



Family
Carers
Ireland

**Budget 2017:
Achieving Fairness
for Family Carers**



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Why Carers Count in Budget 2017

Ireland's 187,112 family carers provide 6.2 million hours of care each week, which:

- Equates to a contribution of over **€4 billion** to the Irish economy each year.
- Is equivalent to almost **one third of the total annual cost of the HSE** (€13 billion)
- Is **four times** what carers cost the Department of Social Protection in income support (€900m)
- Means the average fulltime carer receiving Carer's Allowance contributes almost **€67,000 in unpaid work each year** in return for a maximum Carer's Allowance payment of €10,608.

In February 2016, the people of Ireland elected 158 TDs to Dáil Éireann. Many were elected based on their promises to build a more equal, fair and inclusive society; to protect the vulnerable; secure greater investment in public services; and reform the health service. Family Carers Ireland also received a written commitment from each political party that, if elected, they would publish a refreshed National Carers' Strategy, backed by dedicated funding to support its implementation¹. We are pleased that many of these promises have been carried through to the Programme for Government, in particular the commitment to implement the National Carers' Strategy in full; increase funding for home care packages and home help; improve supports for persons with mental health difficulties; and ensure greater involvement of family carers in the preparation of care plans, together with integrated care pathways, more accessible training and respite care, and access to counselling. The Programme for Government also commits to increasing Carer's Allowance, Carer's Benefit and Disability Allowance and reducing prescription charges.

Family Carers Ireland will hold Government to account in Budget 2017, and expects that the promises made in the run-up to Election 2016 and committed to in the Programme for Government will begin to be delivered. Our election campaign included a detailed manifesto which set out carers' priorities for the new Government. Many of these are budgetary matters and so remain our focus in Budget 2017.

1. Publish phase two of the National Carers' Strategy with ring-fenced funding for implementation
2. Ensure family carers are not financially burdened as a result of their caring role
3. Create a more 'carer-friendly' health service
4. Recognise the home as a *centre of care*
5. Invest in the futures of young carers

1. Publish Phase Two of the National Carers' Strategy with ring-fenced funding for its implementation

The National Carers' Strategy, published in 2012, signalled Government's commitment to respecting carers as key partners in care, and to responding to their needs across a number of policy areas. At the time of its publication, Taoiseach Enda Kenny warned of the need to be pragmatic in terms of the limited financial resources available to deliver the National Carers' Strategy, but promised that, as Ireland's economy recovered, Government departments would be given the opportunity to revisit the Strategy and propose additional actions supported with the necessary funding.

Family Carers Ireland is proud of the progress that has been made to date with little or no additional spending, and we acknowledge the spirit of partnership that has been shown by Government

¹ A written commitment was given by Fine Gael, Fianna Fáil, Labour, Sinn Féin, People Before Profit Alliance and the Social Democrats. <http://familycarers.ie/get-involved/join-a-campaign/general-election-2016/election-2016-commitments/>

departments in working with the National Carers' Strategy Monitoring Group in implementing very practical changes aimed at better supporting family carers. While there has been progress, however, it has been limited by the lack of ring-fenced funds, with many of the cost-neutral actions now dated and offering little opportunity for progression. Family Carers Ireland is therefore calling on Government to commit to publishing a renewed National Carers' Strategy, setting out a clear action plan for 2017-2021 and backed with appropriate funding.

Priorities for Budget 2017

- Ring-fence funding for the publication and implementation of phase two of the National Carers Strategy 2017 – 2021.
- Seek views from the public on a new strategy for carers that will reflect their lives now, including their health and financial concerns, and give them the support they need to live well while caring for a family member or friend².

