Election 2020
MANIFESTO
FOR FAMILY CARERS

NO ONE SHOULD HAVE TO CARE ALONE
On February 8th the Irish people will be asked to vote in a General Election. The 158 men and women elected to the 33rd Dáil are key to building an Ireland where family carers are respected and recognised for the huge contribution they make to families, society and the economy. Where carers feel supported not only to cope with the challenges of looking after someone, but to have a life of their own alongside their caring role. A life which includes caring but is not overwhelmed by it.

It is estimated that Ireland’s 355,000 family carers provide €10 billion in unpaid care each year supporting an adult or child who is ill, frail, disabled or has a mental health difficulty. Despite the enormity of their contribution carers have experienced a ‘lost decade’ with the legacy of the economic crisis still felt by them today. Research published in 2019, which replicated a 2009 survey, shows that the situation of family carers has gotten worse in the ten year period since 2009\textsuperscript{1,2}. Carers’ health, both physical and mental, has deteriorated as has their access to vital supports, including respite.

**In the last decade there has been a:**

- 70% increase in carers diagnosed with depression;
- 24% increase in carers reporting poor health;
- 30% increase in carers experiencing anxiety;
- 65% increase in carers who have no access to respite

Even when services are available, carers report that they are often inconsistent, inadequate, inaccessible or of poor quality.

**The rate of Carer’s Allowance is less in 2020 than it was in 2008.**

\textsuperscript{1}Family Carers Ireland, College of Psychiatrists of Ireland & University College Dublin (2019) Paying the Price: The Physical, Mental and Psychological Impact of Caring, Ireland: Family Carers Ireland.

\textsuperscript{2}Family Carers Ireland, College of Psychiatrists of Ireland & University College Dublin (2019) Paying the Price: The Hidden Impacts of Caring, Dublin: Family Carers Ireland.
Family Carers Ireland is asking each political party and election candidate to indicate whether, if they form part of the next Government, they will commit to each of the following pledges over the lifetime of that Government.

1. **Reform the Means Test for Carer’s Allowance** within the lifetime of the next Government, by:
   - Increasing the Carer’s Allowance income disregard from €332.50 to €450 (single) and €665 to €900 (couple) by 2025
   - Increasing the capital disregard from €20,000 to €50,000 in line with the existing disregard for Disability Allowance

2. **Introduce Legislation to Provide a Statutory Basis for Homecare** and incorporate a guarantee of basic supports to family carers who provide 80% of all community care.
   - Urgently address the homecare crisis by significantly increasing homecare funding
   - Give full-time carers a right to a Carer Needs Assessment and 20 days respite each year
   - Abolish the postcode lottery in carer supports by funding the delivery of the ‘Carers Guarantee’ of €3.2m

3. **Extend the GP Visit Card to Carers in Receipt of the Carer’s Support Grant**

4. **Introduce the Transport Support Scheme** promised since 2013 and ensure that existing transport schemes are accessible to people who need them in spite of not having a visible disability.

5. **Reform the System of Tax Reliefs and Credits** for carers by:
   - Increasing the Dependent Relative Tax Credit to match the Incapacitated Child Tax Credit
   - Extending eligibility for the Home Carer Tax Credit to include single working carers
   - Allowing carers to claim tax relief on the cost of employing a home carer if incurring this expense at same time as claiming the Dependent Relative/Incapacitated Child Tax Credit
   - Making Carer’s Allowance exempt from tax as is the case with other income supports such as Jobseeker’s Allowance, Disability Allowance and Working Family Payment

6. **Ensure that ‘Just Transition’ Provisions are Applied to Family Carers** who are being penalised for unavoidable costs under the polluter pays principle e.g. waste charges and carbon tax.

7. **Make Appropriate Transition Arrangements for Family Carers on Commencement of the Assisted Decision-Making (Capacity) Act 2015** in line with those being made for the state’s own Wards of Court system.

8. **Abolish Waiting Lists for Essential Therapies** including Speech and Language, Occupational Therapy, Physiotherapy and Psychology for children with special needs.


10. **Deliver on Pay Restoration** for organisations funded under section 39 of the Health Act (as promised in 2017) and undertake not to discriminate against charities that are not unionised in future pay decisions in regard to the voluntary sector.
1. Reform the means test for Carer’s Allowance within the lifetime of the next Government.

