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

Background
There are currently 2.5 million people living with cancer in the UK. By the end of 2016 there will be more than 1,000 people diagnosed with cancer each day. 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 – 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.

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 provider. Social care needs were defined as personal and practical needs associated with daily living (e.g. 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.
• 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.

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 closely 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 (43%) 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.

What needs do people living with cancer have?
Mobility – around one in three people with cancer (32%) are either completely unable to walk 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 look after their children or other relatives 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 fear or more distressing or concerning emotional issues in the past week, such as fear, anxiety, loneliness, depression or anger

What support do people living with cancer receive?

<table>
<thead>
<tr>
<th>Needs</th>
<th>Personal and practical needs</th>
<th>Emotional needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobile</td>
<td>64%</td>
<td>78%</td>
</tr>
<tr>
<td>Practical support</td>
<td>36%</td>
<td>22%</td>
</tr>
<tr>
<td>Do not have any personal or practical needs</td>
<td>40%</td>
<td>44%</td>
</tr>
<tr>
<td>Have needs and get enough support</td>
<td>64%</td>
<td>72%</td>
</tr>
<tr>
<td>Have needs and get formal support</td>
<td>32%</td>
<td>20%</td>
</tr>
<tr>
<td>Have needs and get good enough support</td>
<td>16%</td>
<td>12%</td>
</tr>
<tr>
<td>Support from family and friends</td>
<td>36%</td>
<td>32%</td>
</tr>
</tbody>
</table>

What is the impact of not receiving enough support?

• 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.

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References

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