

# Facts about carers

These statistics are compiled from a number of different sources. All Carers UK reports can be found in our policy library - <https://www.carersuk.org/for-professionals/policy/policy-library>

## Who are carers?

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Carers provide unpaid care by looking after an ill, older or disabled family member, friend or partner. It could be a few hours a week or round the clock, in their own home or down the motorway.

## How many people are carers?

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- **The 2011 Census found that 6.5 million people in the UK are carers**

*Number of carers in England, Wales, Scotland and Northern Ireland, Census 2001 and 2011*

	Number of carers 2001	Number of carers 2011
England	4,877,060	5,430,016
Northern Ireland	185,086	213,980
Scotland	481,579	492,031 <sup>1</sup>
Wales	340,745	370,230
<b>UK Total</b>	<b>5,884,470</b>	<b>6,506,257</b>

<sup>1</sup> Alternative estimates from the Scottish Household Survey indicate the number of carers in Scotland may be higher, at 759,000 (17% of the population).

The 2011 Census is the biggest dataset concerning carers which exists which allows for the most comprehensive breakdown of local areas. These figures for the UK show an 11% rise in the number of carers since the last Census in 2001 - increasing by over 620,000 to 6.5 million in just 10 years.

## **Larger estimates of number of carers**

More recent research using different datasets or polling suggest that the number of carers is much larger than the Census or projections based on the Census have suggested.

- In 2019, using population projections from the ONS and polling by Carers UK, it can be estimated that 8.8 million adults in the UK are carers<sup>2</sup>.
- Research published by the Social Market Foundation in 2018 using the Understanding Society dataset estimated that there are 7.6 million family carers over the age of 16 in the UK<sup>3</sup>.
- The 2019 GP Patient survey found that 17% of the population in England over the age of 16 are carers<sup>4</sup>.

Carers UK continues to use the Census figures as they are the biggest dataset concerning carers in the UK alongside more recent estimates.

## **The carer population is not static**

Each year millions of people take on caring responsibilities whilst caring comes to an end for millions of carers as the person they care for recovers, increases independence, moves into residential care or passes away. Between 2007 and 2032, the number of people aged 65 and over who require unpaid care is projected to have grown by more than one million.<sup>5</sup>

- **Every year over 2.1 million adults become carers and almost as many people find that their caring responsibilities come to an end.**<sup>6</sup>

This 'turnover' means that caring will touch the lives of most of the population, as we all need or provide care or support family members caring for loved ones at some point in our lives.

- **3 in 5 people will be carers at some point in their lives.**<sup>7</sup>

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<sup>2</sup> Carers UK (2019) Juggling work and care

<sup>3</sup> Social Market Foundation (2018) Caring for Carers

<sup>4</sup> NHS England (2019) GP Patient Survey

<sup>5</sup> Government office for science (2016) Future of an ageing population

<sup>6</sup> Analysis conducted for Carers UK by Michael Hirst (2014) Transitions into and out of unpaid care

<sup>7</sup> Carers UK (2001) It Could Be You – A report on the chances of becoming a carer

## Number of hours of care provided

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- **1.4 million people provide over 50 hours of unpaid care per week.**<sup>8</sup>

According to the 2011 Census almost 4 million of the UK's carers care for 1-19 hours each week whilst 775,000 provide 20-49 hours and 1.4 million provide 50 hours or more unpaid care.<sup>9</sup>

There is also strong evidence of a trend towards individual carers providing more hours of care per week. The numbers caring round the clock (i.e. for 50 or more hours or more each week) are rising faster than the general carer population - an increase of 25% in the last ten years compared to an 11% rise in the total number of carers.

Analysis of the Understanding Society data also suggests relatives providing more intensive support - showing increase in the hours of care provided, between 2011/13 and 2015/17. There was a 2-percentage point increase in the proportion of adults who help parents with activities of daily living (ADLs)<sup>10</sup>.

According to the Personal Social Services Survey of Adult Carers in England 2016-17<sup>11</sup>, over a third of carers (36%) are caring for over 100 hours a week. 13% of carers care for 19 hours or less a week; 15% care for between 20 and 49 hours a week and almost 15% care for between 50 and 100 hours a week.

However the impact of caring is not just dictated by the number of hours of care provided. If a carer is working full-time, combining caring with looking after young children, or having to travel long distances to provide care, then even having to provide a few hours of care a week can have a serious impact on their life.

## Valuing carers

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The vast majority of care in the UK is provided by family and friends, who make up the UK's carer population. Social services and the NHS rely on carers' willingness and ability to provide care and without it they would collapse.

