



West Cork Carers Support Group

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Pre-Budget Submission for Budget 2015

West Cork Carers Support Group makes this submission to the following Government Departments in preparation for the 2015 Budget:

- **Department of Social Protection**
- **Department of Environment, Community and Local Government**
- **Department of Health**
- **Department of Children and Youth Affairs**
- **Department of Finance**
- **Department of Education and Skills**

Background

West Cork Carers Support Group (WCCSG) is a voluntary organisation that provides Carers with a wide range of training, supports and information, a voice to Carers issues, and lobbies for improved services and supports. Collaborative working with the HSE and many other statutory, voluntary and community groups enhances our work which is cost effective and efficient.

West Cork Carers Support Group is fully aware of the dramatic changes to our economy and the continuing demands on Government to fund the Health Service, Social Protection system, and various other community initiatives. However, we call on Government to use Budget 2015 as an opportunity to signal their commitment to recognising and valuing Carers as specified in the mission statement of the National Carers Strategy:

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

It is estimated that every week 8 million hours of care is provided by the 274,000 Carers across Ireland contributing over €5 billion to the economy every year. If Carers feel valued and supported to manage their caring responsibilities, this will allow individuals to continue in their roles as Carers, thus implementing Government policy to care for people in their own homes for as long as possible as well making considerable savings for the State.

Carers in West Cork

In West Cork, Carers play the primary role in the support of people at home. Without this vital care and support, many recipients of care could not continue living at home. The Carer's role may involve a 24-hour-day seven-day-week commitment. While providing care to a loved one may be willingly given, the cost to the Carer can be unacceptably high.

Research has shown that many Carers experience reduced physical, mental and emotional health, social isolation and financial hardship once caring commences and over time the effects may be intensified. Carers in rural West Cork are also faced with additional barriers of physical and social isolation and a lack of services (both in terms of access and availability).

Additional issues which Carers in rural areas may face include: lack of specialist services; lack of respite; difficulty in accessing medical support; isolation and lack of companionship; information gaps; difficulties with transport and employment; poverty and the additional costs of living in a rural area.

As a result many Carers are not able to participate in their wider community, in leisure and activities or take up education, training or paid work. This not only impacts on their health and well-being, but on their immediate and long term financial security.

Thus, it is imperative that Carers should be supported, so that their own health and well-being is effectively maintained. If it is not, then the burden and cost of care will revert to the State.

Government must therefore continue to support Carers and protect them from cutbacks in services and financial supports to enable them to continue their caring role.

Following consultation with Carers in West Cork, we now welcome the opportunity to present this Pre Budget Submission and urge you to take the following recommendations into consideration on Budget Day.

Department of Social Protection

Protect the existing Carers Allowance, Half Rate Carers Allowance. Carers Benefit and Respite Care Grant

Income support is vital for the majority of full-time Carers, and the Department of Social Protection must maintain the current level of these payments as a priority.

Reduce processing times for Social Protection Payments

There needs to be a reduction in the processing time for Carers claiming Carers Allowance, Carers Benefit and the Respite Care Grant by ensuring that the Department of Social Protection is adequately resourced to address current backlogs. The length of delay experienced by Carers for decisions relating to entitlements is unacceptable. This increases financial pressure and stress on Carers who are already struggling to cope.

Carers Balancing Employment

Whilst balancing caring with employment can be extremely difficult, it can help the Carer to maintain working skills and social interaction. Carers feel that the income that can be earned from the maximum 15 hours per week employment should be excluded from the Carers Allowance means test.

Restore the Respite Care Grant to €1700

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. The 19 % cut to the Respite Care Grant imposed in Budget 2013 was extremely unfair and disproportionate to the cuts applied across the general Social Protection budget. As the economy begins to recovery WCCSG urges that steps towards the restoration of the Respite Care Grant back to €1,700 begin in Budget 2015.

Introduce a pro rata payment of the Respite Care Grant

We also call for the introduction of a pro rata payment of the Respite Care Grant to Carers who have lost their loved one during the year and who would not otherwise be eligible for the June payment. Currently if a Carer has provided care for eleven and a half months but ceases to be caring on the first Thursday in June they are not eligible for the grant. We strongly urge that the criteria be adjusted immediately to re address this injustice and Carers are able to claim a proportion of the grant if their caring ceases before the first week in June.

Habitual Residence

Remove the Habitual Residence Condition as a barrier to eligibility for Carers Allowance for persons returning to Ireland to care for a loved one.

