

Supporting Carers to be Healthy and Connected

Research Summary for Carers Week 2018



Carers Week is an annual awareness campaign which takes place to celebrate and recognise the vital contribution made by the UK's 6.5 million unpaid carers¹.

¹ Census 2011

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About the research

The survey findings are based upon the 6,828 responses to our State of Caring 2018 survey from individuals in the UK who are currently providing care.

This includes 5,051 carers from England, 547 from Northern Ireland, 645 from Scotland, and 514 from Wales.

We have explored the results looking at different groups of carers. Below, the sample sizes for these groups are set out.

Sandwich carers (those who also have childcare responsibilities for a non-disabled child under 18)

786

Carers who are in paid work (including full-time, part-time and self-employed)

2,001

Round the clock carers (those caring for 50 hours or more each week)

3,817

Carers who identify as female

3,287

Carers who identify as male

850

Carers providing care to a disabled child

865

Young adult carers (aged 18-24)

36

Older carers over 65

856

Older carers over 75

228

Carers who report they are struggling to make ends meet financially

1,682

As fewer than 100 young adult carers responded to the survey, we have included proportions rather than percentages for this group. We have not included analysis of responses from young carers (under 18) as too few responded to the survey.

Introduction

Carers Week is an annual campaign to raise awareness of caring, highlight the challenges carers face and recognise the contribution they make to families and communities throughout the UK.

For Carers Week 2018, we are looking at all the ways we can support carers to stay Healthy and Connected; building communities which support carers to look after the person they care for well, while recognising that they are individuals with health and well-being needs of their own.

Caring can have a significant impact, with the pressures of providing support taking a toll on both carers' physical and mental health. Those providing 50 hours or more of care per week are more than twice as likely to be in bad health as non-carers.¹ We've published this report to provide an insight into the challenges that carers across the UK face in maintaining their physical and mental health.

¹ Census 2011

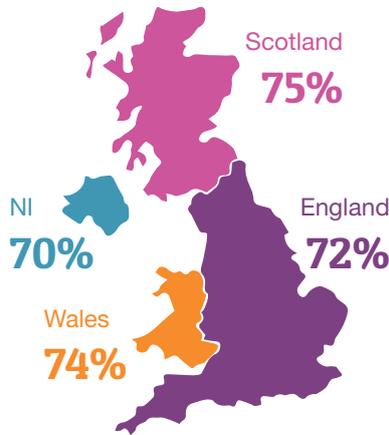




Key findings

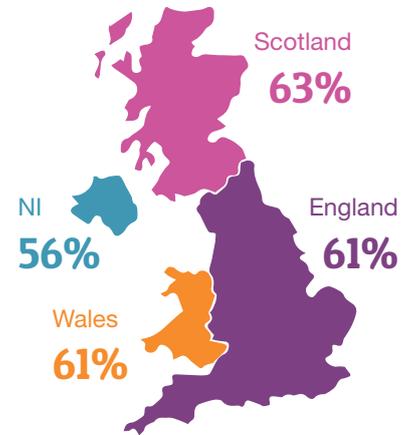
72%

of carers in the UK said they had suffered mental ill health as a result of caring.



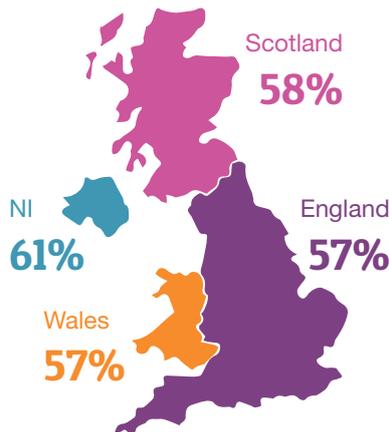
61%

of carers in the UK said they had suffered physical ill health as a result of caring.



