

WORRIED SICK: THE EMOTIONAL IMPACT OF CANCER

Research for
Macmillan Cancer Support
conducted by
Opinion Leader Research
April 2006

**WE ARE
MACMILLAN.
CANCER SUPPORT**

Acknowledgements

Macmillan Cancer Support would like to thank Opinion Leader Research and Wild Duck for their assistance with this research project. We would also like to thank Chris and Julie for giving us permission to use details of their experience to help others. Finally, thank you to the thousands of people who took part in this important survey. Without you, this research project would not have been possible.

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Contents

Page

2 Foreword

2 Peter Cardy, Chief Executive, Macmillan Cancer Support

4 Background and introduction

4 Research objectives

4 Research sample

5 Research methods

6 Chris's story

7 Main findings

7 The impact of cancer on everyday living

7 Living with cancer every day

9 Experience of the cancer information and support system

10 The physical impact of cancer

11 The impact of cancer on emotional well-being

12 Cancer, anxiety and depression

14 Cancer and relationships

16 Julie's story

17 The impact of cancer on carers

18 What people expect from cancer care organisations

20 Implications for Macmillan Cancer Support and recommendations to government

Foreword

Worried Sick: the emotional impact of cancer puts the spotlight on the impact of cancer on the everyday lives of patients and those close to them. The first *Cancer Plans*¹ published at the beginning of this century successfully focused on improving the speed and amount of treatment, and hence survival with cancer.

Now we are examining what life is like for people living with cancer, in many cases for much longer than they would have done even a decade ago. The picture that emerges is not good. All too often, the stress of managing everyday life following diagnosis and treatment is immense; the psychological and emotional impact continues long after the cancer itself is treated, the impact on personal finances can be devastating and the damage to relationships is far more widespread than generally realised.

With the number of people living with cancer continuing to rise as the population ages and survival improves, much more effort is needed to enable people whose cancers are cured, in remission or still being treated to live an acceptable life. Quantity of life for many cancer patients is improving steadily; now we need to do the same for quality of life. The new cancer plans needed for all four nations of the UK must take this as a central theme and ensure that adequate resources are made available through the social care systems as well as the NHS, and that these systems join up to support people affected by cancer.

This has been Macmillan's business for almost 100 years and many of our best known innovations have been directed to this goal. Long before the benefits system provided a safety net, Macmillan was giving grants to families for basic needs and comforts; this continues but now on a huge and growing scale. It has led directly to the benefits advice services we have piloted across the UK and to our award-winning Better Deal campaign² that points out to government and others how financial support for people affected by cancer could be improved.

Macmillan nurses, the first of whom were created only in the mid-1970s, gave direct and practical help to patients and families in their own homes. Their first-hand accounts of the devastating impact on partners, parents and children of patients led to the carers' support schemes Macmillan is setting up around the country.

We develop these schemes and others with partners who take up our innovations and give them continued life as mainstream services.

As the trajectory of many cancers changes and life with cancer is lived mainly at home rather than in hospital, Macmillan is changing too. We intend, over a short timescale, to be a source of support for everyone affected by cancer who needs us. And we will be a stronger force for change through innovation, campaigns and effective communication to improve cancer care everywhere.

Governments across the UK should also rise to meet the unmet needs identified by our report. We call on them and the NHS to create and fund services that meet the emotional and practical, information and support needs of everyone living with and affected by cancer.

A handwritten signature in black ink that reads "Peter Cardy". The signature is written in a cursive, flowing style.

Peter Cardy

Chief Executive

Macmillan Cancer Support

Background and introduction

Research objectives

Macmillan Cancer Support's *Worried Sick* report presents a summary of the findings of a major quantitative survey conducted by Opinion Leader Research (OLR).

The survey explores the impact of a cancer diagnosis on the lives of both **people with cancer** (who have received the diagnosis) and **people affected by cancer** (family members and friends who often help them cope with their cancer experience).

Specifically our research objectives were to examine the impact of a cancer diagnosis on:

- Living with cancer every day, including people's experience of the cancer information and support system and the physical impact of cancer
- People's emotional well-being and relationships
- People affected by cancer (informal carers, who may be a relative or friend)

The research also aimed to establish any differences between the views and experiences of people living with or affected by cancer, and those who had never been affected by the disease.

Research sample

In total, 1,751 people took part in our survey between December 2005 and February 2006. The current UK demography of people with cancer and people affected by cancer is not yet known – there is no national data to this effect. However, we ensured that we captured the diversity of the UK demography through the samples. In total, Macmillan Cancer Support spoke to the following:

- 606 people **with** cancer
- 550 people **affected by** cancer
- 595 people **not affected by** cancer

Of the people with cancer:

- One in ten (15%) received their cancer treatment from a private source or from a combination of NHS and privately funded sources
- More than eight in ten (86%) said that this was their first cancer diagnosis
- Half (53%) said that they were diagnosed between one and five years ago
- 18% were diagnosed less than one year ago

Of the people affected by cancer:

- Nearly a quarter (23%) said they were a 'primary carer' and 23% said they were a 'secondary carer'
- Less than half (45%) said the person with cancer was diagnosed between one and five years ago
- 19% said that the person with cancer was diagnosed less than one year ago

For the purposes of this report, a person affected by cancer is someone who:

- Provides unpaid or informal care for, or supports, a person living with cancer for the majority of the time (primary carer)
- Spends time caring for or supporting a person living with cancer, but is not the main carer (secondary carer)
- Provides support to someone living with cancer because they spend time with them and help them with errands

Research methods

To recruit people across the UK to take part in our research we used a number of methods, including: a telephone omnibus (regular) survey; an online panel (of a large number of people who have agreed to take part in research); and letters to trade and regional newspaper editors.

We gave people with cancer the option of being either interviewed by telephone or completing the questionnaire online. We offered people affected by cancer the opportunity to take part via the telephone. We interviewed people not affected by cancer via the telephone omnibus questionnaire only.