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<sup>8</sup> Census 2011

<sup>9</sup> 2011 Census Analysis: Unpaid care in England and Wales, 2011 and comparison with 2001  
<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/articles/2011censusanalysisunpaidcareinenglandandwales2011andcomparisonwith2001/2013-02-15>

<sup>10</sup> Social Market Foundation (2018) Caring for Carers

<sup>11</sup> Personal Social Services Survey of Adult Carers in England 2016-17  
[https://files.digital.nhs.uk/publication/a/o/sace\\_report\\_2016-17.pdf](https://files.digital.nhs.uk/publication/a/o/sace_report_2016-17.pdf)

- **The care provided unpaid by the nations' carers is worth an estimated £132bn per year – considerably more than total spending on the NHS in England.<sup>12</sup>**

## **Carer demographics**

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### **Age**

- **One in five people aged 50-64 are carers.**

The majority of carers are of below state pension age and the peak age for caring is 50-64 - over 2 million people in this age bracket are carers.<sup>13</sup>

- **Almost 1.3 million people in England and Wales aged 65 or older are carers.**

The number of carers over the age of 65 is increasing more rapidly than the general carer population. Recent polling suggests that there could now be over 2 million people aged 65 or older who are carers.<sup>14</sup>

Older carers, those aged 85 and over, are most likely to be a carer for someone with dementia (53.6 per cent). For over 50 per cent of this age group they are also supporting care needs related to physical disabilities, therefore is likely that the cared for person has multiple needs. 90.1 per cent of older carers, those aged 85 and over have caring responsibility for someone aged 75 or over<sup>15</sup>.

The 2011 Census indicated that almost 178,000 under 18s have caring responsibilities. The vast majority are providing under 20 hours of care a week, however thousands provide even higher levels of care. This is a wide spectrum which means caring will affect these young people in different ways. For example, there is a big difference between a child helping parents to bathe a disabled brother or sister and being the sole support for a lone parent with a severe mental health condition. Broader definitions put the figure of young carers higher, as close to three million children live in households with a disabled family member but not all of these will have caring responsibilities.<sup>16</sup>

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<sup>12</sup> Carers UK and the University of Sheffield (2015) Valuing Carers 2015: the rising cost of carers' support – this figure is based on the projection of 6.8 million carers based on ONS projections

<sup>13</sup> Census 2011

<sup>14</sup> Carers week (2019) Getting carers connected

<sup>15</sup> Personal Social Services Survey of Adult Carers in England (SACE) 2016-17 Published 03 August 2017

<sup>16</sup> Becker, Dearden, and Aldridge (2001) 'Children's labour of love? Young carers and care work' in 'Hidden Hands: International perspectives on children's work and labour'

## Gender

- **58% of carers are female and 42% are male.**<sup>17</sup>

The Census shows that women are more likely to be carers than men. The percentage of carers who are female rises to 60% for those who are caring for 50 hours or more a week.<sup>18</sup> Women make up 72% of the people receiving Carer's Allowance for caring 35 hours or more a week.<sup>19</sup>

Caring also tends to affect men and women at different times. Women are much more likely to care in middle age.

- **1 in 4 women aged 50-64 have caring responsibilities, compared to 1 in 6 men.**<sup>20</sup>

Women have a 50:50 chance of providing care by the time they are 59; compared with men who have the same chance by the time they are 75 years old. Women are more likely to be sandwich carers (combining eldercare and childcare) are also more likely to give up work in order to care.<sup>21</sup>

- **59% of carers over 85 are men and 41% are female**

The imbalance reduces amongst older carers; the gender split is 50:50 of carers aged between 75 and 84. Carers over 85 are more likely to be male (59%) than female (41%)<sup>22</sup> – many caring for their partners.

## Black, Asian and Minority Ethnic (BAME) carers

- **The 2011 Census showed that there were just under 600,000 BAME carers in England and Wales.**

2011 data indicates that a smaller proportion of the BAME population provides care than the White British population. However the BAME population is much younger and therefore less likely to have older parents or other relatives needing care. Analysis by University of Leeds has, in the past, suggested that, when age is accounted for, BAME families are more likely to provide care for older or disabled loved ones.<sup>23</sup> The NHS Information Centre Survey of Carers in Households found that BAME carers are more likely than White carers to provide support for at least 20 hours a week (56% compared to 47%).<sup>24</sup>

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<sup>17</sup> Census 2011

<sup>18</sup> NHS Information Centre for Health and Social Care (2010) Survey of Carers in Households 2009/10

<sup>19</sup> Carers UK (2015) The importance of Carer's Allowance: Recognising and supporting family care

<sup>20</sup> Census 2011

<sup>21</sup> Carers UK (2000) It Could Be You and Carers UK (2014) Caring & Family Finances Inquiry UK Report

<sup>22</sup> Census 2011

<sup>23</sup> Carers UK (2001) Who cares wins, statistical analysis of the Census