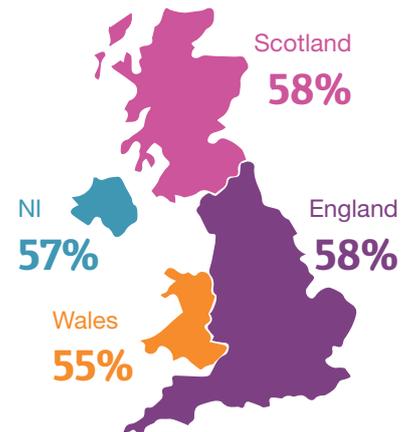
57%

of carers in the UK expect their mental health and well-being to get worse in the next two years.



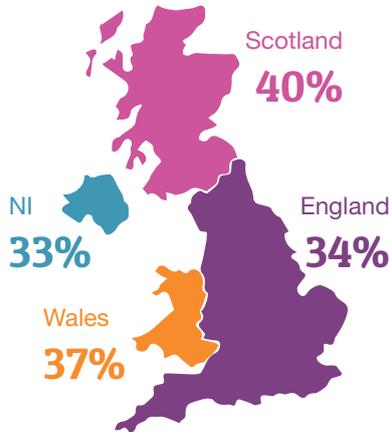
58%

of carers in the UK expect their physical health and well-being to get worse in the next two years.



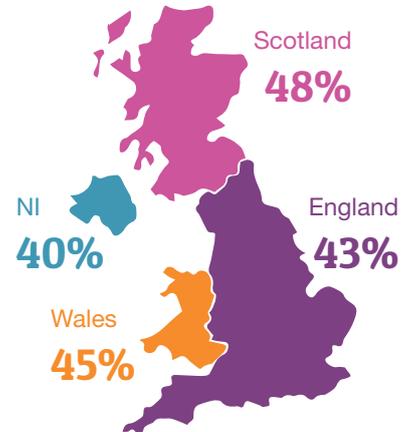
35%

of carers in the UK expect that they will be able to provide less or no care in the future because of poor mental health.



43%

of carers in the UK expect that they will be able to provide less or no care in the future because of poor physical health.



The impact of caring on carers' health and well-being

We asked carers about the impact that being a carer has on their physical and mental health and well-being.

Almost three quarters (72%) of the respondents currently providing care said they had suffered mental ill health such as stress or depression as a result of caring, while well **over half (61%)** said their physical health had worsened as a result of caring.

Just over **1 in 10 (12%)** said their health was no different as a result of caring and only **4%** said their mental health had not been affected.

Young adult carers (those aged 18-24) were most likely to say they had suffered mental ill health as a result of caring, with **31 of the 36 young adult carers who** responded to the survey reporting this. People caring for a disabled child (**81%**), sandwich carers (**80%**) and carers struggling to make ends meet (**80%**) were also among those groups most likely to say their mental health and well-being had suffered as a result of providing care.

Carers struggling to make ends meet were the most likely to report a negative impact of caring on their physical health (**69%**), together with those caring round the clock (**66%**).

31 of 36



young adult carers have suffered mental ill health as a result of caring.

'I work hard to maintain my health but I'm worried about how things will develop'.
(Carer juggling work and care).

'There is no time to consider my own physical or mental health'.
(Female carer providing care to a disabled child alongside other childcare responsibilities, aged 45-49).

'No one seems to care about the health of the carer'.
(Female carer, aged 50-54).

'Things can be really tough...the emotional impact of caring is often ignored'.
(Female carer, aged 45-49).

'I don't sleep well and worry constantly'.
(Sandwich carer, juggling work and care, aged 50-54).

Carers' expectations for their own health in the future

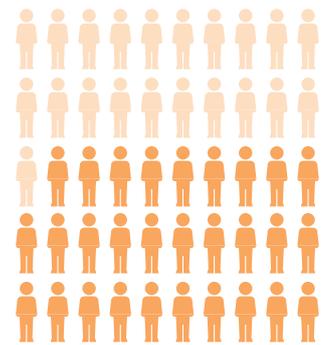
When asked about the future, worryingly, the majority (58%) of carers said that they expect their physical health to get worse in the next two years. Only 3% said they thought their health and well-being would improve.