Water Rates

The introduction of Water Rates will bring additional financial pressure to Carers particularly where there is increased water use due to their caring role (extra bathing/washing, toilet flushing etc.). WCCSG acknowledges Government's announcement that it will put in place water affordability measures to assist pensioners, persons with disabilities, and Carers to meet the costs of water charges by increasing the Household Benefits Package by approximately €100 a year. However, it is still unclear from the Commission on Energy Regulation what the cost per litre of water will be and therefore if the allowance will be adequate to meet the essential water needs of households with additional requirements due to caring responsibilities.

We also suggest the extension of the water allowance to all full time Carers, regardless of whether they are in receipt of a Household Benefits Package. Such households could easily be identified through the non-means tested Respite Care Grant or by providing medical certification.

Contributory State Pension entitlement for Carers

Many Carers do not have the capacity for making life savings and will be dependent on the State pension for subsistence in their older age. However, many long term Carers are commonly not meeting the qualifying conditions for the Contributory Pension because they have remained at home to take care of family members and are now at a disadvantage with regard to PRSI contributions. The provisions offered under the Homemakers Scheme have been dramatically undermined by recent changes in the contribution requirements for State pensions as they require 520 paid contributions accrued during periods of paid employment. Ensuring that Carers do not suffer social insurance or state pension disadvantages because of periods of caring needs to be addressed urgently.

Extend transition arrangements at the end of a period of extended caring

Carers continue to receive Carers Allowance for six weeks after the death of their loved one. In cases where the caree is admitted to long term residential care, there is no such grace period and payment ceases immediately. The loss of Carers Allowance has a domino effect causing the immediate withdrawal of the Household Benefits Package, Free Travel Pass and the Respite Care Grant resulting in significant financial loss for the Carers involved.

The abrupt withdrawal of all income support can be devastating when a Carer is at a particularly difficult juncture. Measures need to be introduced to assist the transition out of long term caring responsibilities, in particular the extension of the grace period following the death of the caree from six weeks to six months and the introduction of a similar grace period for Carers whose full time caring role has come to an end following the admission of their loved one to residential care.

Liability for failure to collect tax on Carers Allowance and Carers Benefit

Both Carers Allowance and Carers Benefit are taxable sources of income. When a Carer is first awarded Carers Allowance or Carer Benefit the letter sent to them by the Department states (on the reverse of the page) that they must declare this income to their local tax office. However, many Carers miss this or assume that any notification will occur directly between the Department and Revenue.

While WCCSG has makes every effort to inform Carers of their duty to notify Revenue some Carers have stated that they were unaware of this and could now face a significant tax bill in the future.

The automatic notification of a person's receipt of Carers Allowance or Carers Benefit needs to take place directly between DSP and Revenue to avoid this confusion and the Carer having the responsibility of having to declare the payment.

Department of Environment, Community and Local Government

County Council Disability Grants

Government needs to provide sufficient funding for the operation of the Housing Adaptation and Mobility Aid Grants to reflect the increasing number of people cared for at home and the high level care that they require. The Grants are essential to enable and support many Carers who care for family members with limited abilities at home, and for the independence of their carees. Yet, there are still huge delays in approving grants and the current system of means testing of the household places an unfair financial burden on the person with disabilities and their Carers, where assessed household income may not be at the disposal of the applicant of the scheme. The WCCSG would urge an immediate review of the processing of these grants and the means assessment criteria to address these concerns.

Protect the Senior Alert Scheme and Promote the Use of Telehealthcare Products/Services

Protect the Senior Alert Scheme by maintaining funding and provide safety and security systems to all vulnerable people in the community at a nominal monitoring charge to support Government Policy for Independent Living.

Extending the provisions of the scheme to include assistive technology devices, such as motion sensors, GPS tracking devices etc. will provide additional security for individuals who have physical or cognitive difficulties living at home.

Research and Technology Development

Extend and advance assistive technologies with on-going research and technology development of Telehealthcare services, App development etc. to aid Carers and the people that they care for.

Department of Health

The Department of Health needs to be assured of adequate funding to provide the following vital services:

Fair Deal Scheme.

The Fair Deal application process needs to be made less cumbersome and the scheme extended to provide supports to patients who wish to remain in their own homes. The HSE Service Plan 2013 stated efforts to rebalance the disparity between nursing home and community care through the re-allocation of €23 million from the Fair Deal budget towards the development of home and community support services. However, Government continues to prioritise long term residential care over care provided within the home – the exact opposite of Government policy.