2. Ensure family carers are not financially burdened as a result of their caring role

For many families, taking on caring responsibilities results in long-term financial hardship as a loss of income from employment is exacerbated by higher household costs such as heating, laundry, medicines, disability aids, home modifications, health care or specialised transport. The impact of caring can last a lifetime, as years spent on a low income or out of the workforce mean carers cannot repay debt, build savings or contribute to a pension. If caring comes to an end while the carer is of working age, barriers to returning to work often result in carers being 'locked out' of the labour market and faced with long term financial hardship. Even working carers, who manage to remain in employment, are likely to see their working lives adversely affected by having to reduce their hours of work, accept low-paid, precarious work options or sacrifice promotion and career opportunities. For those who qualify for Carer's Allowance, they must agree to provide fulltime care, in excess of 35 hours each week, all for just €16 more than Jobseeker's Allowance (if they qualify for the maximum payment of €204). The condition that carers must work fulltime (the only social welfare recipients required to do so) restricts carers' ability to supplement their income through work and so further increases the financial difficulties they face.

Priorities for Budget 2017

- Increase Carer's Allowance and Carer's Benefit in line with the restoration of public sector pay and towards the rates paid in 2009 of €220.50 and €221 respectively.
- Payment of the Carer Support Grant should be on a pro-rata basis, to include all months that a carer has spent caring. At present, carers whose loved one passes away 12 weeks before the first Thursday in June will not receive the grant.
- Include travel, medical and other care-related expenses as deductible costs when means-testing Carer's Allowance.
- Continue to pay Carer's Allowance for 12 weeks to carers whose caring ends following the admission of their loved one to residential care, bringing it in line with carers who receive the payment for 12 weeks following the death of their loved one.
- Reinstate in full the Household Benefits Package, including the telephone allowance.
- Extend the Free Travel Scheme to include young people in receipt of Domiciliary Care Allowance.
- Increase the hours carers can study/work while receiving social welfare from 15 to 18.5 hours a week³.

² The Irish NCS is modelled on the UK Carers Strategy. In the UK they are currently undergoing their second public consultation on their Carers Strategy to ensure it remains up-to-date and reflective of the needs of carers.

³ 18.5 hours is half of a 37 hour working week.

- Disregard the Half-Rate Carer's Allowance in the assessment of means for Fuel Allowance.
- Reinstate the Diet Supplement, discontinued in 2014, for people with specified medical conditions.
- Review how tax breaks can better support caring families and help carers remain in the workforce e.g. tax breaks to assist with the cost of private care.
- Further increase the Home Carer Tax Credit and income thresholds where one spouse or civil partner works in the home caring for a dependent person.
- Any tax liability arising from a person's receipt of Carer's Allowance should be subject to tax at the standard rather than higher rate.
- Reform social welfare rules to incentivise people to take on part-time work in the home care sector.
- Recognise the contribution and personal sacrifice of lifetime carers (those caring in excess of 20 years) by putting in place mechanisms to maximise their entitlement to a Contributory State Pension when they reach retirement age.
- Lifetime carers whose caring role comes to an end as they approach retirement age should be offered an early retirement option paid at the same rate as Carer's Allowance.

3. Create a more 'carer-friendly' health service

The health service depends on family carers. Without the 6.2 million hours of unpaid care they provide each week, the service would simply collapse. The demand for home care, fuelled by an ageing population and Government policy of deinstitutionalisation, is being met by family carers rather than by the State. Logic would suggest that services to support care in the home should therefore increase in line with demand, but this has not been the case. At best, home care services are being maintained at the previous year's level, and at worst they are being rationed to the extent that even those assessed by the Public Health Service as needing home support cannot access help until another person dies and hours can be 'recycled'. This rationing of home care is in addition to the widespread closure of respite care beds, cuts to disability and mental health funding, and the withdrawal of important transport supports including the Mobility Allowance and Motorised Transport schemes, all of which are forcing carers to fill the ever-increasing gap between the demand for home care and the limited support available.

Family Carers Ireland wants a more carer-friendly health service: one which respects carers as expert partners in care; recognises the high-level, complex care that is routinely provided within the home; and makes available sufficient and sustainable funding to ensure patients receive the best possible care in the most appropriate setting.

