

CANCER CARERS IN THE UK

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Determining the number of carers of people with cancer in the UK and understanding their support needs and the impact caring has on their lives

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Background

In 2011, Macmillan commissioned research to estimate the number of carers of people with cancer in the UK.¹ This found that about 1.1 million people aged 15 and over are carers looking after a family member or a friend with cancer. Cancer carers support people with cancer in a number of ways, including helping with emotional, practical and financial needs.

The number of people living with cancer in the UK is set to rise to 4 million by 2030.² Recent reforms to health and social care may also impact cancer carers. In order to inform the development of services and resources for cancer carers, Macmillan commissioned the research agency YouGov to determine an updated incidence of carers of people with cancer in the UK, and to explore the impact that being a cancer carer has on their lives.

Methodology

In phase 1 of the study, 6,487 people aged 16 and over in the UK were interviewed via the research agency TNS's face-to-face omnibus survey. Fieldwork was undertaken between 26 February and 22 March 2016. Participants were asked four screener questions to identify the number of cancer carers in the population and their socio-demographic profile. Results were weighted and are representative of the UK adult population according to age, gender, UK region and socio-economic group.

Phase 2 of the study was conducted online via YouGov's panel. Respondents were asked four screener questions to identify them as cancer carers, and those who were identified took part in an online survey exploring their experiences. Fieldwork took place between 4 and 18 April 2016. A total of 892 cancer carers were interviewed and results were weighted by age, gender, social grade and region to reflect the overall population of carers identified in phase 1.

Results

How many cancer carers are there in the UK in 2016?

Figure 1: Estimated number of cancer carers in 2016, by UK country



A total of 68% of cancer carers are women, and are concentrated in the middle-age years of 45–64 (47% compared with 30% of the overall population).

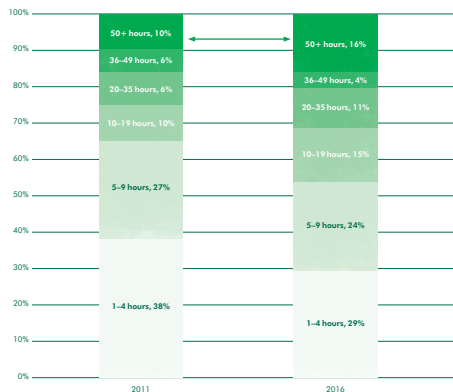
We define a cancer carer as someone who either provides more than five hours of care per week to someone living with cancer, or who provides one to four hours a week and says this affects their life in some way, eg financially or emotionally.

How many hours of support do cancer carers provide?

As well as providing a broader range of support tasks than in 2011, cancer carers today are spending more time providing support than in 2011. The average amount of support provided was 17.5 hours per week compared with an average of 15 hours per week in 2011 (Figure 3).

UK government guidelines recommend that people do not work more than 48 hours per week on average, to help workers balance their responsibilities between their work and home life.³ In 2016, a total of 16% of cancer carers had worked more than this, providing 50 hours or more of care per week (compared with 10% of cancer carers in 2011).

Figure 3: Hours of support provided per week among cancer carers in 2011 and 2016



Conclusions

Since 2011, the overall number of cancer carers in the UK has increased to 1.4 million. Cancer carers are also carrying out a broader range of support tasks than in 2011 and are providing more care each week. Consequently, caring often has an impact on many aspects of people's lives, particularly on their emotional well-being and mental health. The impacts of being a carer vary, with younger carers (aged 16–44), women, those caring for more than 35 hours a week and working carers in particular being heavily affected. The research findings will underpin development of a more tailored information and support offer from Macmillan, including offering emotional support.

Types of support provided by carers

Carers in the UK provide a wide range of support for people living with cancer, with 14 different types of support being identified. The most common type of support was providing **emotional support** through talking and listening, and this is carried out by 74% of carers (n=177).