Less than one in four of Ireland’s 355,000 carers receive Carer’s Allowance due to the strict eligibility criteria attached to the payment – 84,028 carers. Given that 116,000 carers were eligible for the non-means tested Carer’s Support Grant in 2019, it is reasonable to assume that some 31,972 full-time carers do not qualify for Carer’s Allowance due to the means test. These are carers who provide full-time, often complex care, but are not recognised by the State and receive no other compensation for the care they provide. These families are also ineligible for housing adaptation grants, mobility grants and the Medical Card. Urgent reform is needed to make Carer’s Allowance more accessible to genuine, full-time family carers who do not receive the payment or who receive a reduced rate despite living on relatively modest incomes. Currently, a carer with a total household income (including that of their partner) of less than €37,500 will satisfy the means test for a full rate Carer’s Allowance with a tapered reduction in payment up to €63,000.

“A mother who gave up work 5 years ago to care for her two disabled children has no entitlement to Carer’s Allowance because her husband has an income of €65,000.”

• Increase the Carer’s Allowance income disregard from €332.50 to €450 (single) and €665 to €900 (couple) by 2025.

Despite increasing steadily during the period 2000 to 2008, the income disregard for Carer’s Allowance has remained stagnant for the past 12 years, meaning Government has failed to achieve the commitment set out in Towards 2016 to increase the income disregard for Carer’s Allowance so that those on average industrial incomes can qualify (p.55). This is compounded by the fact that the current rate of Carer’s Allowance of €219 is €1.50 less than it was in

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3 CSO’s Irish Health Survey 2015 identified that 10% of the sample population stated they were carers. 355,000 is 10% of the Irish population aged over 15 years.
4 As at January 13th 2020.
5 116,000 recipients of the Carer’s Support Grant less the 84,028 carers in receipt of Carer’s Allowance.
6 Unless the Medical Card is granted on a discretionary basis.
7 Average industrial earnings in Quarter 3 2018 were €7627 while the income disregard for Carer’s Allowance remains at €332.50 (single)/€665 (couple).
2008, despite a 7.5% increase in the Consumer Price Index during this period. This means that the equalised value of Carer’s Allowance at the rate paid in 2008 of €220.50 is €237 in 2019. Furthermore, the failure to increase the income disregard in line with the increase in hours a carer can work from 15 to 18.5 hours (as announced in Budget 2020) means that for some carers, any increase in earnings from work will be offset by a subsequent reduction in their Carer’s Allowance. **Family Carers Ireland** is calling for a phased increase in the income disregard for Carer’s Allowance from €332.50 to €450 (single person) and from €665 to €900 (couple) between 2020 and 2025.

<table>
<thead>
<tr>
<th>Carer’s Allowance Income Disregard 2000 - 2019</th>
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<tbody>
<tr>
<td>-------</td>
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<tr>
<td>Single Income Disregard</td>
</tr>
<tr>
<td>Couple Income Disregard</td>
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- **Increase the capital disregard from €20,000 to €50,000.**

The formula for assessing means from capital (savings, shares and property) for Carer’s Allowance should be increased in line with the Disability Allowance, where the first €50,000 of capital is disregarded rather than €20,000, reflecting the desire of carers to provide for their loved ones after their death. Despite significant changes in Ireland’s economy, the capital formula used for Carer’s Allowance has not changed since 2005.

**Existing Capital Formula**

<table>
<thead>
<tr>
<th>Carer’s Allowance</th>
<th>Disability Allowance</th>
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<tbody>
<tr>
<td>Capital</td>
<td>Weekly means</td>
</tr>
<tr>
<td>First €20,000</td>
<td>Nil</td>
</tr>
<tr>
<td>Next €10,000</td>
<td>€1 per €1,000</td>
</tr>
<tr>
<td>Next €10,000</td>
<td>€2 per €1,000</td>
</tr>
<tr>
<td>Balance (over €40K)</td>
<td>€4 per €1,000</td>
</tr>
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2. **Introduce legislation to provide a statutory basis for homecare and incorporate a guarantee of basic supports to family carers who provide 80% of all community care.**