Priorities for Budget 2017

- The HSE spent less on home care in 2015 (€320m) than in 2008 (€331m), despite a 25% increase in the population aged over 65 years.⁴ Budget 2017 must substantially increase funding for home care services to at least €414m⁵ to meet this 25% increase and ensure no person assessed as needing home support is forced onto a waiting list.
- Publish a timeline to create a statutory entitlement to home care services to balance the statutory entitlement to residential care services established under Fair Deal legislation. In the interim, commit to the immediate amendment of the Nursing Homes Support Scheme to include an alternative package of home care supports, funded under Fair Deal.

⁴ A study undertaken by Age Action, IASW, Alzheimer's Society and UCD in 2016 'I'd Prefer to Stay at Home but I Don't Have a Choice' shows that HSE spent €331m on Home Help and Home Care Packages in 2008 compared to €320m in 2015. However during the same period the HSE increased spending on long term care from €920m in 2008 to €988m in 2015.

⁵ A 25 percent increase in 2008 funding levels of €331m to reflect the increase in the older population would require funding in 2016 of €414m.

- Respite care is universally regarded as one of the key support interventions to support the health and wellbeing of carers and is critical to the sustainability of caregiving efforts. Despite its importance, funding cuts, staff shortages, bed closures as a result of HIQA inspections and the transfer of respite beds to ‘transitional care beds’ has greatly reduced respite availability and denied many carers this vital support. Budget 2017 must increase funding for the provision of flexible respite options, including in-home and emergency respite, for people of all ages, which ensures equity of access irrespective of where a person lives, and is demand- rather than resource-led.
- The budget for disability services has been reduced by €159 million since 2008, leading to the steady erosion of vital community-based supports, significant waiting lists for important therapies and the de facto privatisation of services by forcing families to fund them out-of-pocket. Funding must be restored to the disability health budget to address the serious deficits in disability services that exist and ensure that people with a disability can live with autonomy, dignity and independence.
- Allocate funding to address the deficits in care for those with an acquired brain injury, dementia, disability or a chronic condition aged under 65 years, including funding towards their long-term care where a nursing home is not an appropriate option.
- Reduce prescription charges which impact disproportionately on carers and those with medical conditions and end the double-charging of prescription charges where medications are dispensed in different denominations.⁶
- Address the under-resourcing of therapies including Speech and Language, Occupational Therapy, Psychology and Physiotherapy for children with a disability and put an end to waiting lists which see the most vulnerable denied access to these vital supports. Interventions should include the extension of the GP Visit Card to include access to these services for children and the creation of a National Treatment Purchase Fund model to address waiting times.
- Address the inequalities affecting carers of people with mental health difficulties and implement the actions contained within *A Vision for Change* and the Healthy Ireland Framework, and ensure adequate ring-fenced funding is in place.
- Introduce the Transport Support Scheme, announced in 2014 as a replacement to the Mobility Allowance and Motorised Transport Grant, with appropriate funding, and ensure provision is made to address the needs of people living in rural areas.

4. Recognise the home as a *centre of care*

Home is a special place and the majority of older people and those with care needs want to remain at home for as long as possible. Family Carers Ireland welcomes the reorientation of healthcare away from institutional settings in favour of community-based care. We believe, however, that such a shift is only possible where recognition is given to the unique circumstances of households where high-level care is provided and provision made to meet their housing, social and financial needs. Families who take on significant caring responsibilities should have some degree of certainty that basic supports will be available if and when required, and that they will be recognised rather than penalised for their caring role. While we welcome recent moves by Government to make provision for such households (e.g. the commitment to cap carers’ water bills and ensure households where non-infant continence care is provided will not pay more under pay-by-weight waste regulations laws), it is not always the case that caring households are protected.

