



PAYING THE PRICE

The Physical, Mental and Psychological **IMPACT OF CARING**

This study was a collaboration between Family Carers Ireland, College of Psychiatrists of Ireland, UCD School of Nursing, Midwifery & Health Systems



College of Psychiatrists
of Ireland

Wisdom • Learning • Compassion



UCD School of
Nursing, Midwifery
and Health Systems

ABOUT THE RESEARCH

This report sets out the headline findings of a national Family Carer Health and Wellbeing Survey undertaken between November 2018 and January 2019 by Family Carers Ireland, the College of Psychiatrists of Ireland and UCD School of Nursing, Midwifery and Health Systems. The survey was completed by 1,102 current family carers who are members or part of the network reach of Family Carers Ireland. The survey is a repeat wave of a similar survey undertaken in 2009 and allows us to track changes in the health, wellbeing and burden of carers ten years later.

This report is the first in a series that will provide an insight into the impact that caring has on carers' physical and mental health and the difficulties they experience in accessing support.

A carer is someone who is providing an ongoing significant level of care to a person who is in need of that care in the home due to illness or disability or frailty¹.

PROFILE OF RESPONDENTS



90% were women



and 10% were men



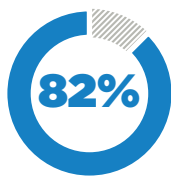
Most respondents were of working age, and the average age was



49 years old.

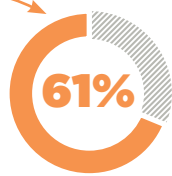
21.3% were in paid work

70% part-time and 30% full-time



82% cared for 50+ hours per week

Out of that 82%



61% cared for 100+ hours per week



11% cared for 20-49 hours per week

6% cared for 1-19 hours per week.

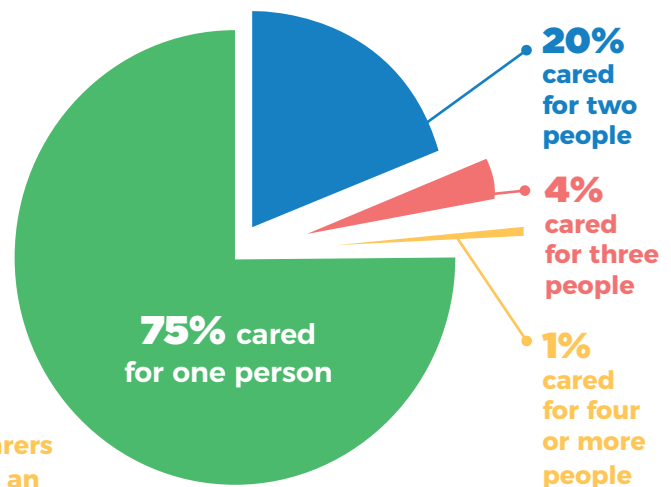
16% were caring for 21 years or more

26% were caring for 11-20 years

26% were caring for 6-10 years

28% were caring for 1-5 years

And just over 3% were caring for less than one year



75% cared for one person

20% cared for two people

4% cared for three people

1% cared for four or more people



47% of carers cared for a child under 18



31% of carers cared for an adult over 65

As not all respondents completed every question in the survey, a number of the figures given in this report are based on responses from fewer than 1,102 carers. This, together with the sample sizes of different groups, should be taken into consideration when reading the results.

¹ Department of Health (2012). National Carers' Strategy - Recognised, Supported, Empowered. Department of Health, Dublin.

INTRODUCTION

Ireland's health and social care system depends on family carers. Without the estimated €10 billion in unpaid care they provide each year the health service would collapse. Despite the enormity of their contribution, this survey shows that the situation of family carers has gotten worse since 2009. Carers' health, both physical and mental, has deteriorated as has their access to vital supports and services, including respite, homecare and therapies. The psychological impact of caring has also worsened with these carers more worried about their finances, the lack of services and fearing for the future care of their loved ones.