'My friend is very independent and tries to manage things herself but likes the talking and moral support I can give her.'
Female, 67, caring for her friend

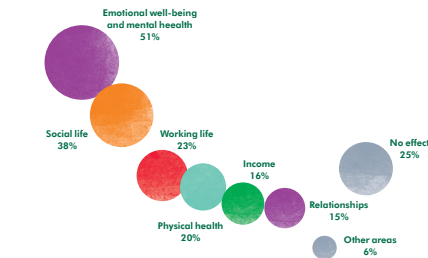
Other areas that carers provide support with can be grouped into five main categories:

- **travel and transport** (including providing transport for appointments and collecting prescriptions)
- **communication** (talking to health and social care staff on the other person's behalf and/or helping with writing letters or emails)
- **household chores** (eg cooking, gardening)
- **personal healthcare** (eg changing dressings, giving medication or helping with toileting)
- **financial support** (either by helping to manage finances or by getting information and advice).

What are the impacts of providing support?

75% of those currently providing support stated that this had affected some area of their life (Figure 4).

Figure 4: Impacts of providing support among cancer carers in 2016



Carers whose emotional well-being and mental health were affected experienced this in different ways, with 45% reporting that they had experienced anxiety and around a quarter (26%) experiencing depression (n=892). Women were more likely to experience various emotional impacts, including stress (56% compared with 40% of men) and anxiety (50% compared with 33% of men).

'... People do not realise how emotionally draining it is when caring for a cancer sufferer and trying to keep yourself in sound mind and body to be able to do the best for your loved one.'
Female, 63, caring for her sister

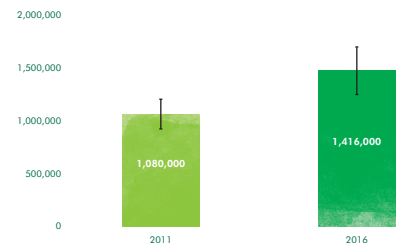
For those carers whose working life was affected, the most common reported impact was poor performance at work (13% of all carers) (n=892).

'Impact on my own general health/well-being led to problems at work [and] eventual dismissal.'
Male, 34, caring for his father

Figure 2: Estimated number of UK cancer carers (rounded to the nearest thousand), 2011 and 2016

The estimated number of cancer carers in the UK has risen since the last survey in 2011 from 1.1 million to **1.4 million in 2016**. In England, the number of cancer carers also increased (1,144,000 in 2016 compared with 905,000 in 2011).

Both increases are statistically significant. The estimated number of cancer carers in Wales, Scotland and Northern Ireland has also increased since 2011; however, the differences are not statistically significant.

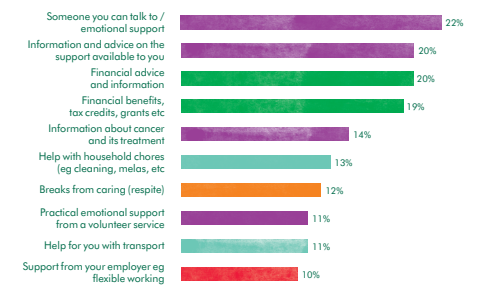


Are there any unmet support needs?

Figure 5 shows the top 10 areas of further support that carers said would be useful. Overall, 65% of carers felt that some further support would be helpful.

The top unmet need was for more emotional support or someone to talk to. Financial support needs were also highlighted, with requests for more financial advice or advice on benefits and tax credits.

Figure 5: Top 10 further support needs that cancer carers identified



Base: all carers in 2016, n=892

Groups particularly likely to have unmet support needs include:

- younger carers (aged 16–44)
- those with children in the household, working carers
- those providing more than 35 hours of care per week
- those feeling that they provide this level of care due to a lack of support from the health and social care system.

References

- 1 Ipsos MORI (2011) *More than a million: Understanding the UK's carers of people with cancer*. Available at: www.macmillan.org.uk/Documents/Cancerinfo/Isomeoneelsehascancer/More_than_a_million.pdf (Accessed: 13 January 2016).
- 2 Maddams J, Utley M and Møller H (2012) Projections of cancer prevalence in the United Kingdom, 2010–2040. *Br J Cancer*; 107: 1195–1202 (Projections scenario 1). Macmillan analysis based on extrapolation of 2010 and 2020 projections that the number of people living with cancer will hit an estimated 2.5 million in 2015.
- 3 UK Government (2016), *Maximum weekly working hours*. Available at: www.gov.uk/maximum-weekly-working-hours/overview (Accessed: 10 May 2016).

June 2016

Working together

YouGov



For more information please contact evidence@macmillan.org.uk
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