The Housing Adaptation Grant Scheme, which is essential to making home care work, has had its funding cut from €95m in 2010 to €56m in 2016, despite a significant increase in its target population; caring households have been hit by the Local Property Tax, whereas nursing homes and other centres of care are

⁶ When a single medication is dispensed in different weights the patient incurs the €2.50 charge twice.

exempted; and carers continue to face unequal treatment in the assessment of local authority rents, with some authorities exempting carer payments while others include them in the assessment of means.

Priorities for Budget 2017

- Increase funding for the Housing Grant Adaptation Scheme and introduce mechanisms to link health and housing policies to ensure funding levels reflect the increasing number of people cared for at home within each Local Authority region.
- Prioritisation for Housing Adaptation Grants should continue to be based on medical need but should also include the prioritisation of works to facilitate discharge from hospital.
- Exclude the income of adult children living in the household from the assessment of means for the Housing Adaptation Grant Scheme and extend the existing disregard of Carer's Allowance to include a disregard of Half-Rate Carer's Allowance.
- Ensure an adequate stock of accessible housing to meet the needs of older people, people with physical and/or intellectual disabilities and those with mental illness who wish to live independently in the community.
- Homes where high-level care is provided should be exempted from the Local Property Tax, in line with the exemption given to nursing homes and other centres of care.
- Introduce a 'weight cap' for household where non-infant continence care is provided to ensure they do not pay more for their waste collection following the introduction of pay-by-weight rules in 2017.
- Ensure water affordability measures are in place to support households with a medical condition.
- Revise the Senior Alert Scheme to include basic telecare and assistive technology supports and extend the provisions of the scheme to include vulnerable adults aged under 65 years.
- Disregard in full Carer's Allowance and the Domiciliary Care Allowance as part of the National Review of the Differential Rent Scheme.

5. Invest in the futures of young carers

Ireland has a hidden cohort of young carers who provide ongoing care to a family member who is physically or mentally ill, disabled or suffering from addiction. Many remain hidden from services due to fear, family loyalty, stigma, not recognising that they are a carer, or not knowing where to go for help. While for many young people taking on modest caring responsibilities can be a positive experience and a normal part of personal and civic development, where the level of caring responsibility is excessive or age-inappropriate, the dangers of leaving vulnerable young carers unsupported can cost them dearly in terms of missed educational opportunities, isolation, worry and the loss of normal childhood activities.

Figures from Census 2011 showing 14,205 young carers aged under 24 years mask the reality of the prevalence of young carers in Ireland. A study undertaken by Dr Saul Becker, a leading international expert on young carers, estimates that Ireland could have as many as 28,000 young carers aged under 18 years, and 52,700 aged under 25 years. A more recent study, undertaken by University College of Ireland, Galway⁷ and published in 2016, shows that 11.9 percent of 10-17 year olds surveyed (n= 11,870) said they provide regular, unpaid personal help for a family member with a long-term illness, health problem or disability. Extrapolation from the sample to the national population would suggest that some 56,118 young people in the 10-17 year age-group alone provide regular unpaid care.

Priorities for Budget 2017

- Explore how young carers can be supported financially while encouraging them to remain in school.

⁷ The Health Behaviour in School-aged Children (HBSC) study which was conducted by researchers in the Health Promotion Research Centre at the National University of Ireland, Galway. Health Behaviour in School-aged Children (HBSC) is a cross-national research study conducted in collaboration with the World Health Organisation (WHO) Regional Office for Europe.

- Commit to the development of a Young Carer Education Strategy, similar to previous strategies published for other vulnerable groups.
- Fund the establishment of a ‘Young Carer Development Team’ to deliver targeted outreach activities across the country. The team would liaise with schools and community services in each HSE region to identify and support young carers early in their caring journey.
- Deliver on the commitment contained within the National Youth Strategy to establish a cross-departmental Young Carer Working Group which will bring together key departments and agencies with a responsibility for supporting young carers.
- Ensure young adult carers are recognised as a vulnerable group and prioritised in the financial support made available to schools, colleges and universities to access and sustain their education.