<sup>24</sup> NHS Information Centre for Health and Social Care (2010) Survey of Carers in Households 2009/10

Carers UK's evidence indicates that BAME carers are less likely to be receiving practical and financial support with caring and more likely to miss out on accessing support for longer – often as a result of a lack of advice and information and struggling to access culturally appropriate services.<sup>25</sup>

## **LGBT carers**

Whilst there are no clear statistics on LGBT carers, the ONS calculates this figure at 1.5% of the population (with 1.5% of men saying they are gay and 0.7% of women saying they are lesbian; 0.3% of men identifying as bisexual compared to 0.5% of women). However, this figure is believed to be much higher, owing to a lingering taboo around reporting of sexual orientation: the charity Stonewall estimates that 5-7% of the population is gay, lesbian, bisexual and transsexual. Based on the estimates from Stonewall that 3.7 million people in the UK are LGBT, Carers UK estimates there are 390,000 LGBT carers in Britain. According to a 2015 Stonewall report, one in twenty (5%) staff in the social care profession have witnessed other colleagues discriminate against or provide a patient or service user with poorer treatment because they are lesbian, gay or bisexual in the last five years.<sup>26</sup>

## **Disabled carers**

Many carers report that caring results in a negative and often lasting impact on their physical and mental health, but as with the rest of the population, many people with existing disabilities or long-term conditions also take on caring responsibilities.

The 2019 GP Patient Survey found that carers are more likely to report having a long term condition, disability or illness than non-carers – 63% of carers compared to 51% of non-carers<sup>27</sup>

According to the NHS Information Centre Survey of Carers in Households, 27% of carers were in receipt of Disability Living Allowance as a result of their own disability or ill health.<sup>28</sup>

Contributions from disabled carers to Carers UK's Caring & Family Finances Inquiry indicated that carers with disabilities are significantly more likely to give up work to care (61% of working age disabled carers compared to 52% of non-disabled working age carers) and were much less likely to be in paid work alongside caring (only 18% were in paid work alongside caring, compared to 33% of carers who were not disabled). Because many working age disabled carers were caring for partners they were also substantially more likely to be on lower incomes or have no-one in their household in paid work - three quarters (74%) of carers receiving Disability Living Allowance were in this situation, compared to 55% of all working age carers.

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<sup>25</sup> Echoing the findings of Carers UK (2001) Who cares wins, statistical analysis of the Census

<sup>26</sup> Stonewall (2015) Unhealthy Attitudes: The treatment of LGBT people within health and social care services

<sup>27</sup> NHS England (2019) GP Patient Survey 2019

<sup>28</sup> NHS Information Centre for Health and Social Care (2010) Survey of Carers in Households 2009/10

Carers who have an illness or disability themselves were also significantly more likely to be in debt and much higher levels of debt than other carers – with these carers reporting this resulted from a combination of their own additional disability-related costs and reduced earnings. Of respondents to Carers UK's State of Caring 2016 survey, 57% of those who considered themselves to have a disability said their financial circumstances were affecting their health.<sup>29</sup>

## What kind of care do carers provide?

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The amount and type of care that carers provide varies considerably. A carer might provide a few hours of care a week - shopping, collecting medication and taking someone to medical appointments - or they may care around the clock. According to the NHS Information Centre Survey of Carers in Households<sup>30</sup>:

- 82% provide practical help such as preparing meals, doing laundry or shopping.
- 76% keep an eye on the person they care for
- 68% keep them company
- 62% take the person they care for out
- 49% help the person they care for with financial matters
- 47% help the person they care for deal with care services and benefits
- 38% help with aspects of personal care
- 38% provide physical help

The type of care provided varies with the number of hours a carer provides and whether they are caring at a distance or not.

- For example 57% of those caring for 20 or more hours a week helped with person care, only 21% of those caring for less time did the same
- 54% of carers who cared or 20 hours or more per week provided physical help; in comparison 23% of carers who cared for less than 20 hours provided this type of help
- 54% of carers who provide more than 20 hours a week help their cared for person by giving medicines but only 17% of those providing fewer hours of care did.
- Those caring for someone in their household, rather than at a distance, were more likely to perform more personal tasks such as personal care (54% compared with 22%), physical help (49% compared with 25%) and giving medicines (50% compared with 18%)

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<sup>29</sup> Carers UK (2016) State of Caring 2016

<sup>30</sup> NHS Information Centre for Health and Social Care (2010) Survey of Carers in Households 2009/10

## Who do they care for?

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According to the NHS Information Centre Survey for Carers in Households<sup>31</sup>:

- Most carers (40%) care for their parents or parents-in-law
- Over a quarter (26%) care for their spouse or partner.
- People caring for disabled children under 18 account for 8% of carers and 5% of carers are looking after adult children.
- A further 4% care for their grandparents and 7% care for another relative.
- Whilst the majority care for relatives, one in ten carers (9%) care for a friend or neighbour.

