

# Getting Carers Connected

Research Summary Carers Week 2019



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 carers<sup>1</sup>.

<sup>1</sup> Census 2011

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## About Carers Week

Millions of people across the UK are looking after a family member or friend who has a disability, mental or physical illness or who needs extra help as they grow older. Caring can be a hugely rewarding experience but carers often find it challenging to take care of their own wellbeing whilst caring. Its impact on all aspects of life from relationships and health to finances and work should not be underestimated. Caring without the right information and support can be tough.

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Family care is an essential element of the overall system of care yet is not often put at the heart of the conversation about the social care system.

Carers Week is an annual campaign to raise awareness of caring, highlighting the challenges unpaid carers face and recognise the contribution they make to families and communities throughout the UK. It also helps people who don't think of themselves as having caring responsibilities to identify as carers and access much-needed support.

This Carers Week in 2019, we are Getting Carers Connected. The charities calling for better support for carers and supporting Carers Week 2019 are Carers UK, Age UK, Carers Trust, Motor Neurone Disease Association, MS Society, Rethink Mental Illness and Sense. The headline supporter of Carers Week 2019 is British Gas, part of Centrica, and Nutricia Advanced Medical Nutrition are also supporting Carers Week 2019.



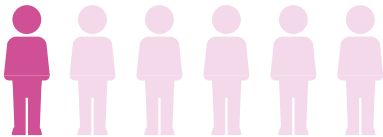


# Key findings

## Unpaid carers

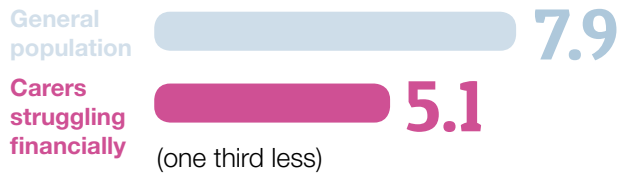
In the UK

**1 in 6** adults are now providing unpaid care.



8.8 million adult unpaid carers

Feeling that the things they do in their life are worthwhile levels out of 10



## Loneliness

I am always or often lonely

Unpaid carers

**35%**



General population

**5%**

(7 times more likely to say they are often or always lonely)

## Anxiety levels out of 10

General population 2.9

Carers 5.4

(nearly twice as anxious)

## Carers receiving no practical support

Loneliness

I am always or often lonely

Carers

**40%**



General population

**5%**

(8 times more)

## Life satisfaction levels out of 10

General population 7.7

Carers 4.4

# Recommendations for action

## UK and Nation Governments

### Funding health and social care

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 for adults and children. **The huge contribution of unpaid carers must be firmly recognised as governments consider care funding in the next Spending Review and future adult social care reforms in England and Scotland.**

### Ending carers' financial hardship

Despite their enormous contribution, too many carers continue to struggle financially with repercussions for their mental and physical wellbeing in the short and long-term. **Financial support for carers must be improved. As a minimum the increases made in Scotland to carers' benefits must be matched in the rest of the UK.**

### Health and care professionals

Carers are still not routinely identified or supported by health and social care professionals. Greater consistency is needed in connecting carers to support available to look after their own mental and physical health and wellbeing. **A duty on the NHS in England, Wales and Northern Ireland to identify and support carers should be introduced to bring a more systematic approach to improving the health and well-being of carers.**

### Workplace

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, connecting carers to workplace support has never been more important. Governments also have a role to play in leading this agenda and **we would like to see workplace rights strengthened with a statutory right to paid carer's leave of at least five days introduced.**

### 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

Carers Week aims to raise awareness and understanding of caring so carers feel valued and supported. **We all have a part to play ensuring the carers in our social circles are understood and connected.**

## Unpaid caring – a growing issue

- The number of people providing unpaid care across the UK is increasing rapidly and has grown to a potential **8.8 million**. This means that **1 in 6** adults are now providing unpaid care.
- Previous estimates had suggested that the carer population would not reach **9 million** until 2037<sup>2</sup>.
- The last Census in 2011 suggested there were **6.3 million** adult carers in the UK – **1 in 8 adults**.
- The number of people aged 65 years or over who are caring has grown from **1.4 million** to over **2 million**. This is a **43%** increase from 2011 to 2019.

Up and down the UK there are millions of people caring unpaid for an ill, older or disabled family member or friend. These people are called carers but they would probably say that they are just being a husband, a partner, a mum, a dad, a son, a daughter, a friend or a good neighbour.