- **Urgently address the homecare crisis by significantly increasing homecare funding**

The commitment to establish a Statutory Homecare Scheme by 2021 is welcome, however families cannot wait until then to see homecare services improve. Pending the introduction of the statutory scheme, interim measures are urgently needed to address the consistent underfunding of homecare which
is leaving thousands of people stuck in hospitals or forced into nursing homes when they could return home or stay at home if appropriate care was provided. It also places enormous pressure on carers to care for their loved one(s) alone and unsupported. Growing pressure on the homecare budget means that the circa 8,000 people currently on the homecare waiting list have little chance of securing home support and further attests the urgent need for additional funding. Family Carers Ireland is calling for the introduction of demand-led access to homecare, which is of particular importance given the safeguarding implications of failing to meet levels of need identified through formal needs assessments.

• Give full-time carers a right to a Carer Needs Assessment and 20 days respite each year.

Identifying the needs of family carers is increasingly viewed as a key intervention in the development of fully integrated health and social care. The positive impact of such assessments on carers, particularly in reducing their stress and depressive symptoms is well documented. Family Carers Ireland welcomes the development of Ireland’s first Carer Needs Assessment tool, created in partnership with the HSE, InterRAI and carer representatives and completed in 2017. The tool offers an important opportunity to recognise the distinct needs of family carers allowing them to identify additional supports they need both to enable them to care and to preserve their own health and well-being. Family Carers Ireland is also calling for full-time family carers to be given a right to 20 days respite each year in line with the statutory leave arrangements available to paid employees. This entitlement could be enshrined within the statutory homecare scheme legislation.

• Abolish the postcode lottery in carer supports by funding the delivery of the ‘Carers Guarantee’ of €3.2m

Enabling people to continue to live independently at home for as long as possible is a long-standing objective of Government and is underpinned by Sláintecare’s vision of delivering “the right care in the right place at the right time”. Despite this objective and the clear advantages of caring for people in their own homes inconsistent funding arrangements has led to a postcode lottery whereby access to essential supports such as homecare, respite, training and therapies is determined by where a person lives rather than what they need. Family Carers Ireland’s ‘Carers Guarantee’ sets out how, for an additional €3.2m in annual funding, we will guarantee the delivery of a core basket of services to carers across the country regardless of where they live. These services will include: access to emergency respite; intensive one-to-one support for carers in

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crisis; a suite of training programmes ranging from basic care skills workshops to QQI accredited ‘Caring with Confidence’ training; targeted support groups and networks for carers and access to information and advocacy clinics in local community centres, primary care centres and hospitals. If Government fails to ensure the uniform delivery of supports across the country, even more carers will reach crisis point, bringing the sustainability of their caring role into question.

3. Extend the GP Visit Card to carers in receipt of the Carer’s Support Grant.

The introduction of GP Visit Cards for carers in receipt of Carer’s Allowance and Carer’s Benefit in 2018 was a welcome first step in recognising the health and wellbeing needs of carers. However, its method of delivery means it only reaches a proportion of carers. It also imposes a means test on carers’ access to the GP Visit Card by virtue of the means test applied to Carer’s Allowance. This is entirely at odds with Government’s plan for the universal roll-out of free GP care and is counter to the universal access afforded to the over 70’s and children under 8 years who are rightly not means tested. In order to reach a greater number of full-time carers and in keeping with Government’s own policy of universal access, the GP Visit Card should be made available to all carers in receipt of the non-means tested Carer’s Support Grant.
4. Introduce the Transport Support Scheme, promised since 2013, and ensure that existing transport schemes are accessible to people who need them in spite of not having a visible disability.

Travelling to and from essential services is a challenge for many carers both in terms of the lack of accessible transport for people with mobility issues, particularly in rural areas, and the significant costs that carers incur when they are forced to pay privately for taxis or meet mounting fuel and parking costs. Family Carers Ireland is calling for the urgent introduction of the Transport Support Scheme which has been a commitment of Government since the withdrawal of the Mobility Allowance and Motorised Transport Grant in 2013 on the grounds of age discrimination. The failure to replace these schemes has led to the illogical situation whereby those who received a Mobility Allowance prior to 2013 have been allowed to keep it while others now equally in need of transport support are locked out. Similarly, those who last received a Motorised Transport Grant in 2013 for the purchase of an adapted vehicle are likely to be driving vehicles that are now at least 7 years old and in need of replacement.