Chris's story

A few years ago I took a career break from my job as a nurse, and spent a fantastic year working in Australia with my then girlfriend. Shortly after our return, we were back at work, buying a house, with a positive future ahead.

Then I was diagnosed with cancer.

It was in May 2001 that life as I knew it was turned on its head. I felt completely well. But I'd found a lump whilst watching TV and asked the advice of a head and neck specialist at work. I was lucky that I had some idea about where to turn although it was still scary waiting for the needle biopsy results. The results of the biopsy were inconclusive but a few weeks later I was told that I had cancer.

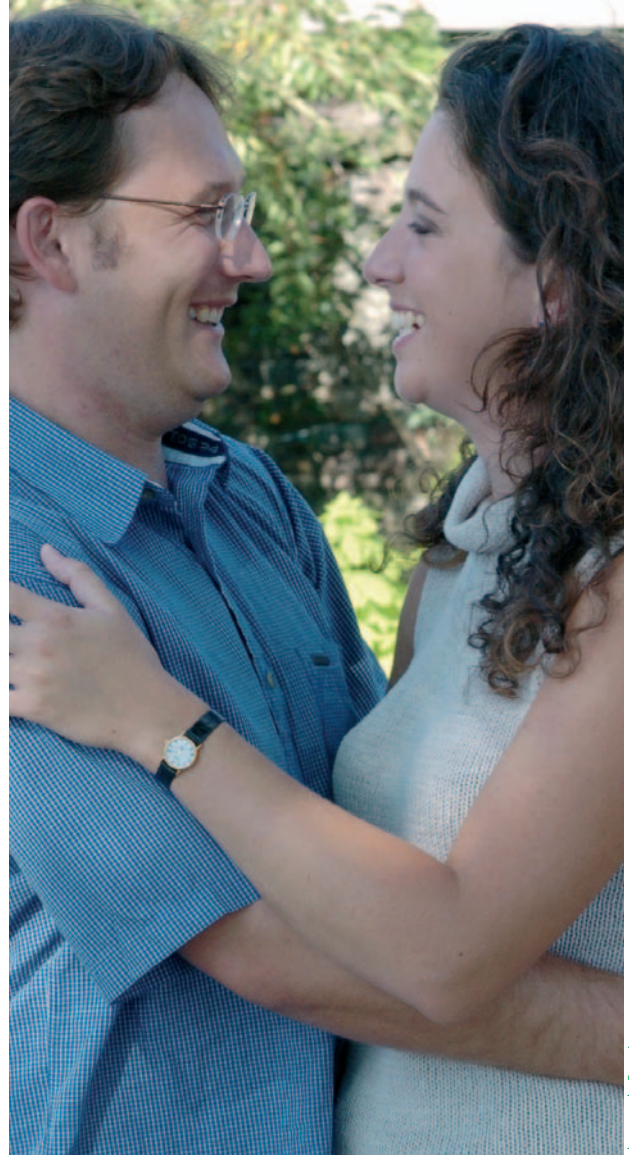
I was petrified. After a cancer diagnosis you lose the focus of control over your life and the next thing you know you're a charity case.

The NHS, well, they forget to ask, 'How are you feeling? How's your partner feeling?'. In the end it was a small charity that helped us both – they told me where I could find out about massage to ease my physical symptoms and we were both told about how to get counselling. I'm still having counselling now.

My girlfriend gave up work to look after me but we were so strapped for cash that she had to go back. Soon after, her temporary contract wasn't renewed. The worry about money made me even more stressed out.

Then there was the chemotherapy and radiotherapy and, in the end, the stress of the diagnosis, the treatment, the worry – well, it all got too much and we split up.

I couldn't afford to pay the rent on my own so I moved back in with my parents. They were great but even so I found it difficult back at home – starting from scratch when I was in my late twenties and used to being independent.



photograph: Peter Lomas

I found it hard to talk to friends and family about my cancer – I sometimes found myself counselling them.

But things are really looking up for me now. I have a lovely wife, a house, new job, and since January this year, I've been working with a hair studio, helping chemotherapy patients deal with hair loss. I can't complain.

Chris, 32

The impact of cancer on everyday living

Living with cancer every day

Cancer is still the UK's biggest killer, with one in four people still dying of the disease. This can make the prospect of cancer very frightening. However, as the population ages and survival improves, the number of people living with cancer continues to rise. Each year in the UK more than 275,000 people are diagnosed with cancer and overall it is estimated that approximately 2% of the UK population are alive having received a diagnosis of cancer: that's around 1.2 million people. Moreover, cancer does not discriminate. One in three of us will get cancer at some point in our lives and more people will require the relevant support in the future.³

A cancer diagnosis and subsequent treatment can have a devastating and debilitating impact on the lives of the person diagnosed, and their family and friends. This is why it is vital that people know where to go for good information, advice and support.

In *The NHS Cancer Plan*, the government states that:

'We want patients and their families to be confident that they will receive the information, support and specialist care they need to help them cope with cancer, from the time that cancer is first suspected throughout the subsequent stages of the disease. Good communication between health professionals and patients is essential. *The NHS Plan* will introduce new joint training across professions in communication skills. By 2002, it will be a pre-condition of qualification to deliver patient care in the NHS that staff are able to demonstrate competence.'⁴

However, Macmillan Cancer Support's *Worried Sick* report reveals that, of the people we surveyed who had received a cancer diagnosis:

- A quarter (26%) feel abandoned by the health system when they are not in hospital (**Figure 4.2**, page 12)
 - Women are more likely to feel abandoned than men (31% of women compared with 16% of men)
 - Younger people are more likely to feel abandoned than older people (only 16% of the over 65s felt this, compared with 35% of 25-34 year olds, 28% of 35-44 year olds and 33% of 45-54 year olds)
 - People who have completed their treatment are more likely to feel abandoned (27%) than those still to finish their treatment (14%)
- Over a third (37%) find the whole cancer support system confusing (**Figure 4.2**, page 12)
- A quarter (25%) do not feel confident about how and where to access all the health services available (**Figure 4.2**, page 12)
- Over a third (35%) do not feel confident about how and where to access social care and support (**Figure 4.2**, page 12)
- Almost four in ten (38%) people with cancer want information, advice and support about the health and social services available, but nearly half of those people (47%) say that they aren't able to get it (**Figures 2.1 and 2.2**, page 9)

'The person at the hospital said, "We're taking you off the treatment." And my husband said, "Well what happens now?" And they said, "Oh your GP will look after you." So we thought, well that's it then. It sort of put him on the scrap heap, you know.'

