

State of Caring 2017



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State of Caring 2017

Carers UK carries out an annual survey of carers to understand the state of caring in the UK.

This year over 7000 people shared their experience of what it's like to be a carer in 2017.

Of the 7000 people who completed this year's State of Caring Survey, over 600 were from Northern Ireland making it the largest State of Caring Survey carried out by Carers NI to date.

We would like to take this opportunity to thank all of those who took the time to complete the survey and allowing us to get a better picture of the State of Caring in Northern Ireland in 2017.

Context: the State of Caring in 2017

The Bengoa report (2016) and subsequent Health and Wellbeing 2026: Delivering Together Strategy (2016) by the then Health Minister Michelle O'Neill highlighted that carers were "equal partners in care" and "in need of our support". However, with no Executive or Programme for Government in place, the ongoing threat of Health and Social Care Trusts Savings Plans being introduced and the delay in publication of the Review of Adult Social Care and Support, carers in Northern Ireland continue to struggle on with limited support. Rather than a health and care system which values and supports carers, our 2017 survey suggests that too often carers are being pushed into poor health through lack of access to practical support and breaks.

In this context the enormous contribution of family and friends in Northern Ireland, the main providers of care, and estimated to be worth £4.6 billion per year, is more important than ever.

Key Findings:

Health and Wellbeing

57% said their physical health has worsened and 71% said they had suffered mental ill-health (eg stress or depression) as a result of their caring role.

70% find it difficult to get a good night's sleep and 29% have put off health treatment as a result of caring (eg. going to their own GP/ hospital appointments).

Interestingly, only 24% of respondents to our survey said they were

offered a Carers Assessment in the past 12 months whilst 12% directly requested one.

Short breaks

Nearly a third (30%) of unpaid carers in Northern Ireland have not had a day off in over one year, whilst one in five (21%) had not received a day away from caring in over five years.

Carers here named a number of barriers preventing them from taking a break including cost, lack of support on offer, lack of confidence in the care offered and even lack of knowledge about how to request a break.

Practical Support with caring

22% of respondents said they received no practical support with caring whilst 40% said they receive support from family and friends. Only 34% said they received practical support from care workers coming into their home.

28% of respondents were worried that the practical support they do receive or might get in the future, could be reduced. This was even before the recent announcement of potential cuts to domiciliary care as part of the Health and Social Care Trusts Savings Plans (Sept 2017).

Finances

Evidence from carers on the financial impact of caring shows that far from having their contribution appropriately recognised by the social care and social security systems, people providing unpaid care are struggling to make ends meet and unable to protect their future financial security, are being made vulnerable to poverty and financial hardship both in the short and long-term.

35% of Northern Ireland carers said they were struggling to make ends meet, with 17% of respondents saying they are or were in debt as a result of caring. 28% of carers here are using their savings to care whilst 26% have cut back on essentials like food and heating in order to financially survive.

Work and Care

The need for support for carers to enter or return to the workforce after time spent away was identified in last year's Draft Programme for Government (2016). Yet the difficulty of remaining in work alongside providing care comes across strongly again in the 2017 survey.

62% of carers responding to the survey were in work, 37% of whom were in full-time employment whilst 24% had given up work to care. Of those remaining in work, 37% had reduced their working hours to care whilst 57% work the same hours but find their job is negatively affected by caring (eg tiredness, lateness, stress).

It is clear that the way we value and support the contribution of carers is at the heart of addressing some of the current challenges our society is facing. What is of even more fundamental importance; caring and being cared for is part of being human and something which almost everyone will experience at some point in their lives. An action plan for supporting people well when they take on a caring role must be at the heart of the UK Government's agenda and the priorities of national, regional and local government across the UK. We are a caring society, and we should ensure that there is care for the carers.

Impact on carers' health and wellbeing

57% of carers in our survey said their physical health had worsened and 71% said they have suffered mental ill health (i.e stress and depression) as a result of their caring role.



Caring can have a significant impact on health, with the pressures of providing care taking a toll on both carers' physical and mental wellbeing.

Carers' own experiences suggest that back and mobility problems are caused by long term physical stress from moving and handling without the right equipment or training. This impact is often exacerbated by carers being unable to find time for medical check-ups or treatment or being forced to put off treatment because of their caring responsibilities. Without proper support, carers are often pushed to breaking point and have to give up work, stop caring, or even go into hospital themselves.

57% of carers in our survey said their physical health had worsened and 71% said they have suffered mental ill health (i.e stress and depression) as a result of their caring role.

60% of carers have reduced the amount of exercise they take whilst 49% have found it difficult to maintain a balanced diet. 30% of respondents said they have experienced an injury or their physical health has suffered as a result of their caring role.