Family Carers Ireland is also calling for (i) the Disabled Drivers and Disabled Passengers Scheme to be extended to include people with non-physical disabilities equally in need of transport assistance and (ii) for the eligibility criteria for the Disabled Parking Permit Scheme to be extended to include people who cannot walk without considerable psychological distress or the risk of serious harm including people with conditions such as autism, dementia, Parkinson’s and severe arthritis.

5. Reform the system of tax reliefs and credits for carers.

An overhaul of the archaic tax relief and credit system in place for carers is urgently needed as current arrangements wrongly deny any meaningful tax relief to single carers or those caring for a relative other than a child. For example, an Incapacitated Child Tax Credit of €3,300 is available to the parents/guardian of a child, including an adult child, who is permanently incapacitated, either physically or mentally. However, the only tax relief available to a single person caring for their mother or another non-child relative is the Dependent

“1 in 4 carers experience difficulties accessing supports and services due to inadequate transport and/or the distance of services from their home”

9 Eligibility for the Blue Badge Parking Scheme in the UK was extended in 2019 to include people with non-visible disabilities.

Relative Tax Credit of just €70. Equally frustrating is the fact that the Home Carer Tax Credit of €1,600 is only available to married couples or those who are jointly assessed for tax, meaning single carers cannot avail of it.

- Increase the Dependent Relative Tax Credit in line with the Incapacitated Child Tax Credit

The gross disparity between the €70 Dependent Relative Tax Credit available to carers of a ‘non child’ relative (i.e. parent, sibling, aunt etc.) and that available to the parents of a disabled child or adult child of €3,300 through the Incapacitated Child Tax Credit must be urgently addressed. While Family Carers Ireland unequivocally endorses a generous system of tax reliefs for parent carers, we feel equally strongly that such tax relief should be available to all full-time carers, regardless of their relationship to the caree.

- Extend eligibility for the Home Carer Tax Credit to include single working carers

The Home Carers Tax Credit of €1,600 has doubled in value since 2015 making it an increasingly important support for working carer families. The fact that it is available only to married or jointly assessed couples, where one partner works outside the home and the other works predominantly in the home caring for a dependent person, undermines its potential to support a greater number of genuine carers. Family Carers Ireland is calling for the Home Carer Tax Credit to be made available to single carers who work part-time while also caring for a dependent person.

- Allow carers to claim tax relief on the cost of employing a care worker if incurring this expense at the same time as claiming the Dependent Relative/Incapacitated Child tax credit

There is little rationale for the stipulation which prevents carers from claiming Dependent Relative Tax Credit and/or Incapacitated Child Tax Credit while availing of tax relief on the cost of employing a home carer. It is particularly concerning that a carer could potentially lose out on thousands of euros of tax relief on employing a home carer simply because they had also claimed the Dependent Relative Tax Credit of €70.

- Make Carer’s Allowance exempt from tax as is the case with other income supports such as Jobseeker’s Allowance, Disability Allowance and Working Family Payment.

Carer’s Allowance is taxable and carers with another source of income or whose spouse/partner is working are likely to have to pay tax on the payment. The taxation of Carer’s Allowance gives rise to a number of practical issues, not least of which is the failure of many carers to understand their responsibility to inform Revenue of their receipt of Carer’s Allowance and the subsequent tax
liability that may ensue. It is also makes little practical sense that some social welfare payments are exempt from tax (for example Jobseeker’s Allowance, Disability Allowance and Working Family Payment) while Carer’s Allowance, for which carers must provide full-time care, is subject to tax.

6. Ensure that ‘just transition’ provisions are applied to family carers who are being penalised for unavoidable costs under the polluter pays principle e.g. waste charges and carbon tax.

Family Carers Ireland is fully supportive of efforts to reduce our carbon emissions and invest in sustainable and renewable energy generation. However, we believe that the cost of climate action must not fall disproportionately on low income households, particularly those that incur significantly higher and unavoidable energy bills due to their caring responsibilities. In addition to higher than average utility bills, a lack of an integrated public transport system in rural areas also has an impact on caring households who have little choice but use private transport to access public services, healthcare and employment opportunities. As such Family Carers Ireland is concerned that the Climate Action Plan 2019 and Ireland 2040 does not include sufficient detail on how infrastructure to support these communities will be achieved to ensure they are not unfairly impacted by an increase in the carbon tax.