For some, taking on a caring role can be sudden; someone in your family has an accident or your child is born with a disability. For others, caring responsibilities can grow gradually over time: your parents can't manage on their own any longer; your partner's or your child's mental or physical health gradually worsens.



Polling suggests the number of people caring unpaid could be as high as

# 8.8m

The amount and type of support that carers provide varies considerably. It can range from a few hours a week, such as picking up prescriptions and preparing meals, to providing emotional or personal care day and night.

Significant numbers of older people are caring, often co-caring for each other with partners or adult children with learning disabilities.

As more of us are taking on this role it is becoming more urgent than ever for the levels of and contribution of unpaid care to our wider health and care system to be understood.

2 Carers UK (2001) It could be you

### Why is the number of carers growing?

As well as this polling, which used a broader more descriptive definition of caring than the one used in the Census, more recent in-depth surveys suggest a significant increase in carers. Research using the Understanding Society data set suggested that the figure could be higher – 7.6 million. There is no doubt that the trend is upwards in terms of numbers of carers and the amount of unpaid care being provided too.

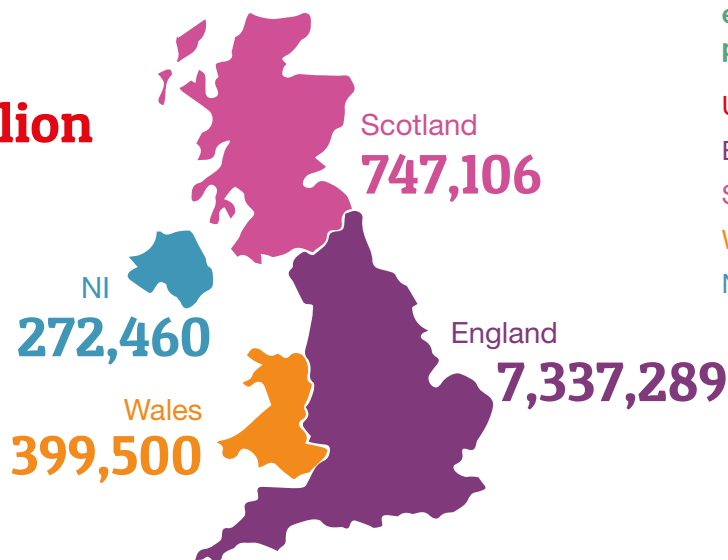
As well as a growth in demand for care from an ageing population, a significant rise in the number of people living with long term conditions is also increasing the amount of care that is needed.

In the UK, people can currently expect to live for more than a fifth of their lives in poor health, equating to 19 years for women and 16 years for men<sup>3</sup>. Increases in the period of life spent in poor health are likely to lead to increased demand for long-term care.

A drive to care for people in the community and improved life expectancy for children and young people with disabilities has meant an increasing need for care and support. Yet, publicly funded care and support services have not kept pace with this growing demand. The Local Government Association (LGA) estimates that adult social care services in England face a £3.5 billion funding gap by 2025, just to maintain existing standards of care.

#### Extrapolated adult carer population based on YouGov polling

UK  
**8.8million**



#### Proportion of unpaid carers in the adult population extrapolated from YouGov polling<sup>4</sup>

UK	1 in 6 adults
England	1 in 6 adults
Scotland <sup>5</sup>	1 in 6 adults
Wales	1 in 6 adults
Northern Ireland	1 in 5 adults

<sup>3</sup> ONS, Health state life expectancies, UK: 2014 to 2016 (2017)

<sup>4</sup> General population data is taken from the Community Life Survey for England for April 2017

<sup>5</sup> In Scotland, the Scottish Government chose a number of years ago to utilise the Scottish Health and Experience Survey rather than the lower Census 2011 figure of 492,000. The SHeS was felt to provide the best estimate the number of carers in Scotland. This found there were 759,000 carers which broadly mirrors this YouGov polling.

## Social connections and carers

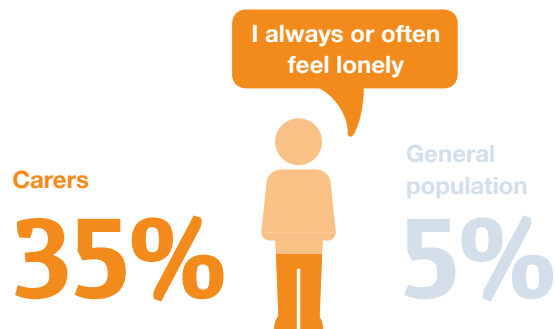
Previous research including from the Office for National Statistics and the Jo Cox Commission on Loneliness has identified caring as a significant risk factor that contributes to loneliness.