Over 70% said they find it difficult to get a good night's sleep whilst 80% said they feel more stressed and 72% said they feel more anxious because of their caring role

Over a quarter of carers (29%) said they have put off their own health treatment as a result of caring (eg. going to their own GP/hospital appointments/planned surgery etc).

When asked what the top three issues were that would make the most difference to improving their health and wellbeing around 50% of carers said good quality care services or health care for the person

being cared for would make the most difference. A better income and regular breaks from caring were also amongst the key issues identified for improving carers health and wellbeing.

Time for a break

Breaks are vital for carers to be able to deal with the physical and emotional strain of providing care and to support them to be able to continue in their roles. However, disappointingly, carers often report not receiving the support they need to take even a short break.

30% of respondents to our survey had not had a break from caring in the last year. 65% had not a week off from caring in the last year and 21% had not had a day away from caring in five years.

The effect of not having a rest from caring is shattering, with carers describing being close to breaking point, desperate for some time to themselves, to sleep, recuperate, and see friends and family.

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.....



Barriers to getting a break

For those struggling to get a break from caring, the most common reasons that people gave were:

- Cost - Paying for or contributing towards the cost of a break (19%)
- Care concerns – Person cared for is unwilling to accept support from others (27%),
- The care for the person I support is not on offer (27%),
- Low confidence in quality of care (16%)
- Lack of awareness – Carers would not know how to request a break (12%)

What does a break mean to you?

We asked carers in Northern Ireland what having a break from caring means to them:

- *“Life Changing. Improves the quality and quantity of Care and Support I am able to give”*
- *“It’s a chance to get away to recharges my batteries”*
- *“Having a bit of “me” time to do what I want to do - gives me the belief that I can keep going in providing the support that I need to give”*
- *“It’s a lifeline and something positive to look forward to to keep me going”*
- *“It revitalises me. It’s like starting afresh, gaining a bit of energy and being able to take time out and really think about the bigger picture of how things are going. When you are doing the same thing day in day out with no break it can be hard. If I didn’t get my break every year I honestly believe I would not cope because we all need time out.”*
- *“Freedom to do what I want when I want. To feel content that my Family member is being cared for properly”.*
- *“It makes it possible for me to continue to support my mother”.*
- *“More stress. I worry constantly when I’m not there so I don’t really get a mental break”*
- *“I think the trouble and effort of being on a break with the person I care for would be worse than if I stayed at home”.*

Accessing practical support with caring

220,000 people in Northern Ireland provide unpaid care by looking after an ill, older or disabled family member, friend or partner. Yet often carers struggle for recognition and all too often go without the practical support they and the person they care for need from the wider health and care system, with severe consequences.

Recent public consultations on the Health and Social Care Trust Savings Plans highlight the potential for reductions in domiciliary care packages, closure of hospital beds etc. which will ultimately impact on some carers even more.

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22% of respondents said they received no practical support with caring.
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Practical support with caring

We asked carers about the practical support they receive or buy, for caring. 22% of respondents said they received no practical support with caring. 40% said they receive support/help from family and friends and 34% said they received practical support from care workers coming in to their home to help.

28% were worried that the practical support they might get in the future could be reduced. It is important to note however that this survey was carried out before the Health and Social Care Savings Plans consultation and before the most recent Stormont elections earlier this year.

Only 14% of carers in our survey get a cash sum from their Health and Social Care Trust to pay for care and support services directly and 10% receive a budget to choose the support services they want (direct payments or Self Directed Support).

Carers' experiences of carer's assessments

Carers need support to allow them to continue in their caring role and to ensure their own health and well-being does not suffer as a result. All carers are individuals and, as such, have varying needs. Proper assessment is the first step to accessing services and it is vitally important that carers are offered the opportunity to discuss their own needs and be considered for services in their own right. The Carers and Direct Payments Act (Northern Ireland) 2002 imposed a statutory duty on Health and Social Care Trusts to inform carers of their right to an assessment and to be considered for services to meet their own needs. The carer's assessment looks at each carer as an individual with their own personal circumstances, and will identify particular needs they may have as a result. It is important that the needs of individual carers are properly understood and that service providers are prepared to respond with flexibility, offering carers real choice as to how their needs will be met.

69% noted that the support they need to look after their own mental and physical health alongside caring was not considered (or insufficiently considered) in their assessment or in the support they receive

Whilst recent Department of Health figures show an increase in the number of carers assessments offered regionally, only 24% of respondents to our survey said they were offered a Carers Assessment in the past 12 months whilst 12% directly requested one.