Government’s decision in 2017 to phase-out ‘flat rate’ charges for residual kerbside household waste collection to ensure that Ireland meets current and future waste targets included a commitment to “provide a financial support to persons with lifelong/long-term medical incontinence to help meet the cost of disposal of medical incontinence wear”. Family Carers Ireland is deeply concerned that some three years later, the financial support promised to households where incontinence care is provided, has yet to materialise, and as such we are calling for the urgent introduction of the scheme as part of Government’s ‘just transition’ commitments. Similarly, while the extension of SEAI’s Better Energy Warmer Homes Scheme in 2018 to include carers in receipt of Carer’s Allowance is welcome, enabling more carers to better insulate their homes by further extending eligibility to carers in receipt of the non-means tested Carer’s Support Grant is an additional measure that could be undertaken and aligned to the principles of ensuring a socially just transition for energy poor households.

7. Make appropriate transition arrangements for family carers before commencing the Assisted Decision-Making (Capacity) Act 2015

Family Carers Ireland believes that the Assisted Decision-Making (Capacity) Act 2015, which has not yet been fully commenced has the potential to facilitate much greater legal clarity and certainty to carers of adults with intellectual disabilities or diminished capacity once they have been formally appointed as a Decision Making Representative (DMR). However, we are concerned at the failure to provide for a transitional arrangement for existing carers of individuals
who will require a DMR under the Act. We reject the proposition that since family carers currently have no legal status in terms of decision-making their legal position in the period between the commencement of Part 5 and their being appointed a DMR will be unchanged. In our interpretation, the goodwill, custom and practice on which such carers have traditionally relied on when engaging with health and social carer systems for example, will become illegal on the day that Part 5 is commenced. Our concern has increased as we note the fact that, even though the legislation has not been commenced yet, some hospital consultants are already refusing treatment to certain patients until they have been made a Ward of Court. For this reason we estimate that at least 25,000 family carers will have to apply to the courts for a determination under the Act immediately on its commencement and there is absolutely no prospect of the system being able to cope with this surge. We note that the Act provides for a three year transition period in respect of Wards of Court (fewer than 5,000 cases). The current Government has failed to respond to questions about this issue and, for that reason, as part of the general election campaign we are asking political parties and candidates to commit to an appropriate transition arrangement for long-standing carers of adults with diminished capacity – based on an amendment to the Act if necessary – as part of their election manifestos.

8. Abolish waiting lists for essential therapies including Speech and Language, Occupational Therapy, Physiotherapy and Psychology for children with special needs.

Almost 215,000 children are currently on waiting lists for essential health care services including speech and language, occupational therapy, physiotherapy and psychology, with significant variation in waiting times across the country, further demonstrating the postcode lottery with has come to characterise access to health care. The delays mean that many of Ireland’s most vulnerable children are being denied the early intervention treatment and support that is critical to their future development, and in some cases is causing a regression in the child’s development. This is despite the fact that under the Disability Act 2005 children with a disability have a ‘right’ to an assessment of need within 6 months of making an application.

• Give children with a disability and their parents the right to key worker

There are 81,899 children in Ireland living with a disability\(^\text{11}\). Services to families with disabled children are increasingly delivered through a multiagency model, so it is not unusual for parents to have to navigate their way through complex health, education and social care policies and services with little support. The ‘key worker’ model is a method of service delivery involving a person who works in a guiding role with families. This person acts as a single point of contact for

\(^{11}\) Census of Population 2016.
a family, helping them to coordinate their care, not only within the healthcare system, but also across systems (education, social services, financial resources, recreation, transportation, etc). The main concept of the key worker’s role is to empower parents by providing them with support, resources and information tailored to meet their individual needs. Research strongly supports the ‘key worker’ approach to supporting families and has shown that when a key worker is available the overall quality of life of families with disabled children is improved as does the relationship with service providers, with, better and quicker access to supports and reduced levels of stress.

