

HIDDEN AT HOME

**WE ARE
MACMILLAN.
CANCER SUPPORT**

The social care needs
of people with cancer

March 2015



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FOREWORD

There are many harmful myths about cancer. One of the most unfair is that the needs of people with cancer are purely medical, and so the NHS provides all the care and support they need. At Macmillan Cancer Support we know this is simply not true. People with cancer have a wide range of social care needs – practical, personal and emotional – as well as financial needs. But until now we didn't know how widespread these needs are, or the full picture of how well people are being supported.

New research commissioned by Macmillan has now revealed the stark reality that the social care needs of people with cancer are far more widespread than we had expected, and in many cases levels of support are falling woefully short. People at all stages of the disease are lacking the care and support they desperately need, with devastating consequences for their health and dignity – hundreds of thousands of people are being left housebound, unable to wash or dress themselves, and are even at risk of soiling themselves in their own home.

This lack of dignity is contributing to the huge emotional toll that cancer can inflict. People are living with constant feelings of fear, anger and isolation, not to mention depression and anxiety.

Only one in five of all people with cancer receive any kind of formal support, despite an estimated four in 10 having needs serious enough to be eligible, and one in six have needs but receive no support at all from anyone. The findings remind us once again just how much people with cancer, and the wider health and social care system,

rely on the care provided by family and friends. For half of those with practical or personal needs, support from family and friends is the only help they get, and half of those who provide informal care do not receive any support themselves.

As well as revealing a concerning level of unmet need, this research highlights how these needs are adding to the pressure on the NHS. One in five people with cancer have had to go to hospital for an unplanned or emergency visit because of a lack of support for their practical or personal needs. Failing to meet people's social care needs does not reduce the need for support – it simply shifts the demand elsewhere in the health and social care system. In many cases, this risks increasing the overall cost of care instead of reducing it. Furthermore, the need for social care support in general will only increase as our population continues to grow and age, while the budgets of local government remain under intense pressure.

We must commit to better meeting people's social care needs, at all levels of the health and social care system. At Macmillan we are playing our part. After years of successful collaboration with local government, we want to deepen relationships with local authorities, other partners across the UK and people affected by cancer to help develop solutions to these issues for people with cancer. But we cannot do this alone. The entire health and social care system, and both national and local government, must work towards integrating health and social care and improving the level of support people receive.

One thing is clear: there is no longer any justification to maintain the myth that people with cancer do not have social care needs. And the level of need will only increase. Each year, more and more people are diagnosed with cancer. Survival rates continue to improve. By 2030, there will be at least four million people living with the disease. We must improve the support that people receive to help them reclaim their lives – and their dignity – from cancer.



Allan Cowie
Director and Executive Lead
for Social Care,
Macmillan Cancer Support

'Failing to meet people's social care needs does not reduce the need for support – it simply shifts the demand elsewhere.'

EXECUTIVE SUMMARY

- People living with cancer have a range of social care needs – practical, personal and emotional, as well as financial needs. For the majority of people these are directly related to their condition and the consequences of its treatment.
- 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. This research comprised:
 - A UK-wide online survey of 1,037 people living with cancer in the UK and their carers
 - 24 in-depth face-to-face interviews
 - 15 week-long online diaries
- The research showed that around two in three people living with cancer (64%) have practical or personal support needs, and four in five (78%) have emotional support needs. These include needs related to mobility (e.g. getting in and out of bed, leaving the house), practical tasks (e.g. preparing and cooking food, housework, grocery shopping) and personal care (e.g. washing and dressing themselves, going to the toilet), among many others.
- 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.
- 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. This represents at least 380,000 people with cancer in the UK.
 - 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.
 - One in 10 (11%) are constantly or often housebound as a result of a lack of support. One in 13 (8%) are constantly or often unable to look after their dependants, such as children or other relatives.
- Six in 10 (61%) people caring for someone with cancer experience some kind of impact on their lives as a result of caring and very few receive a formal Carer's Assessment.