Of the 85 people who reported receiving a carer's assessment/re-assessment in the past 12 months:

69% noted that the support they need to look after their own mental and physical health alongside caring was not considered (or insufficiently considered) in their assessment or in the support they receive;

74% felt the support they need to juggle care with work or return to work was not considered (or insufficiently considered) in their assessment or in the support they receive;

70% felt the need to have regular breaks from caring was not considered (or insufficiently considered) in their assessment or in the support they receive;

69% said their ability to have time to themselves was not considered (or insufficiently considered) in their assessment or in the support they receive

Carers' experiences of discharge from hospital



As part of a patient's discharge, hospitals should consult the patient's carer about the discharge process. Of the 162 respondents who had recent experience of hospital discharge, 83% said they were consulted about the patient's discharge but half of those said they were only consulted at the last minute.

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17% of carers reported that the person they cared for could have come home much earlier.
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Many carers providing care for someone who had been discharged from hospital in the last year said they were discharged too early (42%) stating that the patient was not ready to go home or that the support was not available for them to be at home. 7% of carers stated that the patient was discharged from hospital too early and was then readmitted within the following couple of months.

A number of carers also described people having to stay in hospital longer than was necessary as a result of appropriate care and support in the community not being in place or as a result of poor care management in hospitals. 17% of carers reported that the person they cared for could have come home much earlier. It has been well documented that staying in hospital longer than necessary can be detrimental to a patient's wellbeing.

Costs of caring

Northern Ireland's 220,000 unpaid carers provide the majority of care for families, saving the Northern Ireland economy an estimated £4.6 billion per year. Yet Carer's Allowance is the lowest benefit of its kind, at just £62.70 a week for those who are eligible (2017/18 rates), and carers often report struggling financially. We regularly hear of families facing difficulties making ends meet and affording their basic living costs alongside the additional costs associated with caring. Financial constraints are made worse by many carers being forced to give up work as a result of their caring responsibilities, removing their opportunities to support themselves while they are supporting others.

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57% of carers who responded to our survey had an average monthly household income below £2,000, just below the Northern Ireland average monthly household income of £2,208 (Office of National Statistics, 2014).

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35% of Northern Ireland carers said they were struggling to make ends meet, with 17% of respondents saying they are or were in debt as a result of caring. A number of people reported cutting back on items and activities which are fundamental to their wellbeing, including seeing family and friends or hobbies/leisure activities. Just over a quarter of those who were struggling to make ends meet said they were cutting back on essentials like food and heating, whilst 7% were cutting back on paying for support services which help with caring.

These coping mechanisms were reported to be the only way many carers could afford their basic living costs and the additional costs of caring but they were also said to have a significant impact on stress and anxiety and they are unlikely to be sustainable in the long-run.

28% of respondents said they were using savings to care for loved

ones whilst others were reliant on credit cards and family members to support them financially.

No one should have to suffer financial hardship as a result of caring and more should be done to ensure carers have enough money to provide care and support without it being detrimental to their lives.

Juggling work and care

15% of the workforce here combine caring for a loved one with paid work (Census 2011, NISRA). However, the significant demands of caring mean that many are forced to give up work altogether, due to a lack of rights, flexibility and high quality care services at home. Carers need to be supported so that they are able to juggle work and care and to enable them to return to work if they wish.

24% of respondents had given up work to care whilst 26% had reduced their working hours to care.



Of those completing our survey, 62% of respondents were in employment with 37% currently in full-time employment.

Responses illustrate how caring takes a toll on people's employment opportunities, including career development, promotions and pay rises, as well as impacting upon carers' ability to work at all. Indeed, 24% of respondents had given up work to care whilst 26% had reduced their working hours to care. 15% took a less qualified job or had turned down promotion to fit around their caring responsibilities and 9% had retired early to care.

Of those who continue to balance work and care, 57% said they work the same hours but that their job is negatively affected by caring (eg tiredness, lateness, stress).

Of those who reported having a carer's assessment this year, responses suggest that the majority of carers in paid work are not being given the support they need by their Health and Social Care Trust to help them juggle care with work. Over 7 in 10 carers (74%) said the need to combine paid work and caring was either not properly considered in their carer's assessment or in the support they received, or that this received some but insufficient consideration.

We welcome the inclusion and identification of the need for support for carers returning to work in the Draft Programme for Government (2016) but more needs to be done to support carers to remain in employment or return to employment should they wish. We need to work with carers and employers to ensure that workplaces become more carer friendly and that good employees are not lost through lack of support available.

A contribution that is understood and valued?