Summary of Department Priorities for Budget 2017

Department	Action needed in Budget 2017
Social Protection	<ul style="list-style-type: none"> • Increase Carer’s Allowance and Carer’s Benefit in line with the restoration of public sector pay and towards the rates paid in 2009 of €220.50 and €221. • Include travel, medical and other care-related expenses as deductible costs when means-testing Carer’s Allowance. • Continue to pay Carer’s Allowance for 12 weeks to carers whose caring ends following the admission of their loved one to residential care, in line with carers who receive the payment for 12 weeks following the death of their loved one. • Reinstate the Household Benefits Package, including the telephone allowance. • Extend the Free Travel Scheme to include young people in receipt of Domiciliary Care Allowance. • Increase the hours carers can study/work while receiving social welfare from 15 to 18.5 hours a week. • Disregard the Half-Rate Carer’s Allowance in the assessment of means for Fuel Allowance. • Reinstate the Diet Supplement, discontinued in 2014, for people with specified medical conditions. • Reform welfare rules to incentivise people to take on work in the homecare sector. • Recognise the contribution and personal sacrifice of lifetime carers (those caring in excess of 20 years) by putting in place mechanisms to maximise their entitlement to a Contributory State Pension when they reach retirement age. • Lifetime carers whose caring role comes to an end as they approach retirement age should be offered an early retirement option paid at same rate as Carer’s Allowance.
Health/ HSE	<ul style="list-style-type: none"> • Seek views from the public on a new strategy for carers that will reflect their lives now, their health and financial concerns, and give them the support they need to live well while caring for a family member or friend • The HSE spent less on home care in 2015 (€320m) than in 2008 (€331m) despite a 25% increase in the population aged over 65 years. Budget 2017 must substantially increase funding for home care services to at least €414m to meet this 25% increase and ensure no person assessed as needing home support is forced onto a waiting list. • Publish a timeline to create a statutory entitlement to home care services to

	<p>balance the statutory entitlement to residential care services established under Fair Deal legislation. In the interim, commit to the immediate amendment of the Nursing Homes Support Scheme to include an alternative package of home care supports, funded under Fair Deal.</p> <ul style="list-style-type: none"> • Budget 2017 must increase funding for the provision of flexible and appropriate respite options for people of all ages, which ensures equity of access irrespective of where a person lives, and is demand- rather than resource-led. • The budget for disability services has been reduced by €159 million since 2008 leading to the steady erosion of vital community-based supports, significant waiting lists for important therapies and the de facto privatisation of services by forcing families to fund them out-of-pocket. Funding must be restored to the disability health budget to address the serious deficits in disability services that exist and ensure that people with a disability can live with autonomy, dignity and independence. • Introduce specific measures to address the substantial and cumulative cuts to individual and household incomes of people with an intellectual disability in recent austerity budgets. • Allocate funding to address the deficits in care for those with an acquired brain injury, dementia or a chronic condition aged under 65 years, including funding towards their long-term care where a nursing home is not an appropriate option. • Reduce prescription charges which impact disproportionately on carers and those with medical conditions and end the double charging of prescription charges where medications are dispensed in different denominations. • Address the under resourcing of therapies including Speech and Language, Occupational Therapy, Psychology and Physiotherapy for children with a disability and put an end to waiting lists which see the most vulnerable denied access to these vital supports. Interventions should include the extension of the GP Visit Card to include access to these services for children and the creation of a National Treatment Purchase Fund model to address waiting times. • Address the inequalities affecting carers of people with mental health difficulties and implement the actions contained within <i>A Vision for Change</i> and the Healthy Ireland Framework, and ensure adequate ring-fenced funding is in place. • Introduce the Transport Support Scheme, announced in 2014 as a replacement to the Mobility Allowance and Motorised Transport Grant, with appropriate funding, and ensure provision is made to address the needs of people living in rural areas.
<p>Housing, Planning & Local Government</p>	<ul style="list-style-type: none"> • Increase funding for the Housing Grant Adaptation Scheme and introduce mechanisms to link health and housing policies to ensure funding levels reflect the increasing number of people cared for at home within each Local Authority region. • Exclude the income of adult children living in the household from the assessment of means for the Housing Adaptation Grant Scheme and extend the existing disregard of Carer's Allowance to include a disregard of Half-Rate Carer's Allowance. • Prioritisation for Housing Adaptation Grants should continue to be based on medical need but should also include the prioritisation of works to facilitate discharge from hospital. • Ensure an adequate stock of accessible housing to meet the needs of older people, people with physical and/or intellectual disabilities and those with mental illness who wish to live independently in the community. • Homes where high level care is provided should be exempted from the Local