The loneliness carers experience is caused by a range of circumstances, many of them out of their control. Carers may be so busy that they have no time or energy left to see friends and other family, or they may drift away as life becomes so different from that of others. Carers may find the emotional demands of caring for someone unpaid and focussing on their well-being means neglecting their own. The costs associated with caring, particularly if they have left work to care, can mean struggling financially and not being able afford to do some of the social activities they did before. Carers can find that their relationships become increasingly transactional rather than affirming and sustaining.

For many carers, the world simply shrinks. A caring role can become one of providing and co-ordinating care, medical appointments, going to the pharmacy, liaising with care workers. It's easy to feel invisible when putting someone else's needs ahead of their own. It can be lonely bearing so much of the responsibility of caring unpaid for someone.

### Loneliness among different groups of carers

- Carers looking after disabled children aged under 18 are nearly **ten times** more likely to say they are always or often lonely compared with the general population (**47%** compared with **5%**).
- Those supporting someone with a mental health condition report higher levels of loneliness than other carers and are nearly **nine times** more likely than the rest of the population to say they are always or often lonely (**43%** compared with **5%**).
- Older carers, aged 65 or older are **nine times** more likely than the general population of older people to say they often or always feel lonely (**28%** compared with **3%** of the population of people aged 65 years or older).
- Younger carers (aged 18–30) are more than **nine times** more likely to say they are always or often lonely compared with the general population (**46%** compared with **5%**).



Carers are **7x** more likely to say they are always or often lonely compared with the general population.

- Over half (**54%**) of the population say they are never or hardly ever lonely compared with just **1 in 6 (18%)** unpaid carers.

'Leaving work left me isolated. My caring role has changed my support network dramatically – I had to seek out a new support network.'

'I have felt isolated because people often don't understand the impact of living with someone who has mental health issues.'

'I feel isolated because I am the only person responsible for mum.'

### Carers going without support and struggling to make ends meet report higher levels of loneliness

- Carers who do not receive any practical support with their caring role are **8 times** more likely to say they are always or often lonely compared with the general population (**40%** compared with **5%**).
- Carers who report struggling to make ends meet are almost **10 times** as likely to report feeling lonely always or often compared with the general population (**49%** compared with **5%**).

Country/Nation	Percentage of carers who say they are always or often lonely
UK	35%
Scotland	38%
Wales	37%
NI	31%

'I care around the clock for my daughter. The local authority have let us down with the care package and there's nothing available locally anyway so when opportunity arises for carers to have a day trip or a spa break, I can't participate.'

'I have found caring for my parents, while sometimes frustrating and draining, to also provide a deep joy. How amazing to be gifted this extra time with them.'

'My caring role exhausts me so I have no energy left to participate in social activities.'

'I get out to a movement class as often as I can – this has saved my life. Give carers funds for joyful activities that help let them out of the role.'

## Why are carers lonely?

### Carers who described themselves as lonely were asked further questions about the reasons

Almost half of carers said they'd felt lonely because of not being comfortable with talking to friends about caring.

**47%**

Over two thirds of carers said they'd felt lonely because of not having time to participate in social activities.

**69%**

Nearly half of carers said they'd felt lonely because they couldn't afford to participate in social activities.

**46%**

Over half of carers said they'd felt lonely because of not being able to get out of the house.

**56%**



# Carer wellbeing – comparing carers with the national picture

The Office for National Statistics (ONS) assesses personal well-being using four measures. These measures ask people to evaluate how satisfied they are with their life overall, asking whether they feel they have meaning and purpose in their life, and asks about their emotions during a particular period. The following questions are used:

1. How satisfied are you with your life at the moment?
2. How happy did you feel yesterday?
3. To what extent do you feel the things you do in life are worthwhile?
4. How anxious did you feel yesterday?

Carers responding to Carers UK's 2019 State of Caring survey were asked these standard questions and the following data compares the results directly with the ONS national statistics on personal well-being averaged across 2018.

