

# UNDERSTANDING SOCIAL CARE NEEDS

Exploring the needs of people living with cancer in the UK during treatment, survivorship, and end of life

F Smith, C Burley, R Bowden, C Miglio  
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## Background

There are currently 2.5 million people living with cancer in the UK<sup>1</sup>. By the end of 2016 there will be more than 1,000 people diagnosed with cancer each day<sup>2</sup>. In addition to requiring medical care and support, people living with cancer have a range of practical, personal, financial and emotional needs as a result of their condition and the consequences of its treatment.

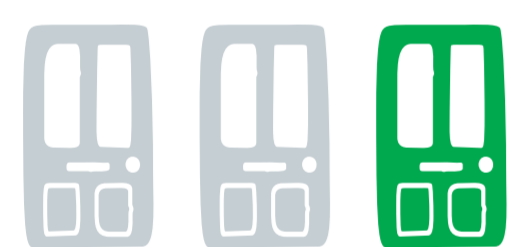
However, there are only limited official data available on the full extent of these kinds of needs, how well people are being supported and by whom, and what impact it has on people when this support is not provided.

To better understand the social care needs of people living with cancer, Macmillan Cancer Support commissioned leading research organisation MRUK to carry out a comprehensive study of this issue. As there is already a range of evidence on the financial impact of cancer – such as Macmillan's *Cancer's Hidden Price Tag* report<sup>3</sup> – we focused on the practical, personal and emotional needs of people living with cancer.

## Conclusions

- The social care needs of people with cancer are far more widespread than expected. Many currently lack the support they need, with distressing consequences for their day-to-day lives and dignity.
- Macmillan will be using this research to support our programme of strategic engagement and partnerships with local authorities and other partners, with the aim of improving and better integrating the planning and provision of personal, practical, emotional, and financial care and support for people living with cancer.

## What needs do people living with cancer have?

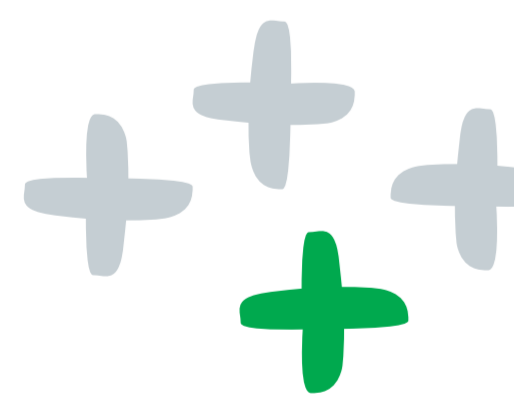


**Mobility** – around one in three people with cancer (32%) are either completely unable to get in and out of bed, move around or use transport **by themselves**, or need a lot of help to do so

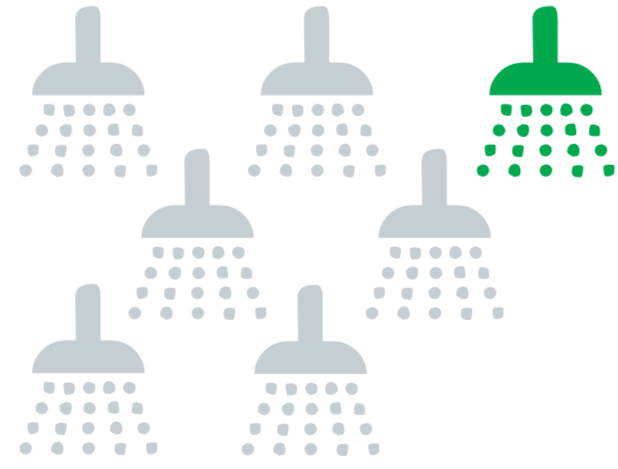
**Practical tasks** – around one in three people with cancer (31%) are either completely unable to do practical tasks such as **prepare and eat food, or do grocery shopping or housework** by themselves, or need a lot of help to do so