- Macmillan will be developing a wider programme of work to deepen relationships with local authorities, other partners across the UK and people affected by cancer to develop new solutions and improve the information and support that people with cancer receive. Local authorities are in a unique position to broker local solutions for people, their carers and communities, and we intend to focus on helping people with cancer, and those who care for them, to do the following:
 - Access more support in the community
 - Develop or regain their abilities and confidence in carrying out day-to-day activities through rehabilitation and reablement services
 - Self-manage their condition
 - Receive targeted early social care interventionWe will focus on ensuring that support is personalised to an individual's needs and preferences, focused on delivering the outcomes that they want, and planned and delivered in partnership with them and other organisations.
- In the meantime, we have a range of recommendations that would improve the lives of people with cancer who have social care needs:
 - Health and social care providers should provide clearer information and signposting to improve access to the services that are currently available, at various stages of the cancer journey.
 - All people with cancer should receive a holistic needs assessment (one that considers their full range of personal, practical, emotional, financial and social needs in addition to their medical needs) and an integrated care plan, which is reviewed and updated at key points of the cancer journey to help prevent further needs developing as well as supporting existing needs.
 - Support should be personalised to an individual's needs and preferences, and integrated with any other health and social care services they receive.
 - NHS, local government and the third sector must work together to identify and support carers and ensure that they receive an appropriate needs assessment and necessary support.

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

THE SOCIAL CARE NEEDS OF PEOPLE WITH CANCER

There are currently 2.5 million people living with cancer in the UKⁱ. By the end of 2016 there will be more than 1,000 people diagnosed with cancer each dayⁱⁱ. 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* reportⁱⁱⁱ – we focused on the practical, personal and emotional needs of people living with cancer.

The research consisted of:

- A UK-wide online survey of 1,037 people living with cancer, at three key stages of the disease: during treatment, 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 this kind of 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.

Macmillan is launching wider programmes of work that include local government, people affected by cancer and other partners to help improve the support available for people with cancer in the community. You can read more about this on page 18.

The findings of our research, summarised in this report, show just how much this work is needed.



'The week after a chemo cycle is very difficult. I can't walk longer distances, or go shopping, and I need to rest a lot at home. I rely on my wife to cook and do the housework. Daily life is very variable now – some days are good, other days really difficult.'

Rick, 64, from London, receiving treatment for lung cancer^{iv}

How widespread are social care needs among people with cancer?

Around two in three people living with cancer (64%) have practical or personal support needs, and four in five (78%) have emotional support needs.

Around two in five people living with cancer (42%) have social care needs that we estimate are serious enough to be eligible for formal support from local authorities or health and social care trusts (needs that could be classified as 'critical' or 'substantial' according to eligibility criteria)⁹.

This rises to four in five people at the end of life (84%), but still applies to one in five of those who have completed treatment and are in the survivorship stage (22%) and around one in three of those undergoing treatment (32%).

To help us consider the overall level of need and support among people with cancer, the research considered all

needs, not just those directly related to people's cancer diagnosis. However, three in four (75%) people with cancer who have practical or personal needs say these needs are caused by their cancer or cancer treatment either entirely, mostly or in part.

In addition, there are clear links between people's practical or personal needs and their emotional needs. For example, if someone is unable to carry out a physical task or activity, such as wash or dress themselves or look after their children, this can cause distress, feelings of humiliation and low self-esteem, as well as contribute to depression and anxiety. The opposite is also true – when someone is experiencing emotional or mental health issues, they may find it hard to make good decisions about practical matters or take care of themselves and those around them.

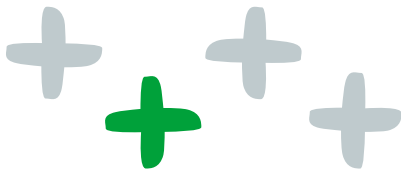
Social care needs of people with cancer



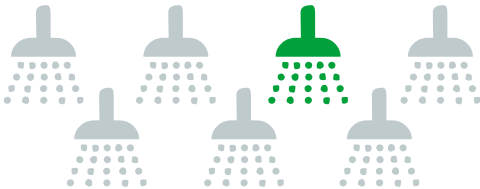
Mobility – around **one in three people with cancer (32%)** are either completely unable to **get in and out of bed, move around or use transport** by themselves, or need a lot of help to do so



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 10 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

How much support do people with cancer get?