	<p>Property Tax, in line with the exemption given to nursing homes and other centres of care.</p> <ul style="list-style-type: none"> • Introduce a ‘weight cap’ for household where non-infant continence care is provided to ensure they do not pay more for their waste collection following the introduction of pay-by-weight regulations in 2017. • Ensure water affordability measures are in place to support households where there is a medical condition. • Revise the Senior Alert Scheme to include basic telecare and assistive technology supports and extend the provisions of the scheme to include vulnerable adults aged under 65 years. • Disregard in full Carer’s Allowance and the Domiciliary Care Allowance as part of the National Review of the Differential Rent Scheme.
Education & Skills	<ul style="list-style-type: none"> • Commit to the development of a Young Carer Education Strategy, similar to previous strategies published for other vulnerable groups. • Ensure young adult carers are recognised as a vulnerable group and prioritised in the financial support made available to schools, colleges and universities to access and sustain their education.
Children & Youth Affairs	<ul style="list-style-type: none"> • Explore how young carers can be supported financially while encouraging them to remain in school. • Fund the establishment of a ‘Young Carer Development Team’ to deliver targeted outreach activities across the country. The team would liaise with schools and community services in each of the four HSE regions to identify and support young carers early in their caring journey. • Deliver on the commitment contained in the National Youth Strategy to establish a cross-departmental Young Carer Working Group to bring together departments and agencies with a responsibility for supporting young carers.
Transport, Tourism & Sport	<ul style="list-style-type: none"> • Introduce the Transport Support Scheme, announced in 2014 as a replacement to the Mobility Allowance and Motorised Transport Grant, with appropriate funding, and ensure provision is made to address the needs of people living in rural areas. <i>(crosscutting action with the Dept. of Health).</i>
Justice & Equality	<ul style="list-style-type: none"> • Promote Carer’s Leave amongst employers and trade unions and ensure the protection of employee rights through the Work Place Relations Act.
Jobs, Enterprise & Innovation	<ul style="list-style-type: none"> • Review how tax breaks can better support caring families and help carers remain in the workforce, e.g. tax breaks to assist with the cost of private care <i>(crosscutting action with the Dept. of Finance).</i>
Public Expenditure & Reform	<ul style="list-style-type: none"> • Ring-fence funding for the implementation of phase two of the National Carers’ Strategy 2017 – 2021.
Finance	<ul style="list-style-type: none"> • Homes where high-level care is provided should be exempted from the Local Property Tax, in line with the exemption given to nursing homes and other centres of care. • Review how tax breaks can better support caring families and help carers remain in the workforce, e.g. tax breaks to assist with the cost of private care. • Further increase the Home Carer Tax Credit and income thresholds where one spouse or civil partner works in the home caring for a dependent person. • Any tax liability arising from a person’s receipt of Carer’s Allowance should be subject to tax at the standard rather than higher rate.



Have your say in Budget 2017

For more information on how you can become a member of Family Carers Ireland or have your say in Budget 2017 please visit: www.familycarers.ie