Despite Ireland's meteoric recovery, the scars of the economic crisis remain etched in the reality of carers' lives.

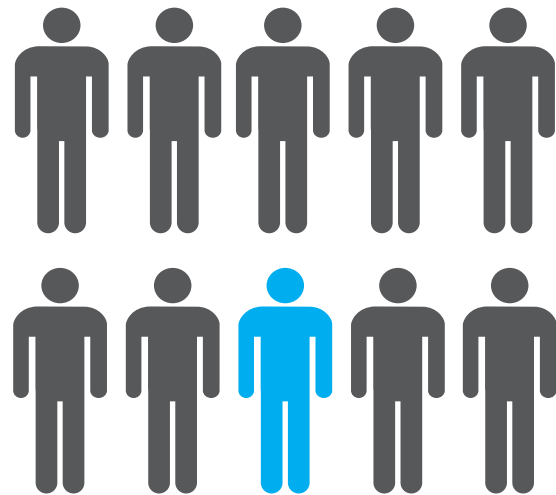
At best, community care services are being maintained at the previous year's level, and at worst they are being rationed to the extent that even those assessed as needing support cannot access help until another person dies and hours can be recycled.

This is in addition to the widespread closure of respite beds, cuts to disability and increased demands on Mental Health Services and the withdrawal of important supports such as the Mobility Allowance and Motorised Transport schemes, all of which are forcing carers to fill the ever-increasing gap between the growing care needs of the Irish population and an ever decreasing level of support. This comes at a significant personal cost to carers, who are paying for these failures both financially and personally.

Today **1 in 10 people in Ireland is a family carer.** By 2030, we will need twice as many carers to meet the needs of our ageing population and the increasing number of people with a disability or chronic condition. Unless urgent action is taken to better support carers and address years of underspending on home care, respite and carer payments, families will be unwilling to take on a caring role and the pressures on our already overburdened health and social care system will significantly increase.

355,000
family carers
in Ireland

1 in every 10 adults



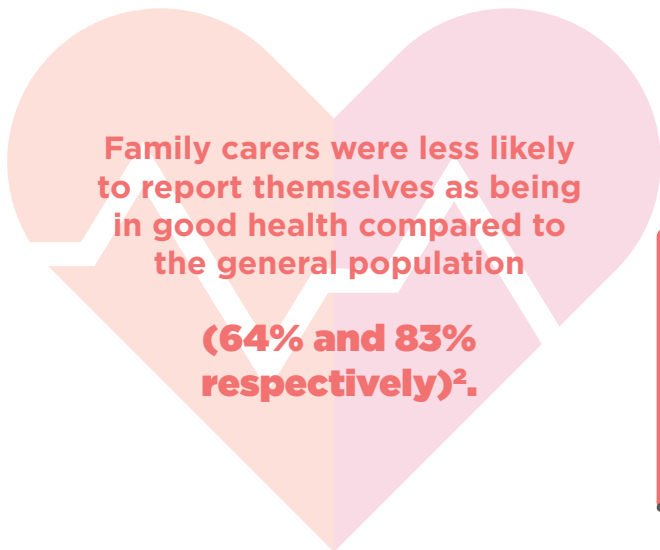
Saving the state

 **€10**
BILLION

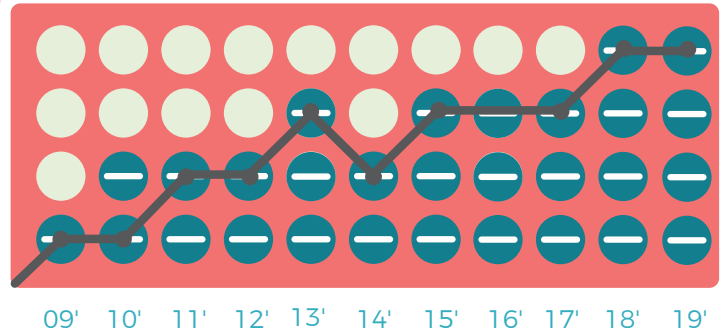
each year



KEY FINDINGS



Family carers reporting poorer overall health and wellbeing increased by 24% between 2009 and 2019



