

MORE THAN A MILLION

Executive Summary: Understanding
the UK's carers of people with cancer

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CANCER SUPPORT**

Macmillan has an extensive programme of support specifically for carers of people with cancer, including national and local support services, information resources, learning and development opportunities, self-help and support groups, and lobbying and campaigning on issues which affect this group. To date however, a detailed picture of the number, profile and needs of those providing unpaid care for someone living with cancer in the UK has not been available. Macmillan commissioned Ipsos MORI to conduct this research into carers of people with cancer to fill this knowledge gap, and ensure we reach and support carers as effectively as possible.

This document is a summary of the research but a full report from Ipsos MORI is available at [macmillan.org.uk/morethanamillion](https://www.macmillan.org.uk/morethanamillion)

Research approach

The research involved two elements:

- A quantitative in-home face-to-face survey of the UK general public aged 15+, to screen for and survey carers of people with cancer. In total 18,449 members of the UK public were screened using Ipsos MORI's weekly omnibus survey, and 386 people were identified as carers of people with cancer.
- Qualitative interviews with 10 carers from a range of backgrounds and needs, who took part in the quantitative survey and agreed to discuss their experiences in more depth.

People were identified as carers if they were currently providing five or more hours of support a week to someone with cancer, or providing one to four hours of support a week which they said has an impact on their lives. Please note that carers aged under 15 were not included within the scope of this research.

Findings

How many carers are there, and what do they do?

- Around 1.1 million people in the UK aged 15+ are carers of someone with cancer. The research found that 2% of people are currently caring for a person with cancer and these results were extrapolated onto the UK population.
- Most carers (62%) are women. The most common age band for cancer carers is 45–54 (at 22%).
- The great majority of carers of people with cancer look after one person and most live separately from the person or people they support. Carers are most likely to help somebody with breast cancer, followed by cancer of the lung, prostate or colorectal/bowel cancer. Half of them support a person with cancer currently undergoing treatment.
- Carers are most likely to support a middle-aged person, aged 45–64. Carers are more likely to look after women (61%) and most often support a member of their family. A third of carers say they care for a friend or neighbour.

- The most common motivation given by carers is simply that they want to provide this support or that they love the person or people they help.
- Only a minority actually consider themselves to be 'carers'; half of them say this word describes them little or not at all. In particular, those who provide less intensive support, male carers and those looking after someone younger than 65 are less likely to identify with the term.

What do they do and how does it affect them?

- Carers of people with cancer give an average of almost 15 hours of support each week, and the most common type of support is emotional. This is followed by helping with errands or offering transport.
- Most carers are affected in some way by the support they provide, and they most frequently say it impacts on their emotional well-being/mental health, followed by their social life, relationships, working life and finances.

What support are they receiving, or do they need?

- Half of carers say they get no support.
- Almost half of carers identify at least one type of support they're not currently receiving that would be helpful for them such as advice and training on how to give care, information on the general support available and someone to provide emotional support.
- Almost half of carers say the person they help does not receive support which would be useful. This includes someone the person with cancer can talk to, financial advice and help and respite breaks.
- The most common source of statutory support received by carers is from a GP or another element of the NHS. Only one in twenty carers receives Carers' Allowance and only 5% have had a Carers' Assessment.

Which carers are particularly affected?

The impact on carers' lives, the level of support already received and the need for additional support are all greater among groups of carers who provide more extensive support. These include those who:

- Live with someone with cancer
- Provide over 20 hours of care a week
- Support an older person aged 80+
- Care for someone with progressive cancer
- Care for more than one person
- Look after a spouse/partner or a parent/parent-in law, and
- Are affected financially by caring for someone with cancer.

What support have they received from Macmillan?

- A quarter of cancer carers have used or accessed a Macmillan service, most commonly information/advice via the website, or a Macmillan nurse.
- Carers who say they use a Macmillan service often provide more extensive care. They are more likely to care for more than one person, support someone with progressive cancer, or live with someone with cancer.
- Three in five carers can name a Macmillan activity or service they think would be helpful for them personally. Most often this is information or advice via the website, emotional support or a Macmillan nurse.

Conclusions

The following conclusions highlight some of the key issues for carers of people with cancer.

Providing support to people with cancer has an extensive impact on carers. It can affect all areas of their life, including their emotional wellbeing; social life/leisure time; relationships, working life; and income/finances.

Despite this, 49% of carers say they do not receive any support to help them look after a person with cancer; and 47% can identify specific types of support that they are missing out on. The research reveals that carers of people with cancer are receiving low levels of statutory support from local authorities and the Department for Work and Pensions. Awareness and take-up of Carers' Assessments and Carers' Allowance is low.

There seem to be a number of barriers currently preventing carers from accessing the services they need:

- There is low identification with the term 'carer', particularly for groups who provide less extensive or intensive support. Male carers and those looking after someone younger than 65 are also less likely to identify with the term. Low identification with the term could have significant implications for the extent to which carers recognise and access information and support aimed at them.
- Carers typically don't think of their own needs or of what help they may need. This means they tend to be quite passive about investigating the support that is available to them.
- Findings from the research suggest carers don't think to ask for help for themselves, partly because they aren't aware of any services that are available, but also because they feel they should deal with things themselves.

In summary, providing care has a significant impact on the UK's 1.1 million carers of people with cancer. The issues above will need to be addressed if these carers are to receive the support they need.