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.

The proportion of people who have practical or personal needs but get no support at all is highest in England compared with the rest of the UK (England – 11%, Scotland – 5%, Wales – 5%, Northern Ireland – 7%).

Practical and personal needs^{vi}

Have needs and get no support at all **10%**

Have needs and get support, but not enough **22%**

Have needs and get enough support **33%**

Do not have any personal or practical needs **36%**



Emotional needs^{vii}

25% Have needs and get no support at all


20% Have needs and get support, but not enough

33% Have needs and get enough support

22% Do not have any emotional needs



People with cancer



'Being diagnosed with breast cancer, with two kids and no family to help, it was difficult. I was restricted after surgery, much weaker physically, and felt ill because of the chemo, which meant that doing chores in the house just didn't happen. Because I was unable to drive and my partner works full time, I had to find friends to take me to appointments as well as organise childcare.'

Elaine, 46, from the West Midlands, living with breast cancer

Who provides support?

Of people with personal and practical needs, three in 10 (30%) receive formal support, such as formal social care provided or funded by their local authority or the NHS. This translates into one in five (19%) of all people with cancer.

There is some variation across the UK. The majority of people in Scotland do not receive any formal support from their local authority, but they are slightly more likely to receive this support than people in England (of those with personal and practical needs in Scotland, 30% receive support from their local authority, compared with 23% in England^{viii}).

Three in four (76%) people with personal and practical needs receive help from their family and friends. This translates into half (49%) of all people with cancer. People in Scotland are also more likely to receive support from family and friends compared with people in England (of those with personal and practical needs in Scotland, 85% receive support from family and friends compared with 73% in England^{viii}).

For half (51%) of people with personal and practical needs, support from family and friends is the only help they get. This translates into one in three (33%) of all people with cancer, and more than four in 10 (45%) of all people at end of life.

Of people whose needs are serious enough that they should be eligible for formal social care support (needs that we estimate could be classified as 'critical' or 'substantial' according to eligibility criteria^v), only around one in three (36%) have had a formal needs assessment and no more than one in three receive formal social care from their local authority or health and social care trust. Of all types of support, people with cancer who receive local authority support are most likely to say it is not enough to meet their needs.

The lack of access to formal social care support is likely to be due to a range of factors. These could include not enough support being available in the first place, but also people not being aware of what services are available or that they might be eligible to receive help.

'There was no support after I was discharged. I felt very alone with it all, as if I was alone in dealing with everything. I was in a wheelchair, unable to wash myself or use the loo properly, and I felt very depressed.'

Lisa, 55, from Cheshire, living with womb cancer

Practical and personal needs^{ix}



- 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^x



- 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^{xi}



- Have emotional needs
- Do not have any emotional needs

Formal support (e.g. counselling/therapy, group/peer support, etc)^{xii}



- 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^{xiii}



- 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

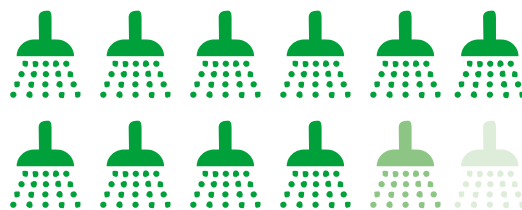
What is the impact of not receiving enough support?



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^{xxii}.

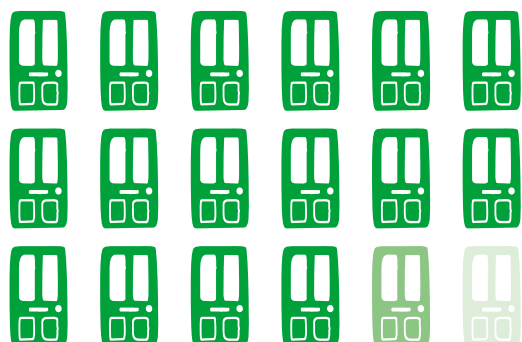
 = 10,000 people



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

Caring for dependants

One in 13 (8%) are constantly or often unable to look after their dependants, such as children or other relatives.