Main findings: The impact of cancer on everyday living

Our report also reveals that the perception of those not affected by cancer does not mirror the reality of living with the disease.

- Eight in ten (80%) people with cancer feel that you have no idea what it would be like to deal with cancer until you get it yourself (Figure 4.2, page 12)

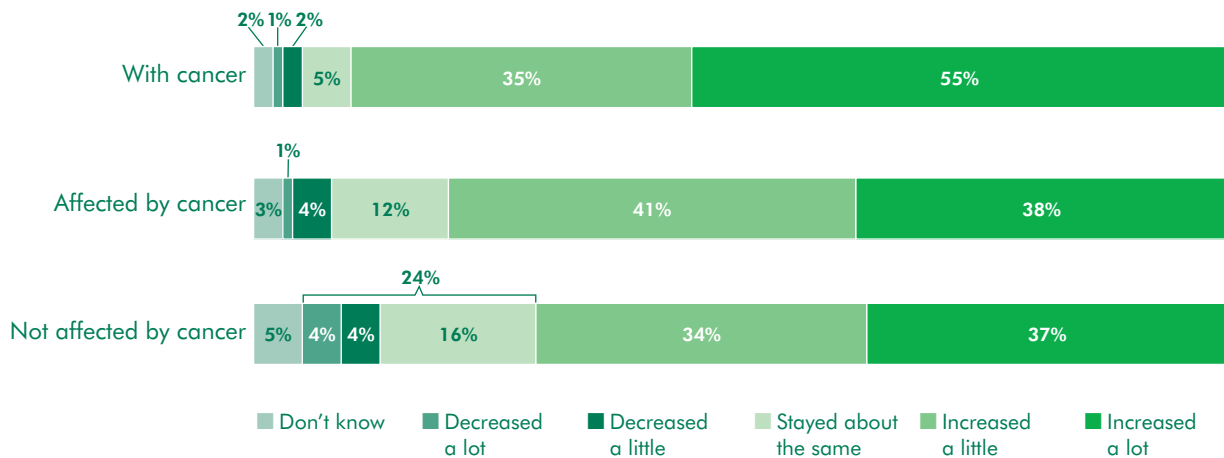
For example, people with cancer are more positive than those who have never been affected by cancer that they will live for longer:

- Nearly a quarter (24%) of people not affected by cancer do not think that survival rates for people

who receive a cancer diagnosis has increased over the last ten years – compared to 8% and 17% for people with and affected by cancer (Figure 1.1)

It is encouraging that people with experience of cancer are positive about their future. But it is worrying that a substantial number of people who have had no experience of the disease still view a cancer diagnosis as a death sentence. There is a need for improved public education and communication to remove the fear often associated with cancer.

Figure 1.1
Over the last ten years do you think that survival rates for people who get a cancer diagnosis has...?



Base (all respondents): not affected by 595; affected by 550; with cancer 606

‘When I was first diagnosed with breast cancer, I thought I was going to die within months. No one explained the concept of ‘living with cancer’ to me at the time. This was something I had to find out for myself.’