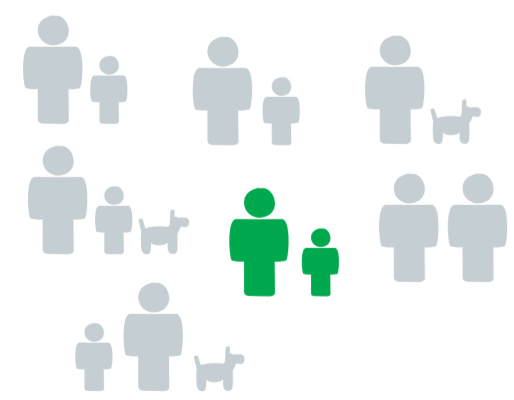
**Medical appointments** – more than one in four people with cancer (27%) are either completely unable to **travel to medical appointments or pick up prescriptions** by themselves, or need a lot of help to do so



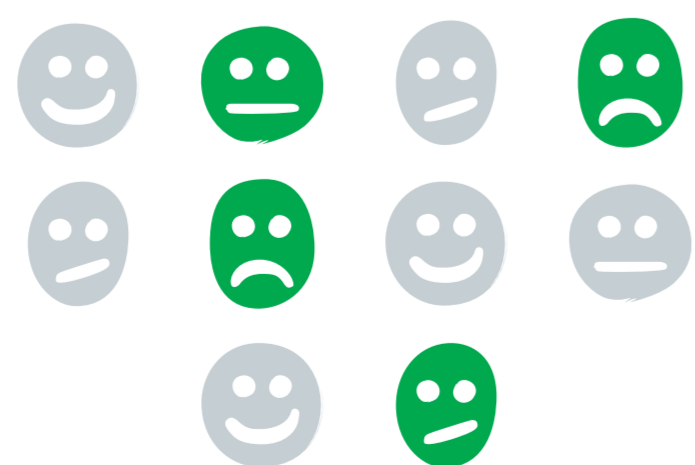
**Personal care** – one in seven people with cancer (14%) are either completely unable to carry out personal care routines such as **bathing, dressing or going to the toilet** by themselves, or need a lot of help to do so



**Looking after dependants** – one in seven people with cancer (14%) are either completely unable to **look after their children or other relatives** by themselves, or need a lot of help to do so



**Emotional needs** – more than four in ten people with cancer (44%) have experienced **five or more distressing or concerning emotional issues** in the past week, such as fear, anxiety, loneliness, depression or anger



## Methodology

The research consisted of:

- Design and cognitive testing of a quantitative survey to explore the nature, level and quality of support people receive according to different categories of need and type of care provider. Social care needs were defined as personal and practical needs associated with daily living (e.g. washing, cooking, cleaning, and looking after dependants) and emotional issues causing distress or concern. The survey was designed to enable the level of need to be mapped against what was formally the Fair Access to Care (FACs) criteria used by local authorities in England to assess eligibility for support<sup>4</sup>.
- A UK-wide online survey of 1,037 people living with cancer, at three key stages of the disease: during treatment, up to 10 years after the completion of successful treatment (survivorship), and at the end of life. Due to the challenges of recruiting people at the end of life for research, the majority of data for the end-of-life stage came from people caring for someone at the end of life or recently bereaved carers. The online survey sample is broadly representative of the UK population but we recognise that it does have limitations, such as being less representative of those without internet access or with low levels of literacy.
- 24 in-depth face-to-face interviews to develop a deeper understanding of people's needs and the support they receive.
- 15 week-long online diaries to capture a snapshot of how support for people's needs, or the lack of it, affects their daily lives.

- In the meantime, we have a number of recommendations that would improve the lives of people with cancer who have social care needs:
  - People living with cancer are not always aware of the practical, personal and emotional support that may already be available to them. Health and social care providers should provide clearer information and signposting to improve access to the services that are currently available.
  - Information and signposting to sources of support must take place at multiple points in a person's cancer experience, not just during particularly intense periods such as diagnosis or during treatment.