Hospital visits

One in seven people with cancer (15%) have had to go to hospital for an unplanned or emergency visit because of a lack of support for their practical or personal needs. One in 20 (5%) are constantly or often having unplanned or emergency hospital visits because of a lack of support.

Impact of providing care on carers

Around half of people (51%) who provide informal care for people with cancer do not receive any support themselves. Anyone who is providing regular and substantial unpaid care for an adult in the UK is eligible to have a formal Carer's Assessment from their local authority or health and social care trusts, which may result in additional support being provided. However, our research shows that very few carers receive a Carer's Assessment. Even among those caring for someone at the end of life, only one in 13 (8%) have received a formal assessment.

Six in 10 (61%) carers experience some kind of impact on their lives as a result of caring. This rises to more than eight in 10 (86%) people who care for someone at the end of life. More than one in four (27%) experience emotional or mental health issues, and one in five (22%) experience physical health issues. Other research, published in Macmillan's recent *Do you care?* report, shows that nine in 10 (89%) healthcare professionals agree that carers often neglect their own health when looking after someone with cancer^{xv}.

'Carer breakdown' can lead to more unplanned hospital admissions for both the person being cared for and the carer. It can also lead to a greater reliance on formal health and social care services if the carer becomes unable to provide care.

'We were 'best friends' with A&E – this happened all the time. But it could have been avoided, if somebody [had] looked after my friend more carefully.'

Karen, 53, bereaved carer for someone with uterine cancer, London^{xiv}

IMPROVING THE LIVES OF PEOPLE WITH CANCER

As well as supporting people affected by cancer directly, Macmillan also campaigns for the transformation of the wider health and social care system to better support people with cancer in need. Our priorities are defined by over 100 years of experience of listening to people living with cancer, their carers and family and friends. As part of our work in this area, we invest in partnerships with a range of other organisations. In 2013, for example, we spent more than £11 million on funding social care schemes^{xvi}. However, as this research starkly demonstrates, there is still much more to be done.

In recognition of this Macmillan will seek to expand our work across health and social care, working with partners and people affected by cancer to develop and co-produce new and innovative ways to integrate care, and improve the information and support that people affected by cancer receive in their own communities. Local authorities are in a unique position to broker local solutions for people, their carers and communities, and we intend to focus on helping people with cancer, and those who care for them, to do the following:

- Access more support in the community
- Develop or regain their abilities and confidence in carrying out day-to-day activities through rehabilitation and reablement services
- Self-manage their condition
- Receive targeted early social care intervention

We aim to ensure that support is personalised to an individual's needs and preferences, focused on delivering the outcomes that they want, and planned and delivered in partnership with them and other organisations.

We will also work with local authorities and health and social care trusts across the UK to help provide information to people who do not meet the eligibility criteria for formal social care, including what other services are available and how they can be accessed (known as 'signposting'), to help support them and prevent their needs becoming more severe. In England, local authorities will have a statutory duty to provide this information and signposting from April 2015, and local authorities in Scotland and Wales also have similar responsibilities to provide information and direct people to alternative sources of support.

Our programme will build on and support our existing work and partnerships in this area. We will use the findings of this new research to help guide the development of the programme and our policies and recommendations in this area.

In the meantime, we have several recommendations that would immediately 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.
- 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.
- To improve support for people caring for those with cancer, the recommendations from Macmillan's *Do you care?* report must be implemented, namely that the NHS, local government and third sector must work together to identify and support carers and ensure that they receive an appropriate needs assessment and necessary support.

'People must be treated as individuals and given choice over how their care and support is planned and provided. Support should be integrated, and personalised to an individual's needs and preferences.'