Most carers care for just one person (83%), but 14% care for two people and 3% are caring for at least three people.<sup>32</sup>

- 58% of carers look after someone with a physical disability
- 20% look after someone with a sensory impairment
- 13% care for someone with a mental health problem
- 10% care for someone with dementia.

Around half of carers are caring for someone in the same household and half care for someone living elsewhere.<sup>33</sup> This changes across different age groups, whilst younger carers are evenly split, carers aged 45-64 are much more likely to be caring for someone living in another household (typically an older parent) and older carers are much more likely to be living with the person they care for as many care for their partners.

### Caring at a Distance

Carers UK's State of Caring Survey 2018 showed that of carers not living with the person they cared for just over a third (36%) lived within walking distance and 45% lived within a 30 minute journey of the person they cared for, but over a quarter lived over half an hour away, including 6% travelling over 2 hours to care.<sup>34</sup> These 'distance carers' are more likely to be providing lower levels of care, but to be combining caring with work and often childcare for young families. The NHS Information Centre Survey for Carers in Households found that 76% of carers providing less than 20 hours of care a week were doing so in another household.<sup>35</sup>

### 'Sandwich' Caring

The number of 'sandwich carers' (people who care for an older or disabled loved one at the same time as they have young children) is growing as the average age for having children rises and care needs amongst older relatives continues to grow.

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<sup>31</sup> NHS Information Centre for Health and Social Care (2010) Survey of Carers in Households 2009/10

<sup>32</sup> NHS Information Centre for Health and Social Care (2010) Survey of Carers in Households 2009/10

<sup>33</sup> NHS Information Centre for Health and Social Care (2010) Survey of Carers in Households 2009/10

<sup>34</sup> Carers UK (2018) State of Caring 2018

<sup>35</sup> NHS Information Centre for Health and Social Care (2010) Survey of Carers in Households 2009/10

ONS analysis using the Understanding Society dataset suggests that 3% of the UK general population, equivalent to more than 1.3 million people, now have this twin responsibility. It suggests sandwich carers are more likely to report symptoms of mental ill-health, feel less satisfied with life, and struggle financially compared with the general population. Almost 27% of sandwich carers show symptoms of mental ill-health while caring for both sick, disabled or older relatives and children<sup>36</sup>.

The peak age for these two family responsibilities to coincide is 40-44 for women, and 45-49 for men. It is women who are more likely to face the pressure of simultaneously shouldering responsibility for young and old. At the age when many women are at the peak of their careers, often raising families of their own, their ageing parents are also starting to need support.<sup>37</sup>

## The impact of caring

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### Financial

Families often face additional costs associated with caring, like care services and assistive equipment; alongside higher living costs as ill health or disability push up household bills like heating and laundry bills and result in additional transport costs and hospital parking charges.

Different carers can face different costs. Carers UK's research indicates that working-age carers of partners and disabled children are most likely to report higher utility bills – reflecting the likelihood of living with the person they cared for. Caring at a distance, often for older parents living in a different part of the country, can result in very high transport costs.

- **Half of working age carers live in a household where no-one is in paid work.**<sup>38</sup>

Just as their living costs rise, families also often face a lower income as caring and ill-health or disability reduce their ability to work.

- **1.2 million carers are in poverty in the UK**<sup>39</sup>

22% of carers live in poverty, this compares to a national figure of 16% living in relative poverty in 2014/15. Poverty levels are highest in the working age carer population and increases with

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<sup>36</sup>ONS (2019) More than one in four sandwich carers report symptoms of mental ill-health [www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/articles/morethanoneinfoursandwichcarersreportsymptomsofmentallillhealth/2019-01-14](http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/articles/morethanoneinfoursandwichcarersreportsymptomsofmentallillhealth/2019-01-14)

<sup>37</sup> Evandrou, M, Glaser, K, *Family, work and quality of life: changing economic and social roles through the lifecourse*, Ageing & Society 24, 2014

<sup>38</sup> Carers UK (2014) *Caring & Family Finances Inquiry UK Report*

<sup>39</sup> New Policy Institute (2016) 'Informal carers & poverty in the UK: An analysis of the Family Resources Survey' [http://www.npi.org.uk/files/2114/6411/1359/Carers\\_and\\_poverty\\_in\\_the\\_UK\\_-\\_full\\_report.pdf](http://www.npi.org.uk/files/2114/6411/1359/Carers_and_poverty_in_the_UK_-_full_report.pdf)

the number of hours of care they provide, with a 37% poverty rate among carers who provide at least 20 hours of care per week.<sup>40</sup>

- **In a 2014 survey of carers providing substantial care, almost 1 in 3 (30%) carers had seen a drop of £20,000 or more a year in their household income as a result of caring.**<sup>41</sup>

Carers can claim Carer's Allowance to help with the costs of caring; however, because of the low level of the payment and other entitlement conditions, including an earnings limit, the benefit is ineffective in preventing financial hardship.