48% of carers said they were diagnosed with mental ill health.³

67% of carers reported they suffered with physical ill health.⁴

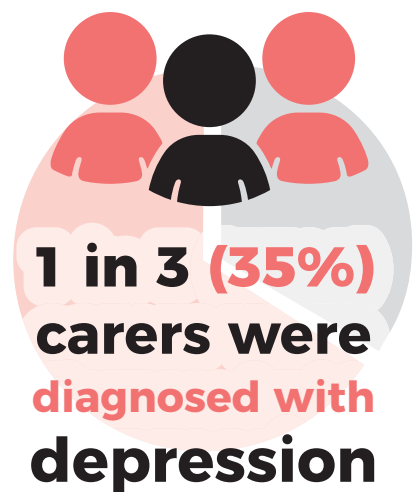
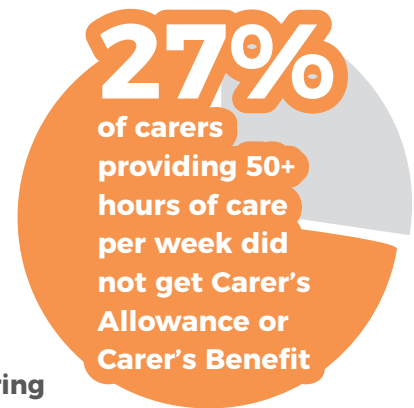
68% of carers felt that their health had suffered as a result of caring

75% of carers said they worried about their own health and wellbeing.

83% of carers' loved ones have no access to suitable respite.

82% of carers provide more than 50 hours of care per week.

39% of carers were diagnosed with anxiety.



² Central Statistics Office, 'Irish Health Survey 2015' <https://www.cso.ie/en/releasesandpublications/ep/p-ihs/irishhealthsurvey2015/ct/> [accessed 25th April 2019]

³ For the purposes of this study, mental ill health specifically relates to depression and/or anxiety. It does not include other mental ill health diagnoses, although some respondents reported additional conditions.

⁴ All physical diagnoses combined

A DECADE LOST: In the ten year period between 2009 and 2019, carers have poorer health, less support and are more worried about the future

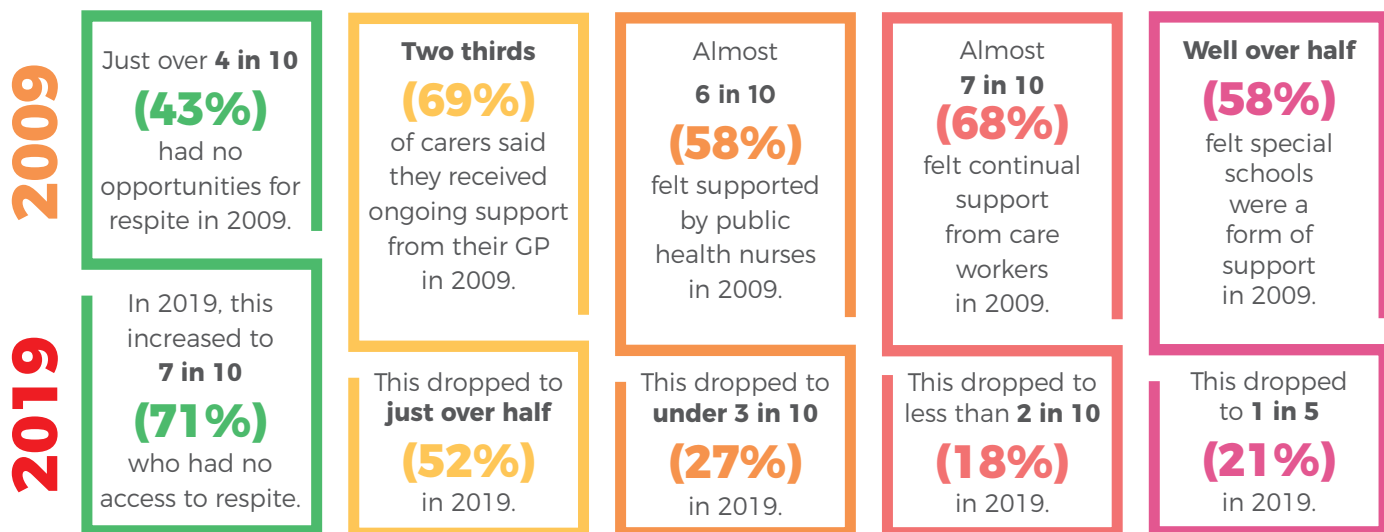
Comparisons between the findings from the **2009** and **2019** surveys show that:

CARERS' PHYSICAL AND MENTAL HEALTH HAS DETERIORATED OVER THE LAST TEN YEARS

- In 2009, over a quarter (29%) of carers reported poor health.
- **This increased to over a third (36%) of respondents in 2019.**
- There has been a 70% increase in the number of surveyed carers diagnosed with depression in the last ten years.
- **In 2019, 1 in 3 (35%) carers were diagnosed with depression, an increase from 1 in 5 (20%) in 2009.**
- The prevalence of anxiety amongst family carers has increased by 30%, **rising from 3 in 10 (31%) in 2009 to almost 4 in 10 (39%) in 2019.**
- In 2009, 3 in 10 (33%) carers suffered with back injury. **In 2019, 4 in 10 (40%) of carers had a back injury.**



THEY HAVE LESS ACCESS TO VITAL SUPPORTS AND SERVICES



THEY ARE MORE WORRIED ABOUT THEIR HEALTH, THEIR FINANCES AND THE LACK OF APPROPRIATE SUPPORTS.

- In 2009, approximately **half of carers** were worried about what would happen if they died or can't care any longer due to their own illness (**56%**) and about not having enough money (**46%**).
- In 2019, carers reported similar worries. However, these worries were much more pervasive, with **three quarters (75%)** of carers worried about money, their own health and wellbeing, the lack of appropriate supports and services as well as fearful for what will happen when they die or cannot care any longer.
- **These findings suggest that rather than the situation of family carers improving things have gotten significantly worse during the ten year period 2009-2019**

ALMOST HALF OF FAMILY CARERS DIAGNOSED WITH MENTAL ILL HEALTH

Carers were asked about the impact that being a carer has on their health and wellbeing. Depression and anxiety were common. **Almost half (48%)** of the respondents said they were diagnosed with depression and/or anxiety, and **two thirds (66%)** of these said their mental ill health was caused or exacerbated by their caring role. This is significantly **worse than the 26%** of the general population reporting mild to moderate depression⁵.

Carer burden is a measure of the physical and emotional burden felt by carers which can have real health implications resulting from increased levels of stress⁶. To assess the burden of caring we used a scale that looks at health, finances, social life and interpersonal relations⁷. We found that over **1 in 3 (39%)** carers experienced moderate to severe levels of burden while **1 in 7 (14%)** had severe burden, indicating that many carers are adversely affected by the caring role.

1 in 3 (33%)
carers felt that
psychological
counselling
would improve
their health

“*There is no help,
I'm exhausted and alone.
Every single day is hard.*”
(female, 37, full-time carer)

“*Life is a
non-stop
worry*”
(male, 55, full-time carer)

SHINING A LIGHT ON CARERS WITH DEPRESSION AND/OR ANXIETY

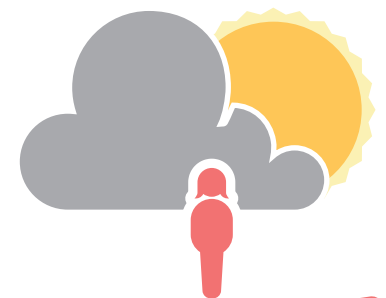
Family Carers with a diagnosis of depression and/or anxiety were more likely to experience an exacerbated burden or higher levels of severe burden to those carers without such diagnoses particularly:

- **Be concerned about what happens if they die or can't care any longer because of their own illness**
- **Worry about their own health and wellbeing**
- **Worry about the lack of appropriate supports and services**
- **Fear about not having enough money now or in the future**



88%
felt
stressed

Almost 9 in 10 (88%) carers
felt stressed trying to balance
caring with other family and
work responsibilities.