## Results

- Around two in three people living with cancer (64%) have practical or personal support needs, and four in five (78%) have emotional support needs. Practical and emotional needs often arise together, and are clearly linked.
- Overall, almost one in three people with cancer (31%) have practical or personal needs but do not get enough support or get no support at all. Almost half of people with cancer (45%) have emotional needs but do not get enough support or get no support at all.
- Family and friends are often the only source of help, and often receive no support themselves.
- One in five people with cancer (22%) experience a negative impact on their lives as a result of a lack of support for their personal or practical needs – ranging from being housebound, unable to wash and dress themselves, to experiencing unnecessary hospital admissions.

- People must be treated as individuals and given choice over how their care and support is planned and provided. Support should be personalised to an individual's needs and preferences, and integrated with any other health and social care services they receive.
- Health and social care providers must recognise that there is a clear link between people's practical and personal needs and their emotional needs, and identify and address these needs in a more holistic manner.

## What support do people living with cancer receive?

### Practical and personal needs



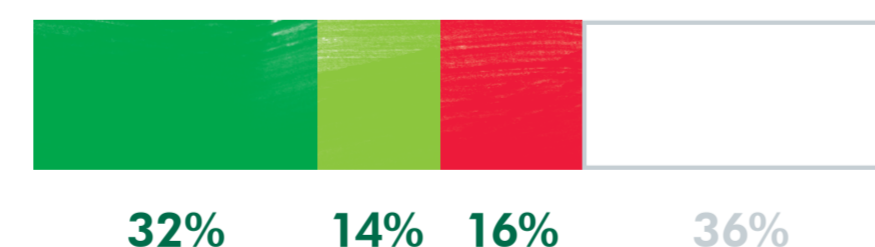
- Have personal or practical needs
- Do not have any personal or practical needs

Formal support (e.g. local authority support, supportive care from the NHS, etc)



- Have needs and get enough formal support
- Have needs and get formal support, but not enough
- Have needs and get no formal support at all
- Do not have any personal or practical needs

Support from family and friends



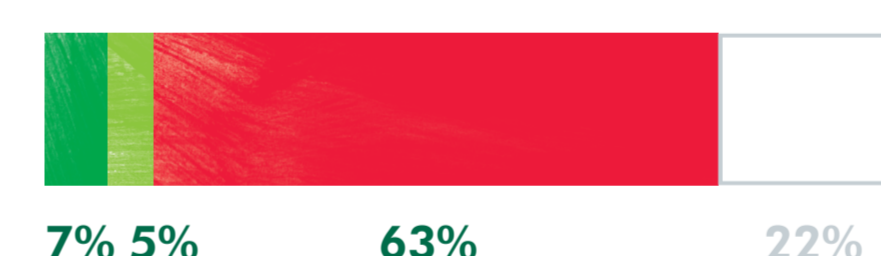
- Have needs and get enough support from family and friends
- Have needs and get support from family and friends, but not enough
- Have needs and get no support at all from family and friends
- Do not have any personal or practical needs

### Emotional needs



- Have emotional needs
- Do not have any emotional needs

Formal support (e.g. counselling/therapy, group/peer support, etc)



- Have needs and get enough formal support
- Have needs and get formal support, but not enough
- Have needs and get no formal support at all
- Do not have any emotional needs

Support from family and friends



- Have needs and get enough support from family and friends
- Have needs and get support from family and friends, but not enough
- Have needs and get no support at all from family and friends
- Do not have any personal or practical needs

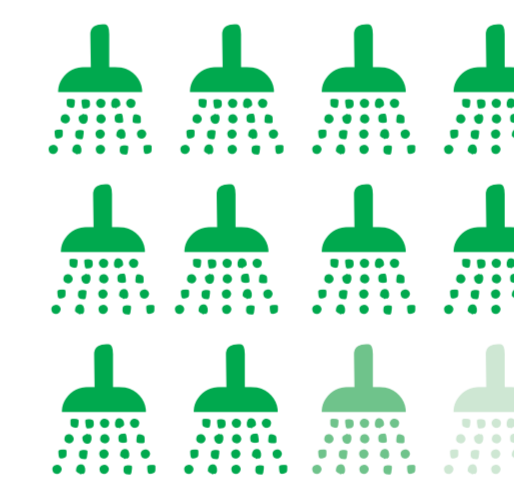
## What is the impact of not receiving enough support?