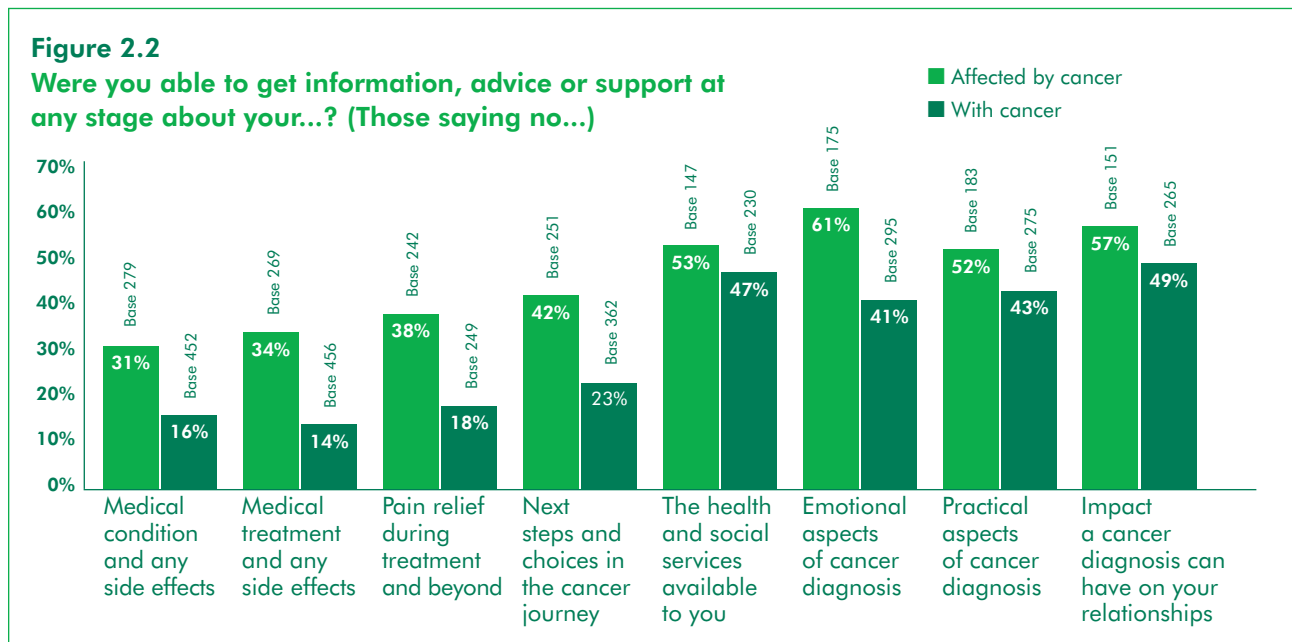
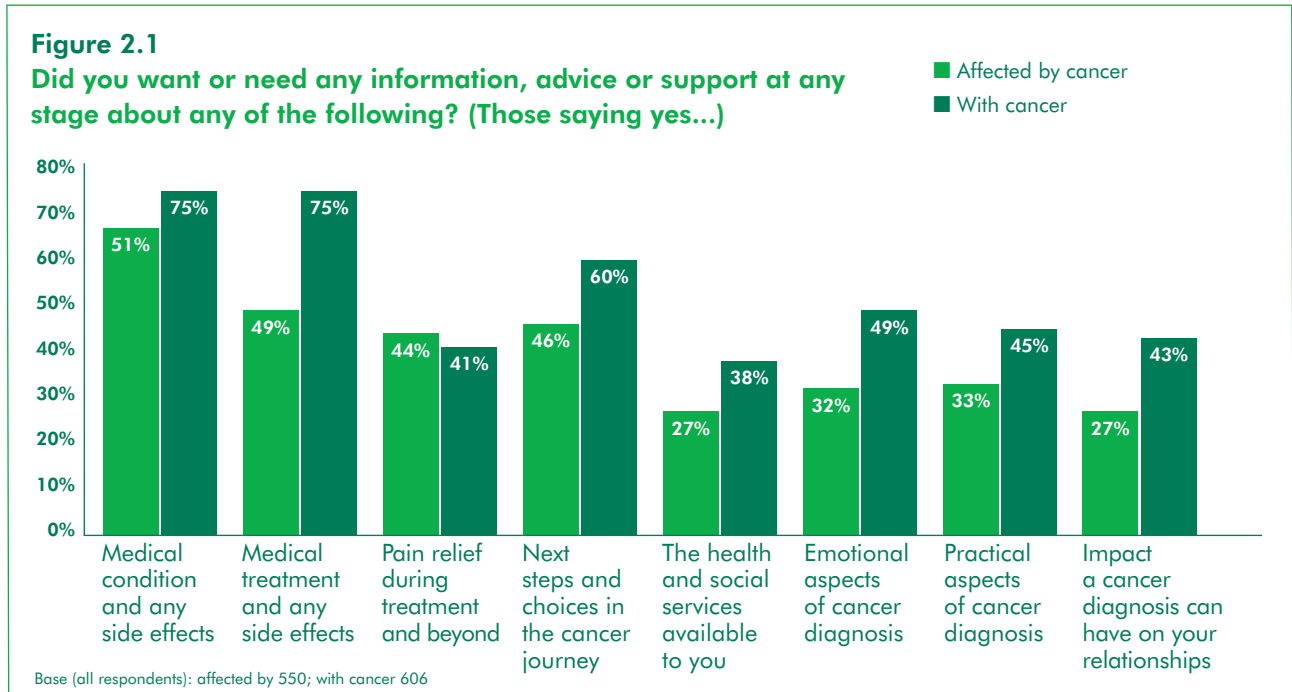
‘Coming to terms with living with cancer and not knowing where to go for help. You know your GP is a very busy individual and you feel a burden when you want to know things. Aftercare was virtually non-existent.’

Experience of the cancer information and support system

Current NHS Cancer Plan⁴ priorities and targets focus on reducing waiting times and mortality rates, and providing information.

However, our *Worried Sick* report reveals that:

- Of the three quarters (75%) of people with cancer who want information, advice and support about their medical condition and any side effects (Figure 2.1), a substantial minority – one in six (16%) – do not get this (Figure 2.2)
- One in ten (11%) people with cancer do not feel well looked after and cared for by hospital staff (Figure 4.2, page 12)



Main findings: The impact of cancer on everyday living

'Sometimes you don't make it to the bottom of the driveway before you throw up. I was ill. I was terrible. I was sick the whole way home, every single time.'

The physical impact of cancer

We know that some people with cancer experience unpleasant side effects following treatment, including fatigue and nausea.

Macmillan's *Worried Sick* report found that of the people with cancer interviewed:

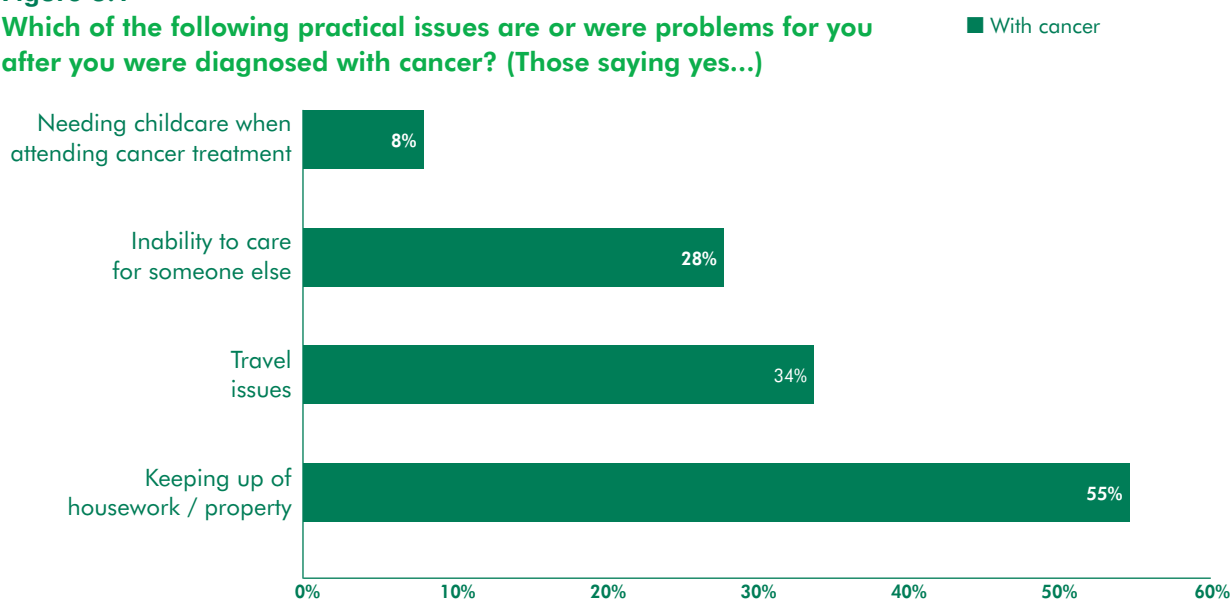
- Four in ten (41%) say that the physical effects are difficult to cope with (**Figure 4.1**, page 11)
 - People who work find the physical effects more difficult than those not working (49% of workers compared to 39% of those not working)