⁵ Irish Health Survey, 2015

⁶ The impact of caring in the family is often referred to as burden, although we recognise that some carers and their loved ones may see it as insulting and stigmatising to be referred to as such. We use it as a reliable way to measure some of the impacts of being a family carer, whilst also acknowledging that providing care can be enriching and rewarding when appropriate supports are in place.

⁷ Hébert, R., Bravo, G., & Prévaille, M. (2000). Reliability, validity, and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia. *Canadian Journal on Aging*, 19, 494-507.

TWO THIRDS OF CARERS DIAGNOSED WITH PHYSICAL ILL HEALTH

Over two thirds (67%) of carers said they suffered with physical ill health, while over half (54%) said their physical health had worsened as a result of caring.

4 in 10 (40%) carers have suffered from back injuries, and almost two thirds (67%) of these felt their back injury was caused or made worse because of their caring role. This is extremely worrying when compared with the prevalence of back injuries amongst the general population (19%)⁸.

Despite the risk of physical injury, less than 1 in 5 (18%) carers received training for their role. Manual handling training was the most common training need identified when carers were asked what training they would like to receive.

Whilst manual care is physically exhausting, the mental stress of being a carer also has physical impacts. Over a quarter (26%) of carers have experienced high blood pressure—significantly more than the general population (16%)⁹—and over half (51%) of these said their caring role caused or made the condition worse.



⁸ Irish Health Survey 2015
⁹ Irish Health Survey 2015

MANY CARERS LACK APPROPRIATE PRACTICAL AND FINANCIAL SUPPORT

4 out of 5 people receiving care do not have access to appropriate respite

The impact of caring on carers' mental and physical health is often exacerbated by carers going without the support they need—being able to take a break, attend to their own medical needs, or spend time with other family members. Breaks are vital for carers to be able to deal with the physical and emotional strain of providing care, supporting them to be able to continue in their roles. Access to regular breaks is essential for all carers but especially since 3 in 5 (61%) provided **more than 100 hours of care per week** and over **1 in 5 (21%)** continued to work alongside caring.

Many carers reported not receiving the support they need. Shockingly, **7 in 10 (71%)** of carers said their loved one did not have access to respite, which would allow them to take a break from caring while the person they cared for was looked after by someone else. Worse, over **1 in 10 (12%)** said that they were offered respite but it was unsuitable. When carers were asked what type of support would improve their own health:

- **2 in 5 (40%)** thought their health would be improved with more access to respite or support during the day or night outside of the home.
- **Almost half (46%)** said assistance with household tasks, such as cleaning and laundry, would make a difference to their health.

“Caring for a child is 24/7. I am very thankful for my child and would never be without him but apart from one or two nights respite care every six to eight weeks, we get no support.”
(female, 39, full-time carer)

“Some freedom would be nice. A chance to be on your own, to take a break, to have a proper relationship. Sometimes these little things are worth more than money.”
(female, 36, full-time carer)

1 in 4 carers providing 50+ hours of care per week did not receive Carer's Allowance or Carer's Benefit

Three quarters (75%) of carers said they were worried about money. For these carers, financial or tax benefits are an important source of support:

- **Over half (56%)** of respondents received Carer's Allowance and the Half Rate Carer's Allowance.
- **Over 2 in 5 (44%)** carers received the Carer's Support Grant.
- **Just under 1 in 3 (30%)** received the Household Benefits Package.
- **1 in 15 (7%)** received Domiciliary Care Allowance.