Carers' expectations for their mental health and well-being were similarly discouraging, with **over half of carers (57%)** saying they expect their mental health to get worse in the next two years and only **4%** saying they expect it to improve.

Carers who said they were struggling financially to make ends meet and those who were over the age of 65 years old or providing round the clock care were more likely than other groups to say they expect their physical health to get worse in the next two years, with between **63% and 66%** of these groups reporting this. Carers who said they were struggling financially to make ends meet, were the most likely group to expect their mental health to get worse in the next two years (**65%**).

Over half of carers

57%



expect their mental health to get worse in the next two years

6

'I already feel exhausted and at breaking point. I dread what the future may bring'.

(Female carer, aged 50-54).

'I find my caring role very stressful and am constantly worried about the future'.

(Female carer, aged 70-74).

'As I get older I have less resilience'.

(Female carer, struggling to make ends meet, aged 65-69).

Carers' concerns about their own health and well-being

We asked carers: 'What three aspects of your own health and well-being do you worry most about?' The impact of stress and anxiety on their health was by far the most common issue that carers reported worrying about. Other leading issues that carers said caused them worry included:

- the impact of caring on their relationships with a partner, friends or family;
- getting enough sleep;
- getting enough exercise;
- putting off health check-ups or medical treatment; and
- persistent injury caused by or exacerbated by the physical strain of providing care.

'I often feel isolated and alone'.
(Carer).

There was little difference in the ordering of these concerns between groups.

The biggest stressors for carers

Not getting enough sleep, providing hands on care for the person they care for, and managing financially were the three things that carers said contributed most to their stress and anxiety. Other leading issues that carers identified included:

- filling in forms for financial or practical support for them or the person they care for,
- worrying about whether the person they care for is eating and drinking the right things,
- arranging health appointments for the person they care for, and
- arranging support from paid health or care workers.

Little difference in the priority of concerns was found across the different nations in the UK or across different groups of carers. Older people over 75 were more likely to list travelling with the person they care for, including concern about using public transport or finding parking, among the top contributors to their stress and anxiety compared to other groups. While young adult carers were more likely to list talking to family and friends about caring as a leading contributor to their stress and anxiety.

'I worry all the time about what will happen to my daughter if something happens to me'.
(Female carer, aged 55-59).

'The opportunity to go out in the evening or have a break would help immensely'.
(Male carer, juggling work and care, aged 50-54).

'I do worry that I may not be able to cope with the stress and that it will make me ill'.
(Female, carer, 65-69).

'I don't know how my partner's [condition] will progress. I don't know what to expect. That is a concern'.
(Female carer juggling work and care, aged 60-64).

Future care: the impact of carers' health and well-being on their ability to care

A carer's health and well-being can have a significant impact upon their ability to provide support for the person they care for. We asked carers whether they thought their physical and mental health would affect their ability to care in the future. Worryingly, **almost half** of carers responding to our survey (**43%**) said they expect that they will be able to provide less or no care in the future because of poor current or future physical health, while **over one third (35%)** of carers said they expect that they will be able to provide less or no care in the future because of poor current or future mental health. **Only half** of respondents (**52%**) said that they didn't think their physical health would affect their ability to provide care in the future. **Sixty per cent (60%)** said they didn't think their mental health would affect their ability to provide care in the future.

'I worry about my ability to provide the care and support needed by those I care for'.

(Female carer, 50-54).

'I don't know what the future holds regarding physical or mental health, I just know I'm managing now'.

(Male carer, aged 65-69).

Older people, especially those over 75 years old, were most likely to say they expected to be able to provide less or no care in the future because of poor physical health (**54% of over 65s and 59% of over 75s**). When all groups were considered, carers in Scotland were more likely than carers in other nations to expect to be able to provide less or no care in the future because of poor physical health (**48% compared to a UK average of 43%**).

Carers struggling to make ends meet were most likely to report that the poor state of their mental health would mean they would be able to provide less or no care in the future, with **over 4 in 10 (43%)** saying this. When all groups were considered, carers in Scotland were slightly more likely to report this than carers in other nations of the UK (**40% compared to a UK average of 35%**).

