

Family Carers Ireland acknowledge the achievements of successive governments in advancing carer policy and developing initiatives to meet carer needs. However despite these efforts, many caring families continue to struggle. Isolation, financial hardship, poor health and exclusion from paid work remain hallmarks of carers' lives. Carers find it more and more difficult to get help, as each year vital respite, home, day and residential care services are chipped away as a result of a €2.7 billion cut in health and social care spending since 2009. Despite this, the number of people caring for a loved one continues to rise, with some 6,287,510 hours of unpaid care provided each week, worth an estimated €4 billion per year.

Now that Ireland's economy is in recovery, we are calling on members of the next Dáil to put carers firmly on their list of priorities. Family Carers Ireland calls for greater fairness for carers, and asks candidates to stand with us in making the following commitments for family carers:

- 1. Ensure family carers are not financially burdened as a result of their caring role**
- 2. Create a more 'carer friendly' health service**
- 3. Invest in the futures of young carers**
- 4. Publish phase two of the National Carers' Strategy with ring-fenced funding for implementation**
- 5. Commit to supporting issues affecting carers both nationally and locally**

## **1. 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 still of working age, barriers to returning to work often result in carers being 'locked out' of the labour market and so facing lasting 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, flexible work options or sacrifice promotion and career opportunities. The financial hardship facing carers is further exacerbated by having to meet the costs of ancillary supports previously provided free of charge e.g. transport, respite and disability aids.

### **Possible areas of action for the new Government**

- Increase Carer's Allowance and Carer's Benefit in line with the restoration of public sector pay.
- Include travel, medical and other care-related expenses as deductible costs when means-testing Carer's Allowance.
- Reinstate in full the Household Benefits Package, including the telephone allowance.
- Increase the hours carers can study/work while receiving social welfare from 15 to 20 hours a week.
- Increase funding for the Housing Adaptation Grant Scheme, and introduce protocols to link health and housing policies to ensure funding reflects the growing number of people cared for at home.
- Reduce costs that impact disproportionately on carers including prescription charges, medical expenses, water charges, hospital parking, etc.
- 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.
- Influence employment policy and practice to create a culture which supports working carers to remain in work. Initiatives could include an 'Employers for Carers' model similar to that widely adopted by employers across the UK.

## 2. Create a more 'carer friendly' health service

Clinical success and corporate failure' has contributed to a worldwide health crisis. Advances in medicine have allowed people to live longer, but failures in how health systems have responded to the consequences means that the A&E crisis, trolley waits, delayed discharges and unnecessary nursing home admissions have become the norm. This does not need to be the case, however. Family carers can play a key role in resolving the health crisis, but only if our health services are rebalanced from an acute to a social care model.

The health service depends on family carers. Without the millions of hours of unpaid care they provide, the service would simply collapse. The rapid growth in demand for care from our ageing population, coupled with policies of deinstitutionalisation and 'hospital at home' models, is being met primarily by family carers. Cuts to vital Home Care Packages, the closure of residential and respite centres, rising medical charges, cuts to Housing Adaptation Grants and the closure of the Mobility Allowance and Motorised Transport schemes are forcing carers to fill the growing gap between demand for care and the limited support available, often at a serious personal cost to their own health and wellbeing. Family Carers Ireland calls on election candidates to create a more carer friendly health service: one which respects carers as expert partners in care, recognises the home as a centre of care and makes available sufficient funding to ensure patients receive the best possible care in the most appropriate setting.

### Possible areas of action for the new Government

- Address the chronic underfunding of community care, which is forcing patients into emergency departments, adding to delayed discharges and pushing older people into nursing homes, by investing in services to support carers who keep their loved ones at home and out of hospital.
- Ensure all fulltime carers are offered a Carer Needs Assessment in the HSE's rollout of the Single Assessment Tool for Older People, and make the assessment available to carers of people of all ages over a five-year period.
- Put an end to 'care cramming', which forces homecare workers to race against the clock through unreasonable time allocations to home care clients, and which places older people at risk of injury.
- Address the inequalities affecting carers of people with mental illness and ensure their needs are addressed alongside those of the patient.
- Replace the Mobility Allowance and Motorised Transport Grant, closed in 2013, with a cash payment.
- Ensure Home Care Packages are available to all people with an assessed need and not rationed in cases where Carer's Allowance is paid.
- Introduce an Ombudsman to monitor health services, including their adherence to discharge and care planning, and to provide a point of redress for individuals who have reason to complain.
- Introduce a 'Carer Friendly Hospital' pilot which will recognise carers as expert partners in care and involve them in conversations about the treatment and care of their loved one. The pilot would also include practical supports for carers - including discounted parking, flexible or extended visiting hours, access to a break room and discounted meals as well as proper transfer of care protocols when a patient is moving from hospital back to home.

### 3. Invest in the futures of young carers

Ireland has a hidden army 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 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, commissioned by the Department of Children and Youth Affairs 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.

#### Possible areas of action for the new Government

- Explore how young carers can be supported financially while encouraging them to remain in school.
- 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 of the four HSE regions 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.
- Include guidelines on supporting young carers in school Child Protection and Welfare Policies, and include young carers as an at-risk group in School Attendance Strategies
- Introduce a classification of 'young carers' in the 'Census at School' which will report on the numbers of young people with caring responsibilities identified in the school system.
- 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.

### 4. 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 care partners, and to responding to their needs across a number of policy areas. At the time of its publication, Government warned of the need to be pragmatic in terms of the limited financial resources available to deliver the Strategy, but promised that as Ireland's economy improved so too would the level of investment allocated, and that departments would be given the opportunity to revisit the Strategy and propose additional actions.

Family Carers Ireland is proud of the progress that has been achieved to date with little or no additional spending. We acknowledge the spirit of partnership that has been shown by Government departments in working with the NCS Monitoring Group in implementing very practical changes aimed at better supporting family carers. While there has been progress, it has been limited by the lack of ring-fenced funds. Family Carers Ireland believes that the vision set out in the National Carers' Strategy holds good; however, many of the cost-neutral actions have become dated and offer little opportunity for progression. We are therefore calling on candidates to commit to adequately fund a renewed Carers' Strategy setting out a clear action plan for 2016-2020.

### Possible areas of action for the new Government

- Publish phase two of the National Carers' Strategy with adequate funds to implement a clear action plan for 2016-2020. This will set out the key activities on which the Government, working in partnership with carer representatives, can focus.
- Commit to working in partnership with the NCS Monitoring Group to drive delivery of the national goals, objectives and actions contained within the Carers' Strategy.

## 5. Commit to supporting issues affecting carers both nationally and locally

Family carers want their elected representatives to pursue national policies that will improve the lives of all carers. However, when faced with the closure of hospital beds, day care centres or respite facilities within their area, they rely on their local TD for support. Family Carers Ireland calls on election candidates to become champions for carers, to highlight the needs of carers in their election campaign and, if elected, to provide a voice for carers both locally and within national Government.

### Possible areas of action for the new Government

- Become a 'Carer Champion' and advocate for investment and services that support carers.
- Act as an agent of change by building momentum on carer issues amongst your political colleagues and seek to influence national policy.

## Why Carers Count in Election 2016

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.
- Amounts to 900,000 hours of caring each week and €77 million per week.
- 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.

## Have your say in Election 2016

For more information on how you can become a member of Family Carers Ireland or have your say in Election 2016 please visit: [www.familycarers.ie](http://www.familycarers.ie)

**National Freephone Careline 1800 240724**