Home Help Services

The Home Help Service eases the physical and emotional pressure, and provides essential backup for the full time Carer and caree. Increased levels of Home Help must be made available to support Carers and their loved ones, including the addition of provisions for more flexibility and for weekend and night cover.

Home Care Packages

Increase the number of Home Care Packages in an equitable divide countrywide.

Support Carers Health and Wellbeing

Carers often forego or neglect their own health and wellbeing due to their caring role and the financial costs involved. The Department of Health should alleviate this situation by:

Full medical card and Annual Health Checks

Provide Carers with a non-means tested, full medical card and annual health checks. A GP card should be provided to Carers as a minimum.

Reduce waiting times at A&E by fast tracking Carers when necessary.

Carers Needs Assessment

Establish the legal right of all Carers to a comprehensive Needs Assessment, including health, social and financial issues, on becoming a Carer followed with regular reviews.

Primary Care Teams

It is apparent that many Carers who do not recognise themselves as Carers, nor do they acknowledge their own needs. There are also many who feel they do not have the support of the system and that they have to fight for everything they need. This could be addressed by the introduction of a Needs Assessment protocol, initiated by the Primary Care Team as soon they identify Carers.

Carers have also highlighted the need for training, education and awareness-raising sessions on Carers issues for all Health Care Professionals. This should include the provision of a compassionate, respectful and dignified approach to enhance communications with Carers.

Increase Specific Support Services for Carers

There is a strong request, from West Cork Carers and our NGO stakeholders, that the core services of WCCSG be expanded. The organisation is however operating within severe financial restraints with an ever increasing demand for our services and

cut-backs to other community services. This continues to be a major challenge to the organisation.

Carers state the provision of accessible information and support services as essential to their ability to continue in their caring role. Continuity of support to Carers dedicated groups such as West Cork Carers Support Group to provide a 'one-stop shop' model of information and supports that reduces Carers isolation is therefore critical.

Patient Discharge Summary/ transfer of Care

Develop a National Patient Discharge Summary and Care Plan for all people leaving hospital care to share with their Carers.

Respite Services

In order to provide Carers with a break from providing care on a 24/7 basis, regular respite is essential. Funding for respite services should be increased to allow:

- Increased access to planned respite breaks for dependents of full time Carers
- Development of flexible in home respite services for Carers and dependents with no access to residential respite services
- Emergency respite services that are responsive to the needs of both the Carer and caree
- Removal of charges for respite services for those who cannot afford them.

Department of Children and Youth Affairs

Support for Young Carers

The role of Ireland's Young Carer's needs to be acknowledged and valued by Government with a specific budget for supports introduced immediately.

WCCSG is aware of the increasing number of children and young adults who are providing significant levels of care. Census 2011 statistics show that there are 8,472 children and young adults providing care in Ireland. Of these 4,228 are aged less than 15 years. This is likely to be a gross underrepresentation of the true picture as many Young Carers remain under the radar.

Whilst some caring experiences can be positive for Young Carers, for other children who take on significant caring roles care there can be serious negative outcomes and the level of support provided must reflect their increased needs.

A national framework of supports and policy guidelines for Young Carers in the education system should be developed.

Department Of Finance

Travel Pass for all Full-time Carers

The free travel pass should be made available for all Carers in receipt of the Respite Care Grant to enhance access to services and reduce isolation, particularly for Carers living in rural areas.

Disabled Drivers and Passengers Tax Relief Scheme

This scheme is seen as a lifeline for many West Cork Carers where public transport is often not available or accessible. Many Carers have to travel a 200 mile round trip for frequent and regular hospital appointments

A condition of the Disabled Drivers and Passengers Tax Relief Scheme is eligibility for the Primary Medical Card. A relaxation of the archaic & stringent criteria currently used in the six-point assessment for the Primary Medical Card is urgently needed.

A review of the Disabled Drivers and Passengers Tax Relief Scheme is needed to take into consideration adults and children with physical or intellectual disabilities who require a special harness or car seat to travel. This presents a real safety issue for many parents and we would urge an immediate review of the medical criteria to address these concerns.

Excise duty on fuel and the replacement Fuel Grant

The excise relief on the fuel element of the Disabled Drivers and Disabled Passengers scheme will be discontinued on the 31st December 2014. While the Department announced that a new Fuel Grant will replace the scheme and has moved to reassure recipients that they will not lose out as a result, concern remains that some disabled drivers and passengers with high fuel costs will lose out financially.