Worryingly, **over one quarter (27%)** of carers providing more than 50 hours of care per week did not receive Carer's Allowance or Carer's Benefit. This implies that these carers were not meeting the strict eligibility criteria for Carer's Allowance¹⁰ or Carer's Benefit. Many carers commented that the eligibility criteria for Carer's Allowance is set too high, meaning they did not qualify for help, despite providing what was often constant and long-term care.

“Carers who are not entitled to Carer's Allowance are either left destitute or are forced back to work. Carer's Allowance shouldn't be means tested. We are providing a service which is essential”
(female, 44, working part-time, full-time carer to two children)



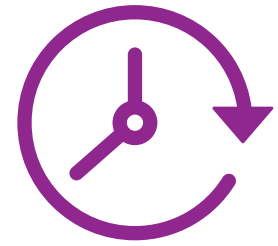
“Financially how I will cope as I have reduced my hours to care, have no pension and am separated”
(female, 52 working part-time and caring over 100 hours per week)

¹⁰ This figure relates to carers caring for up to two people. Further analysis will show the figures for those caring for three or more loved ones.

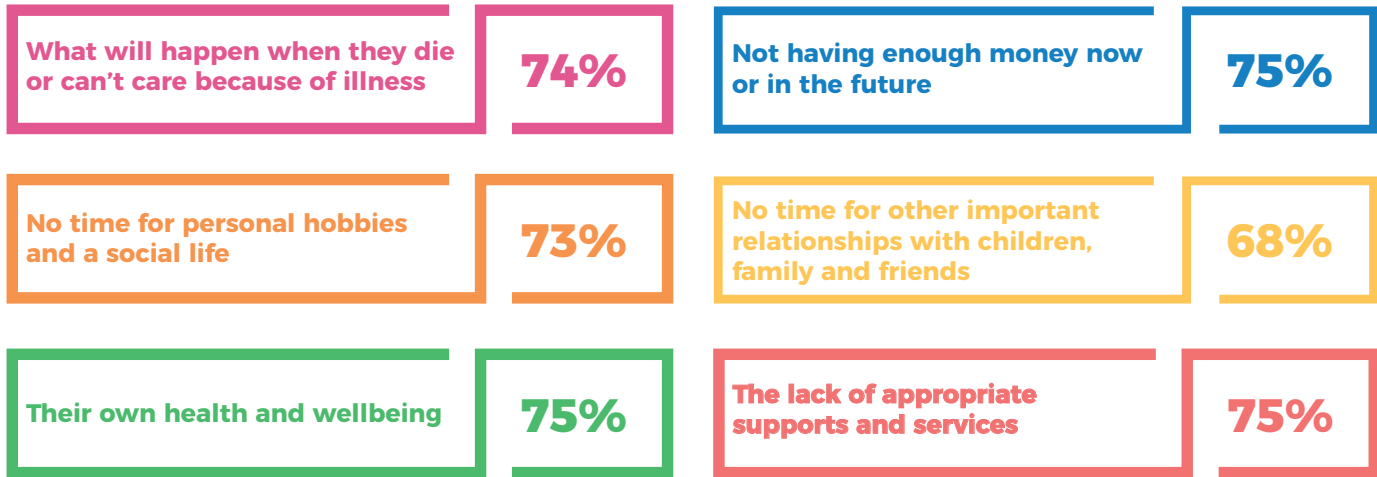
¹¹ Eligibility criteria includes a strict means test as well as preventing recipients of Carer's Allowance, Carer's Benefit or the Carer's Support Grant from working or studying more than 15 hours per week.

THREE QUARTERS OF CARERS WORRY ABOUT THE FUTURE

Carers were asked about their worries for themselves and those they care for.



Carers reported that they were worried about:



Carers were asked if they had any further comments about their health and wellbeing.