'I will just cope and carry on. What are the alternatives?'

(Male, sandwich carer, juggling work and care, and struggling to make ends meet, aged 55-59).

Young adult carers (**27 out of 36**), carers in paid work (**60%**), sandwich carers (**60%**) and those caring for a disabled child (**59%**) were the most likely to report that they didn't expect their physical health to affect their ability to provide care in the future. Carers in Northern Ireland were also slightly more likely to report this than carers in other nations in the UK (**57% compared to a UK average of 52%**). This was similar to carers' views on their mental health, where carers with a disabled child (**64%**) and sandwich carers (**65%**) were most likely to think that their mental health would not affect their ability to provide care in the future. Carers in Northern Ireland were also more likely to say this than carers across all groups in other nations (**65% compared to a UK average of 60%**).

'With the right support, my physical health and well-being would improve and I would be able to care for many years'.

(Carer aged 35-39, supporting two disabled children).

We asked carers whether they had any further comments about their future mental or physical health and their ability to care. In the responses we received, carers spoke about issues including:

- their constant fear for the future;
- how the needs of the person they care for might progress and the impact this might have upon their ability to care, especially as they get older or struggle with their own ill health;
- uncertainty over the support they receive and the strain of constantly having to fight to get help; and
- their worry about who would provide care for their family or friend if something happened to them.

In describing the significant impact of caring on their health and well-being, some carers spoke about feeling isolated and the effect this has upon them mentally and physically.

Some of the carers who included comments in this section spoke more positively, saying that they were managing and that they thought that, with the right support, they would be able to carry on providing care. However, a number of carers said that they already feel like they are at breaking point but have no choice but to continue.

'I just want to be well enough to look after my husband for the rest of his life'.
(Female carer, struggling to make ends meet, aged 75-79).

'I feel that I have no option but to continue caring despite the negative impact on my own health and well-being'.
(Carer, juggling work and care, aged 45-49).

Carers need to be consistently identified by health professionals

GPs can provide invaluable support to carers, offering information and advice on being a carer, and helping them to look after their own health.

We asked carers whether their GP knows they are a carer. Encouragingly, over **7 in 10 carers (72%)** who responded to the survey said their GP does know. However, almost **3 in 10** carers said their GP either does not know they are a carer (**11%**) or that they did not know if their GP knew (**18%**). This suggests opportunities for them to be better supported in their caring role and to help them look after their own health and well-being are being missed.

Older carers were most likely to report that their GP knows they are a carer, with more than **8 out of 10** respondents over the age of 65 (**83%**) stating this

and **88%** of carers over the age of 75. Round the clock carers were also more likely to report that their GP knows they are a carer than other groups, with 80% reporting this. This nevertheless means that as many as **1 in 5 (20%)** of people caring for more than 50 hours a week reported that their GP either doesn't know they are a carer or that they aren't sure whether their GP knows or not, despite them being one of the groups of carers most likely to report a negative impact of caring on their physical health.

Carers in Northern Ireland and carers trying to juggle their caring responsibilities with paid work were least likely to report that their GP knows they are a carer, with **56% and 59%** of these groups saying this was the case respectively.



Carers aren't being routinely offered support with their own health and well-being

We asked carers who reported that their GP knows they are a carer whether the GP had talked to them about any of the following issues:

- Specialist support with your mental health through talking therapies etc.
- Occupational therapists
- Training to support physical caring without injury
- Getting a benefits check
- Free flu jab
- Health check up
- How to arrange paid for care for the person you support
- Flexible or double appointments arranged around your caring role
- How to get regular breaks from caring
- Repeat prescriptions or home delivery from the pharmacy
- Advice with eating healthily
- Information on getting exercise
- Where to go for general information, advice and support as a carer
- Information about making social connections
- None of these

Worryingly, nearly **2 in 5 (38%)** of those who said their GP knows they are a carer reported that their GP had not talked to them about any of these issues.