Carers make a huge contribution to the lives of those they care for and to our wider society. They provide invaluable support often at personal cost to their own mental and physical wellbeing, their relationships with family and friends, and to their own needs. Yet the majority of carers report feeling that their contribution is not understood and is not valued.

70% of carers said they feel that their contribution is not understood or valued by the government.

Almost three quarters of carers (70%) said they feel that their contribution is not understood or valued by the government, whilst only 16% said their contribution is well understood and valued by health and care professionals, despite these being the very people who carers rely on for support.

The majority of carers also felt that their contribution is not understood or valued by the public and society more broadly (57%) and many said they don't feel their contribution is even understood or valued by those closest to them (19%).



The huge contribution carers make to the lives of those they care for and to society more broadly, should be properly recognised. Carers should be better considered in the care and support that health and care professionals provide to the cared for person and their independent needs should always be addressed. Many carers reported that it was particularly difficult to feel valued by government and society when the money they receive for their caring is so little. At just £62.70 a week (2017-18 rates), Carer's Allowance is the lowest benefit of its kind, leaving many experiencing financial hardship, low self-esteem and feeling resentful that their invaluable contribution is not recognised. As one carer put it, "How can we say carers' contributions are valued when (if you qualify) we earn under £2 per hour?"

Recommendations

There is an urgent need for a cross-government plan setting out how improved support for carers will be achieved with targets and milestones so carers can see the progress being made. Any plan needs to also include resources and funding to ensure carers' needs are appropriately met. Whilst we await the outcomes of the Review of Adult Social Care and Support which should include the new Carers Strategy/Action Plan we should consider including measures:

To ensure that carers and our families do not suffer financial hardship as a result of caring:

- Carer's Allowance, just £62.70 per week on 2017/18 rates, needs to be raised significantly over the longer term and in the short term at least raised to the level of Job Seeker's Allowance (an increase of £10 per week. There should be an equivalent increase in the carer premium to ensure that those on the lowest incomes will benefit.
- The earnings threshold for Carer's Allowance needs to rise year on year in line with the National Living Wage, pegged at least to the equivalent of 16 hours a week. A taper should also be introduced.
- To auto-enrol carers in a second pension – a Carer's Pension that recognises the value of unpaid work and ensures that carers do not suffer financial hardship later in life.

To ensure that there is sufficient funding so that older and disabled people get the care they need and which is affordable:

- An urgent new, sustainably funded settlement for social care and the NHS to make legal rights to support a reality and ensure that services are there when carers need them. This must include housing fit for caring and technology that supports caring.
- Good quality, reliable and affordable care services are needed to support the role of carers and ensure we get the breaks we need without putting our lives on hold and our health in danger.

To ensure carers are able to juggle work and care, returning to work if we wish:

- Introduce a new right to paid care leave in the workplace of between five to ten days for carers in work.
- Support for carers and former carers who wish to stay in or return to work.
- Recognition that good quality, reliable and affordable care services are needed to enable us to juggle work and care.

To provide funding to enable carers to take the breaks we need:

- Increase and ring-fence funding for carers' breaks making it transparent so carers know what they are entitled to and to ensure greater consistency in what is available

To create a more 'Carer Friendly' NHS:

- A new duty for the NHS to put in place policies to identify carers and to promote our health and well-being – helping to build a carer friendly NHS.
- New measurements to monitor how GPs are identifying and supporting carers to make sure carers are able to look after their own health, are listened to about the care of the person being looked after and are supported to care well.

Ensure we are all better prepared for caring and can get support early to look after our own health and wellbeing:

- Easily available advice and information for carers to help us plan, prepare and provide for care.

About Carers NI

At times, caring can be profoundly joyful. There's nothing more natural and human than helping our loved ones get the most out of life.

There's also nothing more difficult than focusing on someone else's needs without neglecting our own. Whether we're caring around the clock or balancing caring with work and family life, it can be exhausting.

The 'system' can be bewildering. The emotions can be shattering.

However caring affects you, we're here.

Our vision is a world where carers feel respected, valued and supported for the huge contribution we make. Where the care we provide is not taken for granted.

We are focusing on three priorities to create the world we want for carers.

1. Battling for greater understanding and support for carers in our society, so we can all look after loved ones without putting our own lives on hold
2. Giving carers expert information and advice right from the start, so the answers are available for everyone who needs them
3. Building a network of carer positive employers, so no one has to give up work to care

Carers NI Advice line

For expert advice and information about caring, contact the Carers NI Advice line.

T 028 90439843
E advice@carersni.org

Open Mon-Thurs 9am-4pm, Fri 9am-1230pm

Listening Ear service Mon & Tues 9am-7pm
carersni.org