From April 2019 Carer's Allowance is set at £66.15 with an earnings threshold set at £123 per week after deductions<sup>42</sup>. Whilst the Allowance rises with the Consumer Price Index (CPI), a measure of inflation, neither the Allowance nor the earnings threshold align with the national living wage, meaning that a carer can only work for a maximum of 15 hours per week without losing the Allowance.

According to Carers UK's State of Caring Survey 2019:

- **39% of carers described their financial situation as 'struggling to make ends meet'**<sup>43</sup>

The combination of higher costs and lower incomes can push families into financial crisis and lasting debt – 21% of UK carers are in or have been in debt as a result of caring and only 46% of UK carers can afford their bills without struggling financially.

Carers UK research from 2018 found that the financial impacts of caring can increase over time. The number of carers in debt because of caring increases from nearly one in ten (12%) of people caring for a year or less to one in five (19%) of those caring between five and nine years. A quarter (25%) of people who have been caring for over 15 years report that they have been in debt as a result of their caring role.<sup>44</sup>

- **43% of carers said their financial circumstances were affecting their health.**<sup>45</sup>

The financial impact of caring is often exacerbated by delays in accessing benefits and other financial support. Caring can come as a shock and families, unprepared for the impact on their work and household bills, often report trying to cope with the costs of caring for months or years before they find help. Caring responsibilities which grow over time can also mean that individuals do not immediately recognise they have become a 'carer' or that support may be available. Too often health and social care services fail to identify carers and guide them to support.

- **40% of carers have missed out on financial support as a result of not getting the right information and advice.**<sup>46</sup>

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<sup>40</sup> ibid

<sup>41</sup> Carers UK (2014) Caring & Family Finances Inquiry UK Report

<sup>42</sup> Carers in Scotland are also entitled to a Carers Premium

<sup>43</sup> Carers UK (2019) State of Caring 2019

<sup>44</sup> Carers UK (2018) Caring for your future - The long-term financial impact of caring

<sup>45</sup> Carers UK (2016) State of Caring 2016

## Health

- **Carers providing round the clock care are more than twice as likely to be in bad health than non-carers.<sup>47</sup>**

The pressures of caring can take a toll on carers' physical and mental health. The 2011 Census shows that, in England and Wales alone, almost 390,000 carers report being in bad health.<sup>48</sup>

Carers Week research from 2018 found that 6 out of 10 people (61%) said their physical health has worsened as a result of caring, while 7 out of 10 (72%) said they have experienced mental ill health.<sup>49</sup>

This impact is often exacerbated by carers being unable to find time for medical check-ups or treatment, with two in five carers saying that they were forced to put off treatment because of their caring responsibilities – unable to trust or find suitable and affordable replacement care.<sup>50</sup>

This information was echoed by the 2019 GP Patient Survey<sup>51</sup> which found that carers were more likely to report having health problems compared with the general public, as was also found in the 2018 survey. Carers are more likely to report having a long term condition, disability or illness – 63% of carers compared to 51% of non-carers. In addition 63% of carers reported that their condition led to trouble with day to day activity compared to 58% of non-carers. This difference was even higher for carers who care for more than 50 hours a week, 71% of whom reported having a long term condition, disability or illness

Research by Carers Scotland in 2011 found that almost half of carers with health problems reported that their conditions began after they started caring. Of those whose condition predated their caring role, a quarter said their condition had worsened since becoming a carer.<sup>52</sup> Carers attribute this health risk to a lack of support, with 64% citing a lack of practical support and 50% a lack of financial support, as major reasons for their poor health.<sup>53</sup>

Although most of the carers who were caring for at least 50 hours a week in a Carers UK survey had a GP who knew of their caring responsibilities (84%), of these carers, most (71%) said that their GP didn't do anything differently to accommodate them. Very few had a GP who gave regular carers health checks or did home or telephone appointments.<sup>54</sup>

A Carers Week survey from 2016 found that over half (55%) of carers had not been informed about how to access practical support by their GP and that almost half (45%) of carers' GP

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<sup>46</sup> Carers UK (2016) Missing out: The identification challenge

<sup>47</sup> Census 2011

<sup>48</sup> Census 2011

<sup>49</sup> Carers Week (2018) Supporting Carers to be Healthy and Connected

<sup>50</sup> Carers Week (2012) In Sickness and In Health, published by Carers UK