- Carers in the UK are nearly twice as anxious as general population. Carers placed their levels of anxiety at an average of **5.4 out of 10** compared with a population average of **2.9**.
- Carers in the UK are significantly less likely (**27%**) to feel like the things they do in life are worthwhile compared with the rest of the population – carers rated this at an average of **5.8** compared with **7.9** across the UK population.
- Carers placed their life satisfaction at over a third lower (**39%**) than the rest of the UK population a mean of **4.7 out of 10** compared with **7.7** across the whole population.

- Carers in the UK reported levels of happiness over a third (**37%**) lower than the general population. Carers placed their level of happiness at **4.7 out of 10** compared with a population average of **7.5**.

## Comparing nations across the UK

On average, carers in Scotland reported that their life satisfaction was over a third (**39%**) lower than the population of Scotland as a whole (**4.7** compared with **7.7**) and that their anxiety levels were almost twice as high (**5.5** compared with **2.8**).

In Wales, carers reported happiness levels which are **37%** lower than the whole Welsh population (**4.7** compared with **7.5**) and gave life satisfaction scores which are **39%** lower (**4.7** compared with **7.7**). Welsh carers also report being nearly twice as anxious as the Welsh population (**5.5** compared with **2.9**).

Carers in Northern Ireland report significantly lower life satisfaction and lower happiness compared with the NI average and their anxiety levels were almost twice as high as those reported by the Northern Irish population as a whole (**5.3** compared with **2.7**). However, compared with carers across the UK, carers in Northern Ireland reported being **8%** happier (**5.1** compared to **4.7**) and **8%** more satisfied with their life at the moment (**5.1** compared to **4.7**).

	Whole population in Wales	Carers	Whole population in Scotland	Carers	Whole population in Northern Ireland	Carers
<i>How satisfied are you with your life at the moment?</i>	7.7	4.7	7.7	4.6	7.9	5.2
<i>How happy did you feel yesterday?</i>	7.5	4.7	7.5	4.7	7.7	5.1
<i>To what extent do you feel the things you do in life are worthwhile?</i>	7.9	5.9	7.9	5.7	8.1	6.1
<i>How anxious did you feel yesterday?</i>	2.9	5.3	2.8	5.4	2.7	5.3

### Particular groups of carers experience lower levels of well-being

- Parent carers looking after disabled children under 18 reported higher anxiety levels than other carers. They placed anxiety levels at roughly double the population – **5.9 out of 10** compared with **2.9** across the whole population and compared with an average of **5.4** across the all carers.
- Those juggling caring with paid jobs reported slightly better life satisfaction (**5.2**) compared with other carers (**4.7**). Carers in paid work also felt that the things they do are more worthwhile compared with other carers (**6.1** compared with **5.8**) but levels of anxiety were similar to those of other carers (**5.3** compared with **5.4**).
- Those carers reporting that they are struggling financially were a third less likely to feel that the things they do in their life are worthwhile compared with the rest of the population (**5.1** compared with **7.9**).
- Carers struggling to make ends were on average half as satisfied with their lives as the whole population **3.9 out of 10** compared with **7.7** across the whole population.
- Carers struggling financially also reported anxiety levels more than twice as high as the general population. Carers who said they were struggling to make ends meet placed their anxiety levels at **5.9 out of 10** compared with **2.9** of the whole population.