### Personal and practical needs

One in four people with cancer (26%) experience a negative impact on their lives as a result of a lack of support for their personal or practical needs. This represents at least 380,000 people with cancer in the UK.

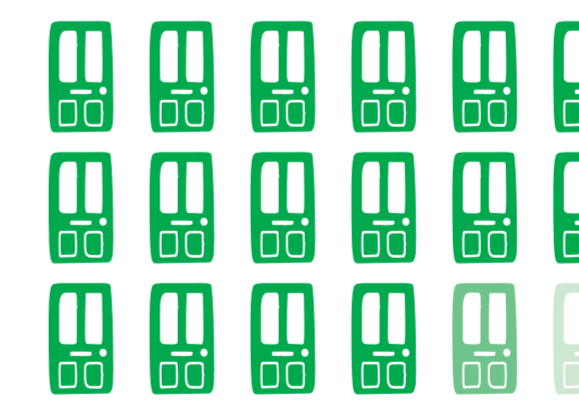
🏠 = 10,000 people



### Personal care

One in 14 people with cancer (7%) are constantly or often unable to wash themselves, dress or go to the toilet because of a lack of support. This represents at least 100,000 people with cancer in the UK.

🚿 = 10,000 people



### Mobility

One in 10 (11%) are constantly or often housebound as a result of a lack of support. This represents at least 160,000 people with cancer in the UK.

👤 = 10,000 people

## Acknowledgements

mruc research

## References

- Maddams J, Utley M, Maller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. *Br J Cancer* 2012; 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.
- Incidence predictions are based on the assumption that age specific all cancer incidence rates remain constant at 2012 rates for the next few years (Mistry et al. 2011 state "there is projected to be almost no change in the overall incidence rates of cancer (for all cancers combined) in the 23-year period 2007-2030"). Predictions based on applying the UK 2012 incidence rates for 5 year age groups from: Office of National Statistics. Cancer Statistics Registrations, England (Series MB1), No. 43, 2012 <https://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=stc%3A77-352128>
- ISD Scotland. All Cancer Types - Scotland: trends in incidence 1988-2012 [https://isd.scotland.scot.nhs.uk/Health-Topics/Cancer/Publications/2014-04-29/i\\_cancer\\_all\\_types.xls](https://isd.scotland.scot.nhs.uk/Health-Topics/Cancer/Publications/2014-04-29/i_cancer_all_types.xls)
- Welsh Cancer Intelligence and Surveillance Unit. All malignancies excluding non melanoma skin cancer, 1985-2012 <http://www.wcis.wales.nhs.uk/pendoc/238708>
- Personal communication with the Northern Ireland Cancer Registry (May 2014) to the ONS's UK population projections (2012-based projections - Principal projection for the UK population by five year age groups and sex [www.ons.gov.uk/ons/re/npp/national-population-projections/2012-based-projections/r11-table-a2-1-principal-projection---uk-population-in-age-groups.xls](http://www.ons.gov.uk/ons/re/npp/national-population-projections/2012-based-projections/r11-table-a2-1-principal-projection---uk-population-in-age-groups.xls)).
- Macmillan Cancer Support. *Cancer's Hidden Price Tag*. April 2013. [www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Hidden-Price-Tag-report-England.pdf](http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Hidden-Price-Tag-report-England.pdf)
- FACs was replaced in April 2015 with updated criteria and a new eligibility threshold for adults with social care and support needs, as set out in the Care and Support (Eligibility Criteria) Regulations 2014. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/366104/43380\\_23902777\\_Care\\_Act\\_Book.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/366104/43380_23902777_Care_Act_Book.pdf)