<sup>51</sup> Carers UK analysis of 2019 GP patient survey data - <https://www.carersuk.org/professionals/policy/expert-comment/6173-what-does-the-gp-patient-survey-tell-us-about-carers>

<sup>52</sup> Carers Scotland (2011) Sick, Tired and Caring

<sup>53</sup> Carers Week (2012) In Sickness and In Health, published by Carers UK

<sup>54</sup> Carers UK (2011) State of Caring 2011

practices did not offer an annual health check.<sup>55</sup> Where GP didn't support carers through signposting or health checks, over half of carers reported that they left a health problem go untreated (54%) and that their mental health got worse (53%).<sup>56</sup>

## **Loneliness, social exclusion and personal relationships**

- **61% of carers said that they were worried about the impact of caring on their relationships with friends and family.**<sup>57</sup>

Carers often report becoming isolated as a result of their caring responsibilities. Carers often attribute this about a lack of understanding about their caring role as well as leaving paid work and being unable to take time off from caring resulting in losing touch with friends, colleagues and family members.

- **8 out of 10 carers (81%) have felt lonely or socially isolated as a result of their caring role. This rises to nearly 86% of carers providing 50 hours or more a week**<sup>58</sup>

When asked what makes them feel lonely or socially isolated<sup>59</sup>, a third (32%) of carers said they had felt lonely or isolated because of not being comfortable talking about caring with their friends. 48% said not having time to spend on social activities has made them feel lonely or isolated and 31% said not being able to afford to participate in social activities made them feel lonely or socially isolated. Half (49%) said the difficulty of not being able to get out of the house much has made them feel lonely or socially isolated.

- **Carers Week 2019 research found that carers are 7 times more likely to say they are always or often lonely compared with the general population.**<sup>60</sup>

In 2013 our State of Caring survey of carers who were more likely to be caring for over 50 hours a week highlighted how many carers care alone, without support – with 37% saying they cared without any support from services or from friends and family, and a further 29% who cared with support from friends and family but none from services.

In 2017, State of Caring survey results showed that 4 in 10 carers said they had not had a full day off from caring in over a year and 25% had not had a full day off in the last five years.<sup>61</sup>

In addition to direct discrimination as a result of the condition of the person needing care, the Equality Act 2010 also recognises that carers can face indirect discrimination as a result of their association with disability. One in eight carers responding to a survey in 2011 felt they and/or the person they cared for had been denied services as a result of their disability or their caring responsibilities, 17% felt they were treated negatively because they received benefits and a shocking 14% had been victims of crime like damage to property or verbal abuse.<sup>62</sup>

<sup>55</sup> Carers Week (2016) Building Carer Friendly Communities

<sup>56</sup> Carers Week (2016) Building Carer Friendly Communities

<sup>57</sup> Carers UK (2015) State of Caring 2015

<sup>58</sup> Carers UK (2017) The world shrinks: Carer loneliness

<sup>59</sup> Carers UK (2017) The world shrinks: Carer loneliness

<sup>60</sup> Carers Week (2019) Getting carers connected

<sup>61</sup> Carers UK (2017) State of Caring Survey 2017

<sup>62</sup> Carers UK (2011) State of Caring Survey 2011

- In 2017, the majority of carers felt that their contribution is not understood or valued by the public and society more broadly<sup>63</sup>

## Work and caring

- 3 million people combine caring for a loved one with paid work.<sup>64</sup>
- According to the UK Census around one in nine workers in the UK has caring responsibilities<sup>65</sup> but polling from 2019 suggests that this may be close to one in seven<sup>66</sup>

The 2011 Census found that around half of the UK's carers combine work with unpaid caring responsibilities. Over two million carers work full-time and one million part-time. Whilst part-time working is much more common amongst carers than non-carers, carers are also more likely to stop working altogether as they struggle to switch to part-time hours.<sup>67</sup> Recent polling suggests that not only has the carer population increased but the proportion of working carers has also increased with 5 million people now combining paid work and caring.

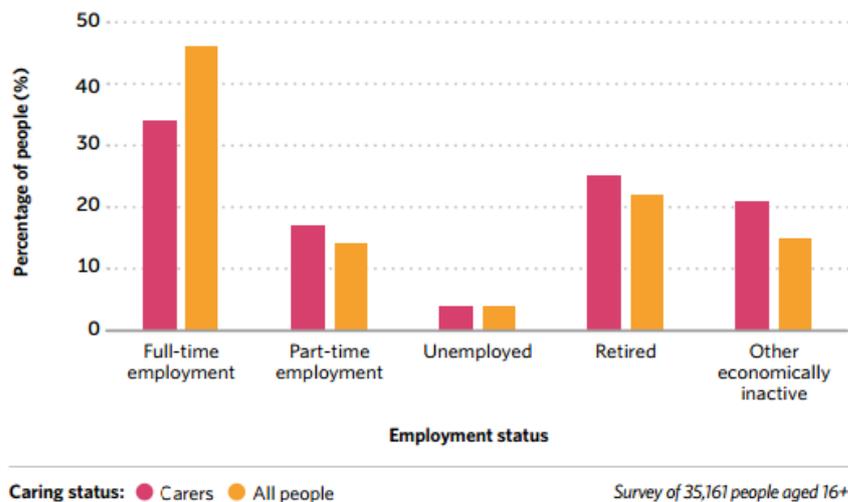


Figure 2.5: Employment status for adult carers and all adults in the UK, 2013/14<sup>44</sup>.

