

New study reveals huge contribution of carers of terminally ill

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Credit: Newcastle University

The Dimbleby Cancer Care funded study shows family carers of people with cancer on average provide almost 70 hours of care a week to look after their relatives in the last three months of life.

The study, which was carried out by the Universities of Newcastle,



Manchester and Groningen in the Netherlands, has been published in this month's *Palliative Medicine*.

The team received responses from 1,504 carers through a national postal survey in the autumn of 2015. The survey was sent via the Office for National Statistics to 5,271 relatives who registered a death in May 2015. Local carers groups helped shape the material.

Findings of survey

The survey revealed:

- The main type of care provided was social/emotional support but carers also undertook considerable practical help, <u>personal care</u> and healthcare tasks
- Carers had an average of £370 out of pocket expenditure during the last three months of the decedent's life
- A quarter of carers spent £100 of this on additional medical equipment and care supplies
- One in six had 'one off expenses' during their whole time caregiving with costs of £2,000
- Most of the care in the study—around 75%—was carried out at home.

The research team studied the work of carers by tasks including preparing food, shopping, cleaning, attending appointments and general administration.

Barbara Hanratty, professor of <u>primary care</u> and public health at the Institute of Health and Society, Newcastle University, said: "This study suggests that carers' contribution to end of life care is substantial, and higher than previous estimates.



"Carers are providing a huge amount of practical and emotional support, and they also spend significant amounts of money out of their own pockets.

"At a time when social care services are facing financial pressures, it is crucial that the role of family carers is acknowledged and their needs are not overlooked."

Dimbleby Cancer Care

Dimbleby Cancer Care was set up in 1966 in memory of broadcaster Richard Dimbleby and is based at Guy's Cancer Centre in Southwark, London. It provides practical and psychological support to people living with cancer and to their families and carers.

The Dimbleby Cancer Care Research Fund awards up to £300,000 per year to research projects looking at all aspects of cancer care.

Chair of the charity, broadcaster Jonathan Dimbleby, said: "I have had personal experience of caring for someone with terminal cancer. It is draining in every way.

"Through the work that Dimbleby Cancer Care does we know how vital informal care is and the huge economic contribution it makes to the NHS and social services."

This is the first of three sets of findings to be published from the study. Results focusing on the emotional distress and wellbeing of the carers and the economic value to society of their work will be published at a later date.

Provided by Newcastle University



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