- Many feared for the future, worrying about who will provide care for their loved one if something happened to them, where their loved one would be cared for, and the quality of care provided in their absence.
- Many worried about their ability to continue to provide constant care, especially as they get older and struggle with their own ill health as the needs of the person progress.
- There is a lot of uncertainty about the supports available with carers describing the strain of constantly having to battle for services.
- The lack of recognition from family and friends, healthcare providers, the HSE and Government made many carers feel undervalued.
- Many were concerned about the impact of financial instability on their family.
- A lot of carers described their sense of isolation and worried about what would happen to them when their loved one died.

Carers over 65 were the most likely to worry about the impact of their death or illness (80%).



The majority (90%) of carers felt afraid about what the future holds for the person(s) they care for.



SUPPORTING CARERS TO BE HEALTHY: RECOMMENDATIONS

The National Carers' Strategy 2012 commits to respecting carers as expert partners in care, protecting their health and wellbeing and empowering them to participate fully in economic and social life. Despite these commitments, this survey has showed that for many carers services are inadequate to meet their needs, many receive no extra help and large numbers of carers report feeling mentally and physically drained. Caring should be a shared responsibility, where the burden of care doesn't fall completely on families. Rather, those who take on significant caring responsibilities should have certainty that basic supports will be provided if and when they are required; that services will be in place to help them maintain their own health and wellbeing; that they will be able to work and have a life of their own alongside their caring role; and that they will be recognised rather than penalised in terms of access to financial supports. Carers can no longer be expected to fill the deficits of a poorly configured health and social care system – the care must be shared between the State and families.



Enshrine in the Statutory Homecare Scheme the right to 20 days respite each year:

Respite care is consistently identified as a key intervention to support the health and wellbeing of carers and is critical to the sustainability of their caregiving efforts. Despite its importance access to respite care remains discretionary, inconsistent and underfunded meaning many carers are denied this vital support. **A minimum entitlement to 20 days guaranteed respite each year should be enshrined in the impending statutory homecare legislation in line with the statutory leave available to paid workers.**



End the postcode lottery in carer supports:

Inconsistent funding across the country means that access to essential supports such as emergency respite, training, counselling/one-to-one support and information is subject to a postcode lottery, whereby where a person lives, rather than their need will determine if they can access a service or not. This applies also to access to specific mental healthcare inputs which should be based on a carer's clinical need rather than their ability to pay or where they live. **Urgent additional funding of € 3.2 million per annum is required to support family carers and ensure carers are guaranteed access to a basket of supports and services regardless of where they live.**



Ensure adequate incomes for caring households:

For many families caring can result in financial hardship as a loss of income from employment is exacerbated by higher household costs such as heating, laundry, medicines, home modifications or specialised transport. The financial impact of caring can also last a lifetime as years spent on a low income or out of the workforce mean carers can't repay debt, build savings or contribute to a pension. 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. Despite the financial impact of caring, only 1 in 5 of Ireland's 355,000 carers receive Carer's Allowance due to the strict eligibility criteria attached to the payment. Reform of the Carer's Allowance means-test is urgently needed to ensure that it is more accessible to genuine, full-time family carers who exceed the current income threshold despite living on relatively modest incomes. Even though the income disregard for Carer's Allowance increased steadily from 2000 to 2008, it has stagnated for the last 10 years. **Increasing the income disregard for Carer's Allowance from €332.50 (single) and €665 (couple) to €450 (single) and €900 (couple) and extending allowable deductions would allow carers struggling to make ends meet to qualify for this much needed financial support.**

SUPPORTING CARERS TO BE HEALTHY: RECOMMENDATIONS



Ensuring carers don't miss out:

For many carers, looking after an ill, older or disabled loved one does not have a name, it is 'just something you do'. However, not recognising you are a carer means missing out on help, advice and information that can have serious personal and financial implications. A duty on health professionals to identify carers would help prevent them from missing out on important supports and ensure professionals take a 'whole family' approach, helping embed carers as expert partners and helping achieve better health outcomes for all involved. Having awareness and understanding of the carer population is a key starting point.