CONCLUSION

In 2014 the final report from the Commission on the Future of Health and Social Care in England, also known as the Barker Commission, called for the integration of health and social care and for more social care to be provided for free at the point of need^{xviii}. The report cast a much-needed spotlight on the need to improve access to social care support. Unfortunately it also led to some commentators using people with cancer as an example of a group who they believe already have all their care and support needs met, because they consider these to be purely medical in nature^{xix}. As our research emphatically shows, this is far from the truth. The majority of people with cancer in the UK have social care needs, and significant numbers are experiencing a serious negative impact on their health and dignity because these needs are not being met.

Sadly we cannot labour under the illusion that the healthcare side of cancer is 'fixed' either. Survival rates in the UK continue to lag behind Europe^{xx} and national waiting time targets are regularly being missed across the UK. Last year in England a national cancer waiting time target was breached for the first time since they were introduced in 2009, and the target is still being missed a year later^{xxi}. There are now 2.5 million people living with cancer in the UKⁱ. We face a crisis in cancer care if we do not take action now.

The health and social care system as a whole is facing record levels of demand and there are many signs that it is struggling to cope. Making cuts in one area is simply putting more pressure on others. However, in some ways the landscape is changing for the better. There is an increasing recognition by health and social care leaders and professionals that care and support should be personalised to the individual. By this we mean people having all their individual needs assessed, met in the setting of their choice, by the type of support that they want, when they want it – and being able to contribute equally to the planning and delivery of their care and support from the start. This should make it much harder to justify reducing support in one care setting over another for arbitrary financial reasons.

We need to make it a national priority to provide personalised care and support and improve integration between health and social care, at all levels of the system. All people with cancer should receive a holistic needs assessment and an integrated care plan, which is reviewed and updated at key points of the cancer journey to help prevent further needs developing as well as supporting existing needs.

We can and must do much more in this country to meet all the health and social care needs of our population, regardless of the underlying condition responsible.



'We need to make it a national priority to provide personalised care and support and improve integration between health and social care.'

REFERENCES

ⁱ Maddams J, Utley M, Møller 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.

ⁱⁱ 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 <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-352128>
 - ISD Scotland. All Cancer Types - Scotland: trends in incidence 1988-2012 https://isdscotland.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.wcisu.wales.nhs.uk/opendoc/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/rel/npp/national-population-projections/2012-based-projections/rft-table-a2-1-principal-projection---uk-population-in-age-groups.xls).

ⁱⁱⁱ Macmillan Cancer Support. *Cancer's Hidden Price Tag*. April 2013. www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Costofcancer/Cancers-Hidden-Price-Tag-report-England.pdf

^{iv} Some names have been changed

^v The survey mapped respondents' answers to England's Fair Access to Care Services (FACS) criteria. Scotland, Wales and Northern Ireland use similar criteria, although precise definitions differ. Mapping of FACS criteria is based on self-reported information rather than a formal assessment:

Q. Thinking about last week, please tell us to what extent you were able to do each of the things below without help from anyone else? Please tell us regardless of whether this is related to your cancer/its treatment or not	I'm not limited at all	I'm slightly limited	I'm moderately limited	I'm severely limited	I'm completely unable to do this on my own	Prefer not to say
Ability to carry out personal care routines (such as dressing, washing, going to the toilet, etc.)	1	2	3	4	5	X
Ability to carry out domestic routines (such as cooking, cleaning, gardening, etc)	1	2	3	4	5	X
Ability to go to work	1	2	3	4	5	X
Ability to be involved with your education or learning activities	1	2	3	4	5	X
Ability to sustain your personal relationships (e.g. with a partner, children, family)	1	2	3	4	5	X
Ability to sustain your social relationships (e.g. seeing your friends, colleagues, neighbours as much as you would like)	1	2	3	4	5	X
Ability to sustain your family role, responsibilities or commitments (e.g. looking after children, caring for a partner, supporting dependants)	1	2	3	4	5	X
Ability to sustain a wider social role, responsibilities or commitments (e.g. volunteering for charities, community work, civic engagement)	1	2	3	4	5	X

References cont.