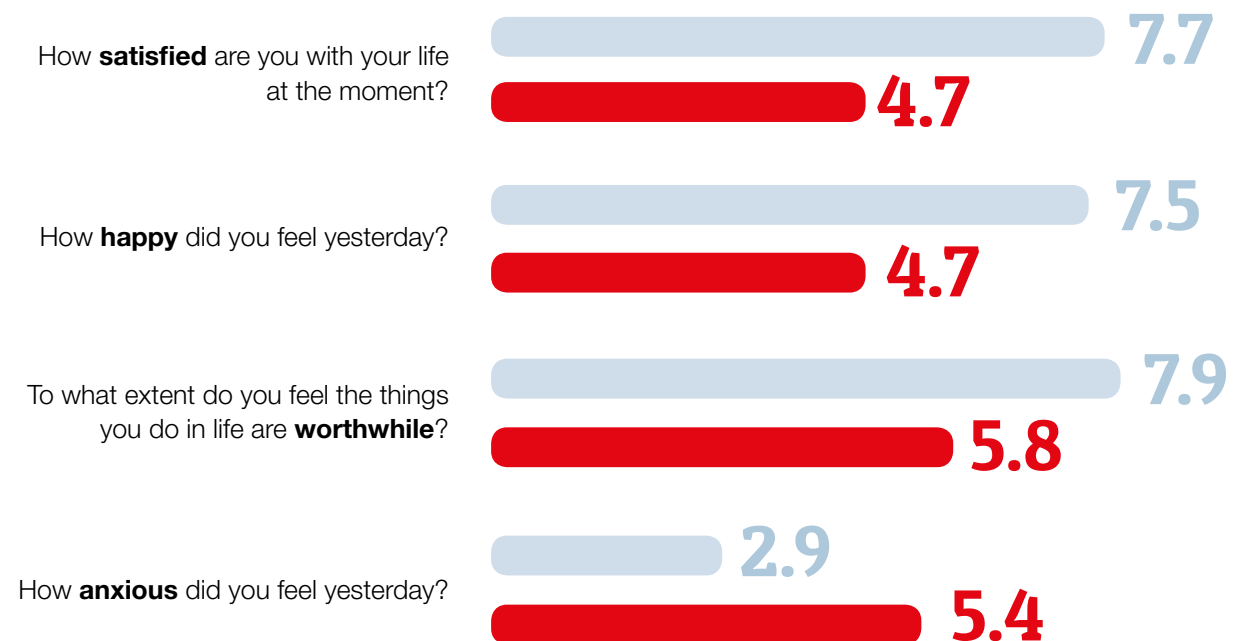
### Carers going without support and struggling to make ends report having worse well-being

- Carers receiving no practical support with their caring role are half as satisfied with their lives as the rest of the population – carers going without any support placed their level of life satisfaction at **4.4 out of 10** compared with a population average of **7.7**.

Whole UK population



All current carers



## About the research

### Higher carer numbers based on YouGov Polling and ONS mid-2017 population estimates

The rise in number of carers was extrapolated from polling carried out by YouGov in December 2018 and January 2019. Taking 17% of the adult population who say they are a carer in response to polling carried out in Dec 2018 and Jan 2019. Applying it to mid-2017 population estimates of those aged 18 and over for each nation in the UK.

### ONS Loneliness

ONS Analysis of characteristics and circumstances associated with loneliness in England using the Community Life Survey, 2016 to 2017. Published in April 2018.

### ONS Wellbeing

Population data on Wellbeing is taken from the Personal well-being estimates for personal wellbeing averaged across 2018. Scotland, Wales and Northern Ireland comparisons are to the figure for that nation's whole population.

[www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/datasets/headlineestimatesofpersonalwell-being](http://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/datasets/headlineestimatesofpersonalwell-being)



### State of Caring Survey

Carers UK carried out the online survey between March and May 2019. A total of 8,096 carers and former carers responded to this survey – only responses from the 7,525 people who are currently providing care are included in this report.

Compared to the carer population as a whole, respondents to this survey were more likely to be female and caring for a high number of hours every week.

Of respondents to the survey:

- **72%** live in England, **10%** live in Scotland, **10%** live in Northern Ireland, and **8%** live in Wales
- **81%** identify as female and **18%** identify as male.
- **24%** consider themselves to have a disability.
- **1%** are aged 0–24, **4%** are aged 25–34, **12%** are aged 35–44, **30%** are aged 45–54, **32%** are aged 55–64, **14%** are aged 65–74 and **6%** are aged 75 and over.
- **3%** identified as lesbian, gay or bisexual.
- **19%** also have childcare responsibilities for a non-disabled child under 18.
- **39%** are in paid work (**48%** full-time and **52%** part-time).
- **31%** have been caring 15 years or more, **15%** for between 10–14 years, **24%** for 5–9 years, **26%** for 1–4 years and just **4%** have been caring for less than one year.
- **45%** care for 90 or more hours every week, while **17%** care for 50–89 hours, **24%** for 20–49 hours and **14%** care for 1–19 hours a week.
- Most (**74%**) care for one person, **19%** care for two people, **5%** for three people and **2%** care for four or more people.

As not all respondents completed every questions in the survey, a number of the figures given in this report, including those presented in this Appendix, are based upon responses from fewer than 7,525 carers. This, together with the sample sizes of different groups, should be taken into consideration when reading the results.

Carers Week is made possible by Carers UK joining forces with Age UK, Carers Trust, Motor Neurone Disease (MND) Association, Multiple Sclerosis (MS) Society, Rethink Mental Illness and Sense.

Headline supporter



Also supported by



These organisations have joined together to make Carers Week happen in 2019



Find out more and get involved at [carersweek.org](http://carersweek.org)



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