People with cancer also tell us that they have problems keeping things 'normal', such as running the household:

- Over half (55%) of people with cancer say this is a problem (**Figure 3.1**)
 - Two thirds (66%) of women say keeping up with housework and maintaining their property is a problem compared with only one third (32%) of men
 - Two thirds (66%) of people with cancer who have children under 18 years old are more likely to state this as a problem compared to half (51%) of those who are not parents
 - Older people are less likely to state this as a problem – a third (33%) of over 65s state this as a problem compared with 65% of 25-34 year olds, 61% of 35-44 year olds, 67% of 45-54 year olds and 54% of 55-64 year olds
- Nearly half (46%) of people who have children under the age of 18 agree that they are not able to care for their family in the same way as they did before

Figure 3.1

Which of the following practical issues are or were problems for you after you were diagnosed with cancer? (Those saying yes...)



Base (all respondents): with cancer 606

The impact of cancer on emotional well-being

Cancer can be frightening for the person diagnosed with cancer, and for family and friends who might be caring for them. Combined with the physical side effects of cancer and the difficulties of keeping life as normal as possible, the emotional impact of a cancer diagnosis can be enormous. More people who took part in our research cited the emotional effects of a cancer diagnosis as the most difficult to cope with.

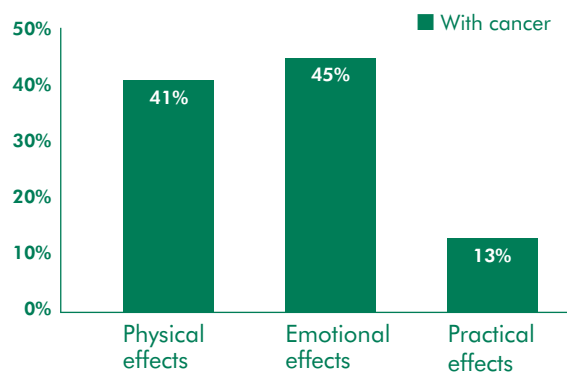
- More than four in ten (45%) people with cancer say that the emotional aspects of cancer are the most difficult to cope with, as compared to practical and physical effects (**Figure 4.1**)
 - More people with children under 18 years old find the emotional effects the most difficult to cope with than those people without children (55% compared to 42%)
 - More people from lower socio-economic groups find the emotional effects the most difficult to cope with than those from higher groups (59% of DEs compared to 41% of ABs)
 - More women than men find the emotional effects the most difficult to cope with (49% of women compared to 37% of men)
- Nearly six in ten (58%) people with cancer feel their emotional needs are not looked after as much as their physical needs (**Figure 4.2**, page 12)

Figures 2.1 and **2.2** on page 9 show that:

- While nearly half (49%) of people with cancer want or need information, advice or support about the emotional aspects of a cancer diagnosis, four in ten (41%) of these people are not able to get this help

'I think the worst bit is after treatment. The majority of people think, "She's fine now, she's had the cancer." They don't realise that I'm not.'

Figure 4.1
Having thought about the various effects of cancer, from your experience, which are the most difficult effects to cope with?



Base (all respondents): with cancer 606

'My marriage ending, my job ending (went back to work but couldn't cope with the pressures), feeling a burden on society and feeling weak in the head for not being able to get on with life. I am a big bloke who used to play rugby and for four years after treatment not being able to talk to people and spending time crying was and still is unbelievable.'