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The graph, from the Government 'Future of an Ageing Population' report shows that carers are less likely to work full-time and more likely to work part-time, be retired or otherwise economically inactive.

<sup>63</sup> Carers Week (2017) Building a carer friendly society

<sup>64</sup> Census 2011

<sup>65</sup> Census 2011

<sup>66</sup> Carers UK (2019) Juggling work and care

<sup>67</sup> OECD (2011) Help Wanted? Providing and Paying for Long-Term Care

<sup>68</sup> Figure 2.5 from Government Office for Science (2016) Future of an ageing population

Carers managing to juggle work and care describe having to forgo promotion or miss job opportunities because they cannot increase working hours or move to take up a new position. Almost one in four (23%) say they have changed their working pattern to care and a further third were anxious that caring would impact on their capacity to work in the future.<sup>69</sup>

- **Over 2.6 million people have given up work at some point to care for loved ones, 2 million have reduced working hours.**<sup>70</sup>

The peak age of caring also often coincides with the peak of an individual's career in their 40s-60s. National opinion polling for Carers UK's Caring & Family Finances Inquiry from 2014 showed that 70% of carers were over £10,000 worse off as a result of reduced earnings.<sup>71</sup> Carers report very significant drops in income as a result of reduced working hours – 1 in 3 (30%) had seen a drop of £20,000 a year in their household income as a result of taking on caring responsibilities.<sup>72</sup>

Research by the New Policy Institute found that the kinds of occupations that are undertaken by carers are more likely to be low-skilled and administrative and service orientated. This research also found that whilst the amount of care that people provide will constrain the amount of time they have available for work and vice versa, there are still a significant number of people that are doing a full working week alongside a full caring week. 21% of people providing 35 hours of care or more per week were in full-time work over the three years to 2013/14.<sup>73</sup>

Caring can have a long-term impact on ability to work, as a loss of skills, knowledge, experience and confidence make returning to work when caring ends extremely challenging. Evidence from Carers UK's Caring & Family Finances Inquiry indicated that former carers, who are of working age, remain significantly less likely to be in work than non-carers of working age.<sup>74</sup> The loss of earnings, savings and pension contributions can mean carers face long-term financial hardship into retirement.

### **Support for working carers**

- **Half of carers cited problems with accessing suitable care services as a reason they gave up work or reduced working hours.**<sup>75</sup>

When asked why they have reduced working hours, given up work or find combining the two so stressful, carers are most likely to talk about the practical support from care services they receive. Services which are inflexible and cannot fit with working hours or are unreliable can make work impossible, but carers also describe being unable to find suitable care services to meet the needs of the person needing care, or find they are simply too expensive. This echoes a major research study of working carers in 2007, which found that only a quarter of them felt they had adequate support from formal services to enable them to combine work and care. Furthermore between 40 and 50 per cent of working carers said that a lack of flexibility and

<sup>69</sup> Employers for Carers (2011) Caring at a Distance: Bridging the Gap

<sup>70</sup> Carers UK (2019) Juggling work and care

<sup>71</sup> Carers UK (2014) Caring & Family Finances Inquiry UK Report

<sup>72</sup> Carers UK (2014) Caring & Family Finances Inquiry UK Report

<sup>73</sup> New Policy Institute (2016) Informal carers & poverty in the UK

<sup>74</sup> Carers UK (2014) Caring & Family Finances Inquiry UK Report

<sup>75</sup> Carers UK (2014) Caring & Family Finances Inquiry UK Report

sensitivity in the delivery of services is hampering them. The majority of working carers say they need at least one type of formal service which they are not currently receiving.<sup>76</sup>

Of respondents to Carers UK's State of Caring 2017 survey, 43% said they had given up work. Over two thirds (69%) of the carers who had given up work to care highlighted the stress of juggling work and care and almost third (31%) the lack of suitable care services.<sup>77</sup> 14% have had to take a less qualified job or have turned down promotions to fit around their caring responsibilities and 21% have reduced their working hours to care.<sup>78</sup> Working carers often struggle to get time off to co-ordinated care services or attend medical appointments and in 2016, 70% of survey respondents had used their annual leave to care.<sup>79</sup>

When asked in polling about what workplace support they think is most important for carer, a supportive line manager / understanding employer came out top (89% rated this as either very important or fairly important), with the ability to work flexibly second (88%) and a right to additional paid time off work to care between five and ten days as the third most important supportive measure (80%).<sup>80</sup>

### **Impact on the wider economy**

The impact of caring responsibilities on families' ability to work is a growing economic challenge for employers and the UK economy as well as families.