Rural Transport

Maintenance of the existing Rural Transport Scheme and Cancer Connect Service in West Cork was highlighted as essential by many Carers. These services are invaluable resources for Carers in West Cork where public transport is inaccessible for many. Carers also cited the Rural Transport Scheme as an essential service for maintaining social inclusion.

Local Property Tax

Government needs to make households where a high level of care is provided exempt from the Local Property Tax. Current exemptions to the Local Property Tax include nursing homes, hospitals and charity owned care centres, but makes no allowances for Carers despite being the largest providers of care. By contrast, in the UK there are numerous Council Tax schemes which offer reductions or complete exemptions to Carers and those for whom they care.

Department of Education and Skills

Education and Training During Caring:

Carers have a right to be offered the same training opportunities that are currently provided for Health Care professionals in the practicalities of care i.e. patient moving and handling, using aids and appliances, nutrition and personal care etc.

WCCSG recommend the introduction of a Carer Training Plan based on the Needs Assessment & Care Plan mentioned previously so that a Carers' individual training needs are identified and addressed.

Post Caring:

After caring there is a need for training which updates a Carer's skills to assist them back into employment. Frequently a Carer's self-confidence and self-worth can be affected by an extended period of caring. Training programmes ideally need to be cognisant of this by acknowledging and developing the skills that Carers have gained in their caring role.

The availability of training programmes as highlighted above could also greatly enhance a sense of recognition and inclusion amongst Carers and former Carers.

Cross Departmental Measures

National Carers Strategy

The publication of the National Carers Strategy in 2012 was welcomed as this is the first time that the Government has recognised that Carers are key players in the health system. The Strategy is an acknowledgment that Carers deserve respect, recognition and support for the work that they do. However, we find that Carers are showing signs of being increasingly overwhelmed by the physical, emotional and financial demands of caring and are feeling increasingly isolated and alone. We thereby call for more progression in the implementation of the goals set by the Strategy from each relevant department.

Conclusion

Carers make by far the most important contribution to the support of people with disabilities, those with mental illness, the frail, sick, and the elderly living in our community. The costs and special value of the care provided by Carers could never be replaced by health and community care services. We cannot underestimate Carers' invaluable contribution to society and this enormous contribution must be incentivised rather than penalised.

By considering our submission and recommendations for Budget 2015, we believe that Government will go some way to recognising and respecting Carers as key partners in care.

The recommendations made should be considered cost effective for Government, as the consequences of a Carers becoming ill and no longer being able to care, would undoubtedly mean greater cost implications for the exchequer.

We expect that you will use your position as Minister to protect the income and services currently available and work for these much needed additional supports for Carers and that the 2015 Budget will reflect this.

Summary of Recommendations

Department of Social Protection

- Protect the existing Carers Allowance, Half Rate Carers Allowance. Carers Benefit and Respite Care Grant
- Reduce processing times for Social Protection Payments
- Exclude the income earned from the maximum 15 hours per week employment from the Carers Allowance means test.
- Restore the Respite Care Grant to €1700
- Introduce a pro rata payment of the Respite Care Grant
- Remove the Habitual Residence Condition for Carers Allowance for persons returning to Ireland to care for a loved one.
- Extend the €100 water allowance to all full time Carers
- Provide Contributory State Pension entitlement for long term Carers
- Extend transition arrangements at the end of a period of extended caring
- Remove the Liability for failure to collect tax on Carers Allowance and Carers Benefit

Department of Environment, Community and Local Government

- Review the assessment criteria and processing of the County Council Disability Grants
- Protect the Senior Alert Scheme and Promote the Use of Telehealthcare Products/Services

Department of Health

- Review the Fair Deal Scheme
- Increase the Home Help Service
- Increase the number of Home Care Packages
- Full medical card and Annual Health Checks for Carers
- Reduce waiting times at A&E for Carers
- Legislate to ensure a statutory entitlement for all Carers to a Needs Assessment
- Increase Specific Support Services for Carers
- Develop a National Patient Discharge Summary and Care Plan
- Increase respite services and opportunities

Department of Children and Youth Affairs

- Develop national supports for Young Carers

Department Of Finance

- Travel Pass for all Full-time Carers
- Review the Disabled Drivers and Passengers Tax Relief Scheme
- Ensure the replacement Fuel Grant adequately replaces the Excise duty on fuel
- Maintain the Rural Transport Scheme and Cancer Connect Service
- Extend Local Property Tax exemptions to include households where high level care is provided

Department of Education and Skills

- Provide Education and Training Opportunities During Caring
- Develop An Appropriate Post Caring Training programme

Cross Departmental Measures

- Ensure Implementation of the National Carers Strategy