Carers reported that the free flu jab was the most common issue for their GPs to have discussed with them, with **almost half (47%)** indicating this. This means that GPs did not suggest a flu jab to over half of carers, despite the importance it can play in keeping them well. Older people were slightly more likely to report that their GP had spoken to them about a flu jab than other groups, with **52%** stating this.

10

'My GP has never spoken to me about my caring role'.

(Female carer providing care to a disabled child under 18 alongside other childcare responsibilities, aged 45-49).

Repeat prescriptions or home delivery from the pharmacy was the second most common form of support to have been raised by GPs, with **over a fifth of respondents (22%)** reporting that this had been discussed. Other more common sources of support suggested by GPs included specialist support for the carer's mental health through talking therapies, and getting a health check up, which **16%** and **15%** reported respectively.

'It would be nice to know there are services to help support me to support her'.

(Female carer juggling work and care and struggling to make ends meet, aged 55-59).

Disappointingly, **fewer than 1 in 10 (9%)** of those whose GPs know they are a carer said that their GP had talked to them about general information, advice and support for being a carer or where they could go to get this. This was lowest for those providing care for a disabled child (**5%**) and highest for carers over 75 years old (**18%**).

Across the board, only **5%** of carers said their GP had spoken to them about information on getting exercise and eating healthily. And only **1%** of carers said their GP had spoken to them about information on making social connections.

'My GP is very supportive and always makes time for me if I need to talk'.

(Male carer with childcare responsibilities for a non-disabled child, struggling to make ends meet, aged 50-54).

Despite the vital role that breaks can play in helping a carer to maintain their health and well-being, and enabling them to continue to provide care, only **2%** of carers reported that their GP had spoken to them about how to get regular breaks from caring.

Young adult carers and those caring for a disabled child were the most likely to say that their GP had raised none of the issues we suggested, with **half of carers in these groups reporting this (13 out of 26 and 48% respectively)**. Across all groups, carers in Wales were more likely to report this than those in the other nations (**46% compared to a UK average of 37%**).

Supporting carers to be Healthy and Connected

Recommendations

UK and Nation Governments

Supporting the health, well-being and choices of carers must be at the heart of any future decisions on the funding of our health and social care system.

Across the UK, there is a need for sustainable funding of social care support. The huge contribution of unpaid carers must be firmly recognised as the Government looks to review the funding of social care in England. This recognition of the contribution of carers should form part of similar discussions on funding social care that are ongoing in each of the nations.

The new Cross Government Action Plan in England and strategic plans across the nations to improve support for carers should act as a catalyst for the delivery of improved support for carers, using the evidence gathered from carers to inform practice and policies.

Health and care professionals

Carers are still not routinely identified or supported by health and social care professionals. Greater consistency is needed in making carers aware of support available to look after their own health and well-being including access to health checks, flu jabs, supporting with medication and flexible appointment times.

Employers

Employers increasingly recognise their role in supporting the health and well-being of their employees. As more of us juggle work and providing unpaid care, making carers aware of workplace support has never been more important. Government also has a role to play in leading this agenda.

Education settings

Policies to improve the well-being of pupils and students should consider the impact of caring responsibilities and the flexibility and support needed. Schools, colleges and universities should be encouraged to introduce policies and programmes that support carers and improve their experience of education. Such action would also help to support their well-being.

Older carers

Growing numbers of older people are providing care at the same time as managing their own health and care needs. Older carers should be identified and offered support to coordinate care, have regular breaks from caring, and plan for the future as their own health needs change.

All of us

Previous Carers Week research has shown that if carers feel their contribution is valued by society it boosts their resilience.

Carers Week aims to raise awareness and understanding of caring so that all parts of society can play their part. We should show carers in our social networks that they are valued and support them to identify themselves and get connected to information and support.



Carers Week is kindly supported by Nutricia Advanced Medical Nutrition.



Carers Week is made possible by Carers UK joining forces with Age UK, Carers Trust, Independent Age, Macmillan Cancer Support, Motor Neurone Disease Association, the MS Society and Which? Elderly Care.



Find out more and get involved at carersweek.org

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