Main findings: The impact of cancer on emotional well-being

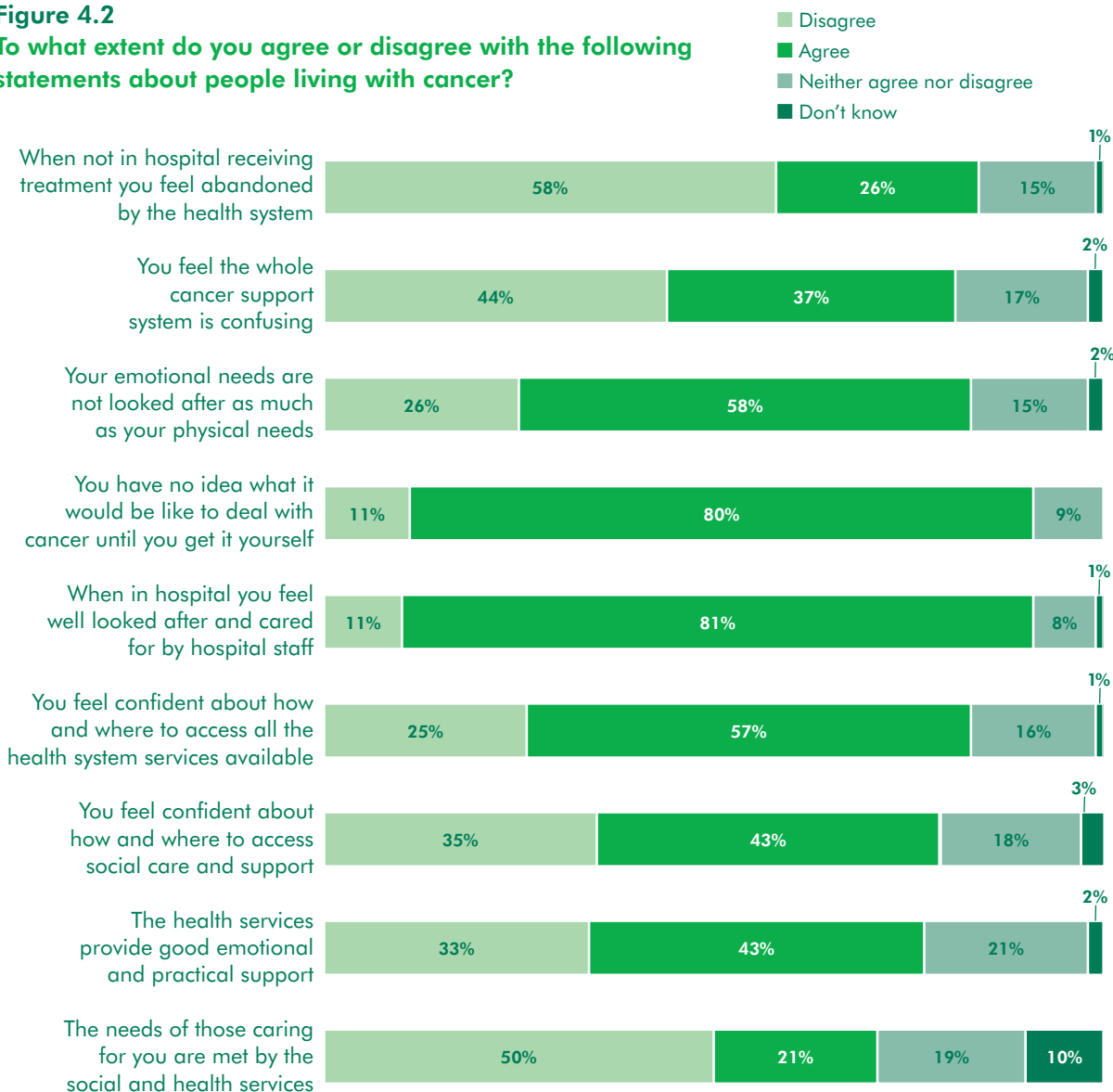
‘Coping with the children. When I was first diagnosed, my children were five, four and a newborn. I had to have the baby in hospital with me.’

Cancer, anxiety and depression⁵

Macmillan’s *Worried Sick* report also reveals that:

- Three quarters of people with cancer (75%) experience anxiety as a result of their cancer diagnosis (**Figure 4.3**, page 13)
 - Less than half of these people (44%) receive information, advice, support or treatment for this (**Figure 4.5**, page 13)
- For those with cancer, 34-44 (76%), 45-54 (87%) and 55-64 (79%) year olds are more likely than those aged 65 and older (56%) to experience anxiety
- Those people with cancer who receive their treatment on the NHS are more likely to experience anxiety (76%) than those receiving treatment privately (60%)
- More women than men say that they experience anxiety (79% of women compared with 66% of men)

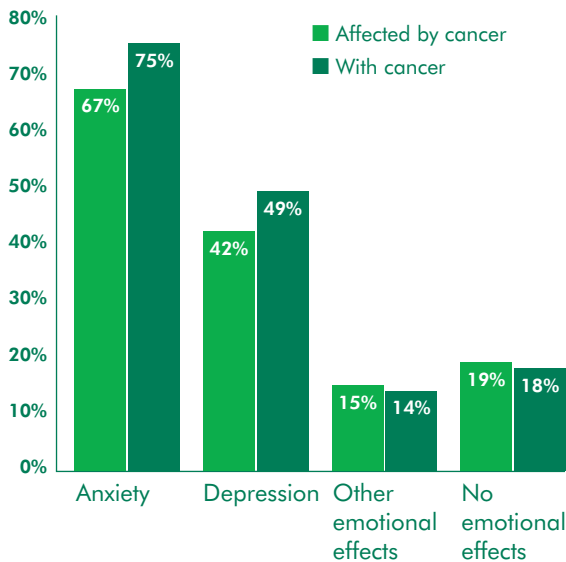
Figure 4.2
To what extent do you agree or disagree with the following statements about people living with cancer?



Base (all respondents): with cancer 606

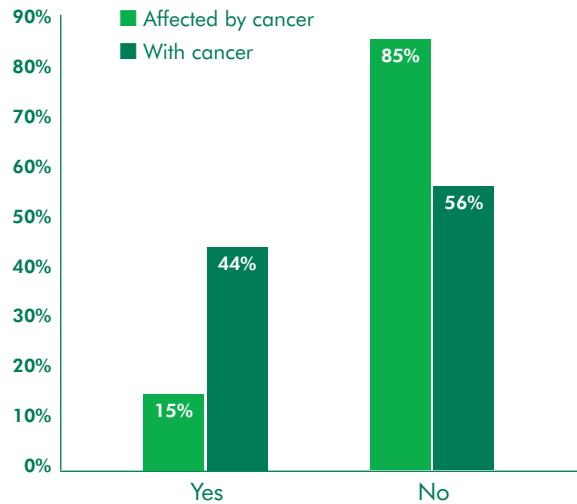
- Nearly half (49%) of people with cancer say they experience depression as a result of their cancer diagnosis (Figure 4.3)
 - Six in ten (60%) who experience depression do not receive any information, advice, support or treatment for this (Figure 4.5)
 - More women than men say they experience depression (52% of women compared with 42% of men)
- Of those who do receive information, advice, support or treatment to help with anxiety, depression and the other emotional effects of cancer, the vast majority rate it as 'good'

Figure 4.3
Have you experienced any of the following emotional effects as a result of the cancer diagnosis? (Those saying yes...)