Research conducted by the Personal Social Services Research Unit at the LSE estimated the public expenditure costs of carers leaving employment in England equivalent to £2.9bn per year. This estimate comprises £1.7bn in social security benefits paid to those that have left jobs due to their caring duties, in addition to another £1.2bn in foregone taxes due to the group's lost earnings.

- **Estimates from Age UK showed a cost of £5.3 billion a year to the economy in lost earnings and tax revenue and additional benefit payments.**<sup>81</sup>

Findings of research by Carers UK's Employers for Carers business forum into the impact of caring on their workforces, particularly sandwich caring and distance caring<sup>82</sup> have highlighted how the loss of key and experienced employees results in expensive recruitment and retraining costs as well as a loss of expertise and knowledge.<sup>83</sup> 9 in 10 employers surveyed about the impact of dementia caring on their staff said these caring responsibilities were affecting their workforce – putting pressure on employees, causing physical and mental health problems and leading to declined productivity, as well as the loss of valuable staff members.

Polling from 2019 indicated that there are lower numbers of people juggling work and care in the private sector (13%) compared to the public sector (19%). Workers in the private sector had

<sup>76</sup> Carers UK (2007) Carers, services and employment report series

<sup>77</sup> Employers for Carers and Carers UK (2015) Caring and isolation in the workplace

<sup>78</sup> Carers UK (2017) State of Caring 2017

<sup>79</sup> Carers UK (2016) State of Caring 2016

<sup>80</sup> Carers UK (2019) Juggling work and care

<sup>81</sup> Age UK (2012) Care crisis wipes over £5.3 billion from the economy <https://www.ageuk.org.uk/latest-press/archive/care-in-crisis-more-than-53-billion-wiped-from-the-economy/>

<sup>82</sup> Employers for Carers and Carers UK (2012) Sandwich caring (2013) Distance Caring

<sup>83</sup> Employers for Carers (2011) Caring at a Distance: Bridging the Gap

less access to supportive policies listed for carers (28%) compared with the public (20%) and third sectors (22%).<sup>84</sup>

## Public awareness of carers

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Carers UK research shows that despite the high numbers of carers in society, half (51%) of the UK public do not think they have a friend or family member providing unpaid care.<sup>85</sup>

- **Only 4 in 10 (39%) of the UK public say they have at least one friend or family member who is a carer.**<sup>86</sup>

Women are more likely to say they know a friend or family member who is a carer (44%) compared with men (33%). Unsurprisingly those who have never had an unpaid caring role are more likely (59%) to say that they do not know any friends and family who are carers. Only 17% of current carers say they do not have any friends or family that are caring.<sup>87</sup>

Of those who know a friend or family member who is a carer, 3 in 5 (58%) have not suggested to them where they could find information on caring. Amongst all of those polled, including those that had not recognised carers in their social circles or at work, two thirds (67%) said they would feel confident providing 'emotional support' to a new carer. Only 2 in 5 (42%) of the UK public would feel confident pointing people in the direction of information about caring.<sup>88</sup>

Research from Carers Week 2017 shows that the public underestimate how likely they are to take on the role of a carer in the future.

- **Half of respondents with no experience of caring (50%) think it's unlikely they would ever become a carer.**<sup>89</sup>

When asked what would worry them most about taking on becoming a carer for a family member or close friend who is frail or facing long-term illness or disability, the public's top worries were being able to cope financially e.g. afford the care services or equipment and home adaptations required (46%) and coping with the stress of caring (43%).<sup>90</sup>

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<sup>84</sup> Carers UK (2019) Juggling work and care

<sup>85</sup> Carers UK (2017) Make connections, get support

<sup>86</sup> Carers UK (2017) Make connections, get support

<sup>87</sup> Carers UK (2017) Make connections, get support

<sup>88</sup> Carers UK (2017) Make connections, get support

<sup>89</sup> Carers Week (2017) Building a carer friendly society

<sup>90</sup> Carers Week (2017) Building a carer friendly society

## **Contact**

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**Carers UK** is a charity led by carers, for carers - our mission is to make life better for carers.

**We give expert advice**, information and support

- **We connect carers** so no-one has to care alone
- **We campaign together** for lasting change
- **We innovate** to find new ways to reach and support carers

For further information visit:

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