Qualified Adult payment on her husband Sean's pension. Orla's mother had a fall last year and was forced to move into Orla's home for five months to recuperate. When her mother returned to live in her own home, the HSE said they could not continue to provide the Home Help service she had been

receiving prior to her fall.

As a result Orla's 94 year old mother lives alone and receives no State assistance. Sean, Orla's husband, has Cancer, and while he doesn't require fulltime care, his illness does place many additional costs on the family. The couple's medical expenses and fuel costs are significantly higher than normal. While they both pay for private health insurance, their insurer will not cover Sean's Cancer treatment or Orla's revision hip replacement.

Income	€	Expenditure	€	Total €
Non Contributory Pension	219	Essential Expenditure		
Qualified Adult	144	Heating & Fuel	50	
Half Rate CA	106	Groceries	150	336
Respite Care Grant	32	Utilities	40	
		Transport (Insurance, Tax & Petrol)	96	
		Medical Expenditure		
		Medical Expenses (Cancer)*	100	160
		Medical Expenses of Carer	25	
		Private Health Insurance	35	
		Savings		
		Savings	5	5
	501			501
INCOME SHORTFALL				€0.00

Cities & Counties	No. of all Carers (Census '06)	Total hours worked per week	Value per year at €13 per hr in millions
Leitrim	1,205	27,344	€18.05
Longford	1,381	34,266	€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 City	2,409	51,381	€34.73
Waterford Co.	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 Co.	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 Co.	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 Co.	14,783	329,961	€223.05
Dublin City	18,356	434,749	€293.89
Grand Total	160,917	3,724,434	€2.5+ Billion



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