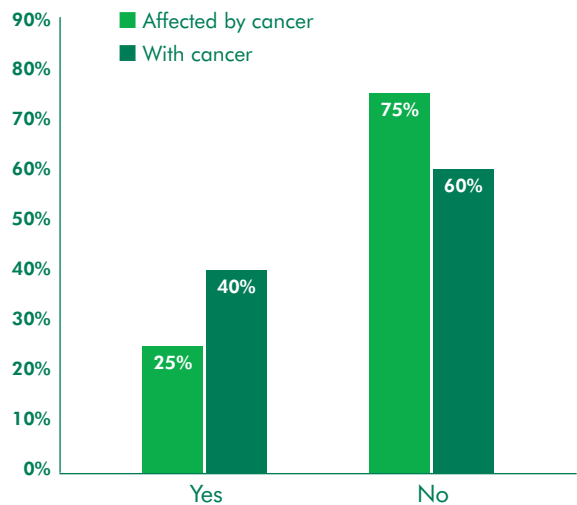
Base (all respondents): affected by 550; with cancer 606

Figure 4.4
Did you receive any form of information, advice, treatment or support to specifically help with this anxiety?



Base those experiencing anxiety: affected by 371; with cancer 454

Figure 4.5
Did you receive any form of information, advice, treatment or support to specifically help with this depression?



Base those experiencing depression: affected by 229; with cancer 294

'With my father, he was a very strong person and he was finding it hard to cope with himself. He wouldn't say how he was feeling, he wouldn't let anything in or out, and it was just difficult to communicate with him.'

Main findings: The impact of cancer on emotional well-being

'My relationship with my wife has deteriorated. Despite her being 100% supportive during the treatment, I feel she considers me unclean to the extent that we have had separate bedrooms ever since I was diagnosed.'

Cancer and relationships

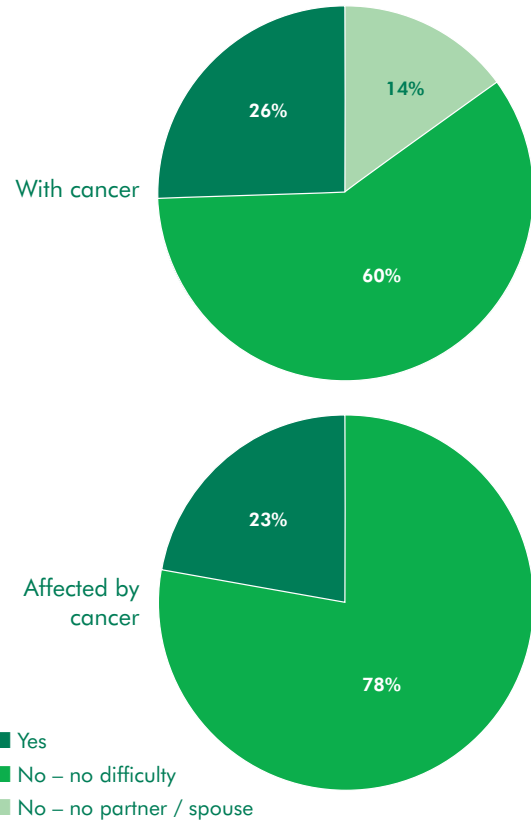
Worried Sick shows that many people experience fear, anxiety and depression because of their cancer diagnosis.

Our report also found that cancer adversely affects people's relationships with partners and other family members:

- A quarter (26%) of people with cancer say they experience difficulties in their relationships with their partner as a result of their cancer diagnosis (**Figure 5.1**)
- A quarter (25%) of people who experience difficulties say that they have broken up with their partner as a result of their cancer – and one in ten (12%) have seriously considered doing so (**Figure 5.2**)
 - More women than men say that they have broken up with their partner (31% of women compared to 11% of men)
 - People with cancer who have children under 18 years of age are more likely to experience difficulties in their relationship with their partner as a result of their cancer diagnosis (42% of parents compared with only 21% of people who do not have children under 18)
- Almost a third of people with cancer (32%) say that their relationships are put under 'enormous strain' (**Figure 5.3**, page 15)
- Four in ten (43%) people living with cancer say that their sex life suffers (**Figure 5.3**, page 15)

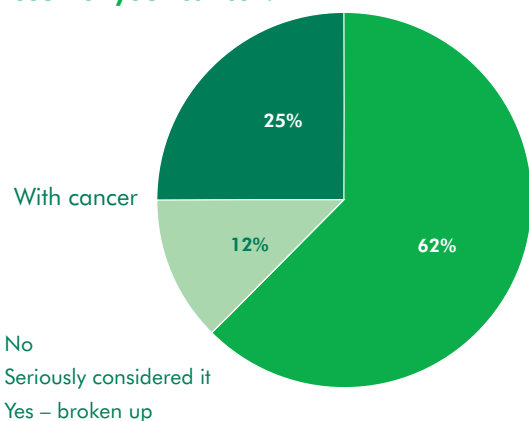
'I think that the person who has the cancer gets information and support. But at no time did anyone speak to my husband. Maybe it would have helped, and we may have even stayed together.'

Figure 5.1
Have you experienced any difficulties in your relationship with a husband, wife or partner as a result of your cancer diagnosis?



Base (all respondents): affected by partners/spouses 80; with cancer: 606

Figure 5.2
Have you broken up with your partner or has either of you seriously considered doing so as a result of your cancer?