- Give sick children living in hospital access to the Domiciliary Care Allowance

Some of Ireland's sickest children are denied access to the Domiciliary Care Allowance because they do not satisfy the requirement that they 'live at home'. As a consequence, their parents, many of whom are forced to give up their employment at remain with them in hospital, are denied Carer’s Allowance. Family Carers Ireland understand that steps have been taken to resolve this anomaly but urge that efforts be expedited to ensure these families are not forced to suffer further financial hardship.


Ireland first 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 while the country was in the midst of the economic crisis, Government warned of the need to be pragmatic in terms of the limited financial resources available but promised that as Ireland’s economy improved so too would the level of investment allocated to the strategy. The strategy itself also contains the commitment ‘that the strategy would be reviewed on a periodic basis to allow departments to propose additional actions as our economic position improves’ (National Carers’ Strategy, p.2). Family Carers Ireland understands that it is the intention of the Department of Health to eventually develop a single Social Care Strategy that will encompass a number of existing strategies, including the National Carers’ Strategy. While we accept the logic of this approach the Department have also made it clear that we are a number of years away from the publication of a Social Care Strategy. It is deeply concerning that during this interim period no formal strategy or roadmap for supporting carers will exist, particularly given their fundamentality to the successful implementation of Sláintecare. Family Carers Ireland believes it is critical that an action plan is in place to support family carers during this important period of health service reform. We have worked with the Department of Health and key Government Departments in identifying priority actions that could be undertaken to support

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carers over the next 3 years, pending the introduction of a Social Care Strategy, and urge that these be formally adopted in an interim National Carers’ Strategy 2020-2023.

10. Deliver on pay restoration for organisations funded under section 39 of the Health Act (as promised in 2017) and undertake not to discriminate against charities that are not unionised in future pay decisions in regard to the voluntary sector.

On 3rd October, 2018 the Minister for Health welcomed a WRC agreement which would “see pay restoration for staff organisations funded by the HSE under section 39 of the Health Act” whose staff “while not public servants… were subject to pay cuts during the economic crisis”. He promised that “almost 90% of staff who saw their pay cut will see an average three quarters of that pay reduction restored in 2019”. The Minister of State with special responsibility for Disabilities noted that the agreement was “particularly important to me given that a majority of staff are employed in organisations which provide essential care and support for people with disabilities across the country. They deserve a fair deal and I believe that is what we have got.” What neither Minister made clear was that the agreement that had been reached only applied to organisations with staff who were members of a trade union – the vast majority of section 39 organisations are not unionised and pay restoration for these organisations has been ignored. Far from a fair deal, the clear implication of this decision is that the only way staff in organisations such as Family Carers Ireland, will secure pay restoration is by joining a union and initiating strike action that disrupts services to their vulnerable clients.

Apart from committing to immediate pay restoration to bring those affected into line with the public service and unionised voluntary organisations, Family Carers Ireland is asking political parties and election candidates for a guarantee that they will not discriminate on the basis of union membership if they are part of a future Government.

Have Your Say in Election 2020:
For more information on how you can become a member of Family Carers Ireland, or have your say in Election 2020, please visit www.familycarers.ie
Family Carers Ireland

Save the State €10 BILLION each year

€219 (Maximum Amount)
Carers are the only welfare recipients required to work full-time but receive just €16 more than the standard welfare rate.

€10 BN

€103bn Fair Deal
The Government spends twice as much on nursing home care than home care.

€500m Home Care

16 MILLION hours of unpaid care each week

36% increase in older population & 63% increase in people with a disability since 2006.

355,000 unpaid carers in Ireland (that’s 1 in every 10 adults)

3,177 receive Carers’ Benefit

By 2030 1 in 5 people will be a carer

57% of carers juggle paid work & caring

84,028 carers receive Carer’s Allowance
Only one in four carers

39% of carers are male

56,118 young people aged 10-17 years provide regular unpaid care

Sources: Callaghan, M., Keane, E., Molcho M. (2016) Short Report HBSC Ireland 2014: Young Carers in the 2014 HBSC study. Galway, Ireland: Health Promotion Research Centre at the National University of Ireland, Galway (NUIG); National Census 2016; CSO Irish Health Survey 2015.