FACS level approximation

1. People were classified as having 'critical' needs if they selected answer option 5 'I'm completely unable to do this on my own' for any of the areas tested
2. People were classified as having 'substantial' needs if they did not select answer option 5 for any areas, and if they selected answer option 4 'I'm severely limited' for any of the areas tested
3. People were classified as having 'moderate' needs if they did not select answer option 4 for any areas, and if they selected answer option 3 'I'm moderately limited' for any of the areas tested
4. People were classified as having 'low' needs if they did not select answer option 3 for any areas, and if they selected answer option 2 'I'm slightly limited' for any of the areas tested
5. People were classified as having 'no care needs' if they did not select answer option 2 for any areas, and if they selected answer option 1 'I'm not limited at all' for any of the areas tested
6. People were classified as having an 'unassigned need level' if they did not select answer option 2 for any areas, and if they selected answer option x 'Prefer not to say' for any of the areas tested

^{vi} Percentages do not add to 100% due to rounding and/or missing or 'don't know' responses.

Please note some of this data is based on modelled assumptions

^{vii} Please note some of this data is based on modelled assumptions

^{viii} The sample size for the subgroups in Wales and Northern Ireland is too small to report the figures here

^{ix} To ensure that the survey was a suitable length, not all instances of support were investigated in depth. Therefore, data for 'enough' and 'not enough' support is modelled based on a reduced number of instances of support that were questioned in detail. 'Not enough' support is defined as any mention of not enough support for any one type of personal or practical support need.

^x Percentages do not add to 100% due to rounding and/or missing or 'don't know' responses

^{xi} To ensure that the survey was a suitable length, not all instances of support were investigated in depth. Therefore, data for 'enough' and 'not enough' support is modelled based on a reduced number of instances of support that were questioned in detail. 'Not enough' support is defined as any mention of not enough support for any one type of emotional support need.

^{xii} Percentages do not add to 100% due to rounding and/or missing or 'don't know' responses

^{xiii} Percentages do not add to 100% due to rounding and/or missing or 'don't know' responses

^{xiv} Some names have been changed

^{xv} Macmillan Cancer Support. *Do you care?* October 2014. www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Carers/DoYouCareHelpinghealthprofessionalstoIdentifyandSupportCarers.pdf

^{xvi} Macmillan Cancer Support. *Annual report and accounts 2013*. April 2014. www.macmillan.org.uk/Documents/AboutUs/RaiseAndSpend/AnnualReviews/AnnualReport2013.pdf

^{xviii} Commission on the Future of Health and Social Care in England. *A new settlement for health and social care*. September 2014. www.kingsfund.org.uk/projects/commission-future-health-and-social-care-england

^{xix} Needham A. If you have cancer, the NHS will pay for care. Got dementia? You're on your own. *Guardian Comment is Free*. 10 September 2014. <http://www.theguardian.com/commentisfree/2014/sep/10/dementia-cancer-nhs-care>

^{xx} CONCORD working group. Global surveillance of cancer survival 1995–2009: analysis of individual data for 25,676,887 patients from 279 population-based registries in 67 countries (CONCORD-2). *The Lancet* 2014. [http://dx.doi.org/10.1016/S0140-6736\(14\)62038-9](http://dx.doi.org/10.1016/S0140-6736(14)62038-9)

^{xxi} NHS England. Cancer waiting times. www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/

^{xxii} Population estimates are based on the 2.5 million figure from reference i. To reflect that our research did not include cancer survivors diagnosed more than 10 years ago, we have excluded the proportion of people living with cancer who were diagnosed 10+ years ago (taken from Maddams J, et al. Cancer prevalence in the United Kingdom: estimates for 2008. *British Journal of Cancer*. 2009. 101: 541-547) from the projected 2.5 million in order to calculate population estimates. Please note that in excluding all those diagnosed 10+ years ago from our population estimates, we will also have excluded a small number of people who are at the end of life, so our estimates may be conservative.

Notes

Cancer is the toughest fight most of us will ever face. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The fundraisers who make it all possible.

Together, we are Macmillan Cancer Support.