Establishing a voluntary 'carers register' enabling access and entitlement to carers' supports and benefits, is one way to ensure carers receive the support they need .



Carers as partners in health have a right to a Carer Needs Assessment:

Family carers should be seen as partners in health and social care and have a right to a Carer Needs Assessment that assesses their physical and mental health and emotional needs, identifies any supports or services that they require and allows them to make contingency plans if they are ill or unable to continue to provide care.

The Carer Needs Assessment tool developed by InterRAI, the HSE and carer representatives, and currently being piloted in CHO 2, should be rolled out nationally and available to all fulltime family carers.



Coordinated approach and psychological supports nationwide:

Enable improved and regular liaison and communication among healthcare practitioners to support a stepped care approach to carers mental health needs. This should/could be done by rolling out the Primary Care Network Teams nationally. **These teams can assess carers' needs and ensure that any mental distress need identified for psychological support is met by the national roll out of the existing CIPC (Counselling in Primary Care) in the first instance.**



Extend the GP Visit Card to all full-time carers in receipt of the Carer's Support Grant:

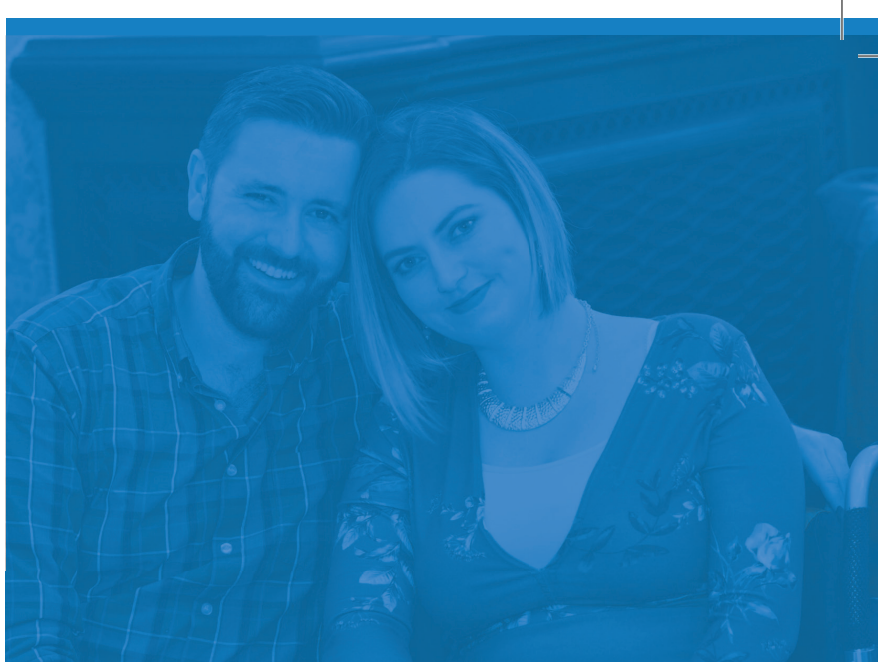
The introduction of GP Visit Cards for carers in receipt of Carer's Allowance and Carer's Benefit is a welcome first step in recognising the health and wellbeing needs of carers. **In order to reach a greater number of full-time carers the GP Visit Card should be made available to all carers in receipt of the non-means tested Carer's Support Grant.**

ACKNOWLEDGEMENTS:

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The design and redesign of the original survey (2009) was crucial to this collaboration. Special thanks to Dr Deirdre O'Donnell, UCD School of Nursing, Midwifery and Health Systems, for her huge contribution to the survey redesign and for providing a robust and thorough statistical analysis of the dataset. We are very grateful to Prof. Finian O'Brien and Prof. Mary Cannon, College of Psychiatrists of Ireland (CPsychI) for their guidance and work on designing the questionnaire and ratings aspect of this project.

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FIND OUT MORE:

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