Base: with cancer 158

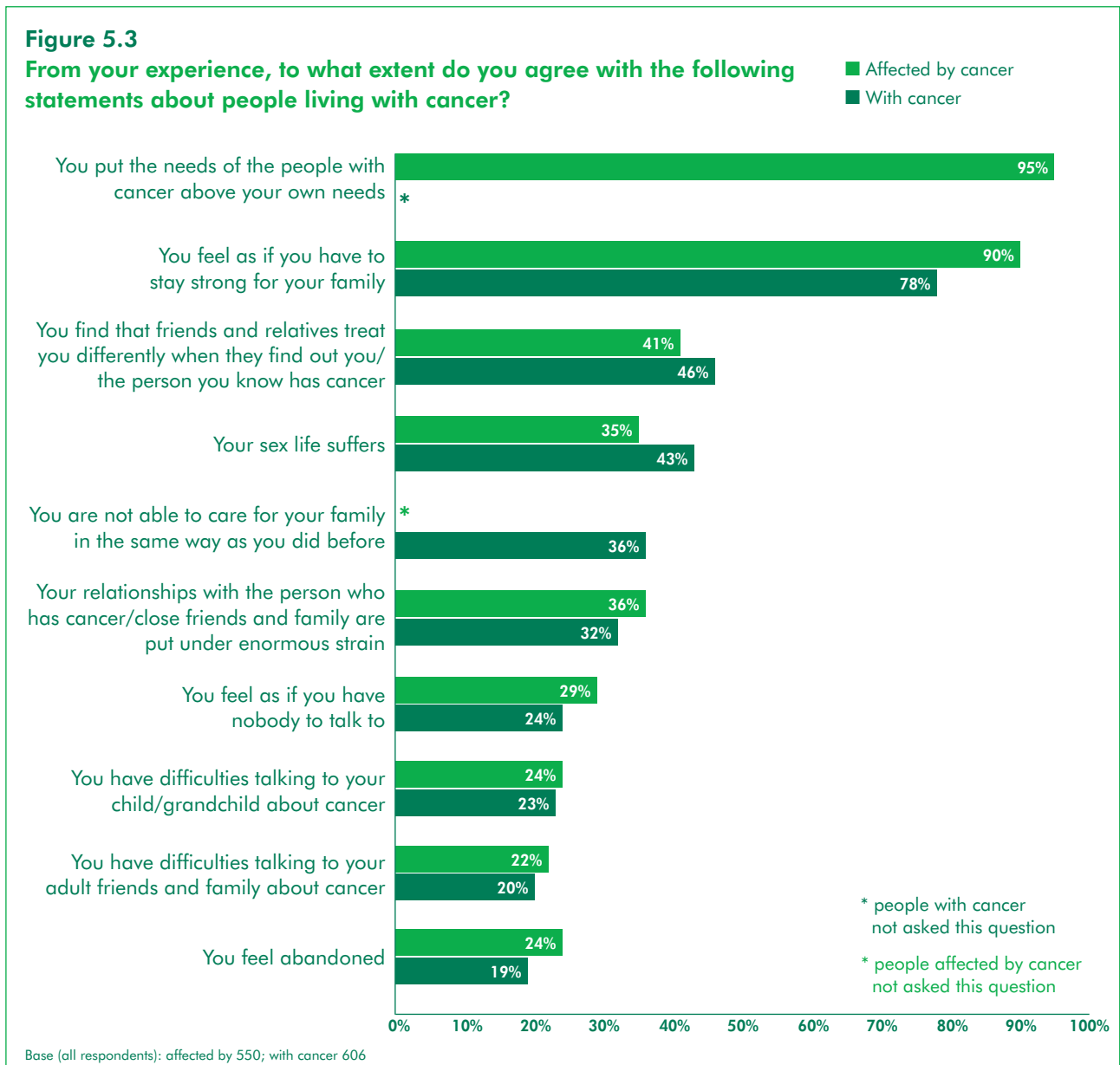
'I was fairly young when I was first diagnosed. I feel I missed out on part of my childhood. While my friends were out finding out about life and relationships, I spent most of my time in hospital. I still find it hard to form relationships.'

Some people with cancer find it difficult to talk about their condition. They do not always know who to talk to, or how to talk to them. This can have a major impact on their relationships with family members and friends.

- One in five (20%) find it hard to talk to their adult friends and family about their cancer
- Nearly half (46%) feel that friends and relatives treat them differently when they find out they have cancer

As **Figure 5.3** shows:

- A quarter (24%) of people with cancer feel that they have nobody to talk to
- Just under a quarter (23%) have difficulty talking to their children and grandchildren



Julie's story

When my Dad was diagnosed with prostate cancer in August 1997, I had no idea what was ahead. At first he put on a brave face – he didn't want to worry us – so as a family we didn't realise how advanced his cancer was. That all changed when I became his main carer.

Four years after Dad's diagnosis I went with him to a hospital appointment. Mum wasn't coping very well and Dad was having panic attacks too. That's when I realised how ill and scared he was; he really needed support.

After that, I went with him to all the appointments and, as his cancer spread, I got more involved with his care at home. It was a relief to know the facts but it was also a big shock. I went from knowing little about his illness to being the one in the room when the consultant delivered the results. Dad also found it hard to take in all the information about his medication, so I started to make notes about all the drugs and doses as well.

The Macmillan nurses were a great support. It was good because they came to Dad at home, which meant he didn't have to travel to hospital every time he needed more pain relief. They were also at the end of the telephone if we had any questions and took a real interest in who was there to support Dad and how we were coping.

The last person I'd thought about was me though – after all Dad was the one with cancer, the one in pain and having to go to the hospital. It wasn't until a nurse asked me how I was that I broke down. I'd been holding everything together, for Dad, for the family.

That's when I was introduced to the Macmillan counsellor. I saw her on and off as Dad's treatment continued and I could ring for an appointment when I needed it. It was my time, a place for me to talk about Dad, my fears, how to cope.



model photograph

I honestly don't know what would have happened if I hadn't been offered this help. I certainly couldn't have gone on as Dad's carer. I could have found myself a counsellor I suppose, but the difference with my Macmillan counsellor was that she understood all the issues that were relevant – Dad's cancer, the pain, the strain of being a full-time carer.

I cared for Dad for three years and thanks to Macmillan's support, I was literally strengthened for the last stages of Dad's illness, which made such a difference to him, me and the whole family.

Julie, 34

The impact of cancer on carers

There are currently six million informal carers living in the UK – ten per cent of the UK population – and women are more likely to be informal carers than men. There are more carers aged 50-59 years than any other age group, and one in five people in that age group provide unpaid care.⁶ In our survey, nearly a quarter (23%) of people affected by cancer defined themselves as a 'primary' carer.

Informal carers often need support so that they can live as normal a life as possible, while caring for the person they know and love who has cancer.

Yet our research reinforces findings of previous studies⁷ which reveal that the needs of carers are rarely considered, let alone met.

When we asked people affected by cancer about their own needs:

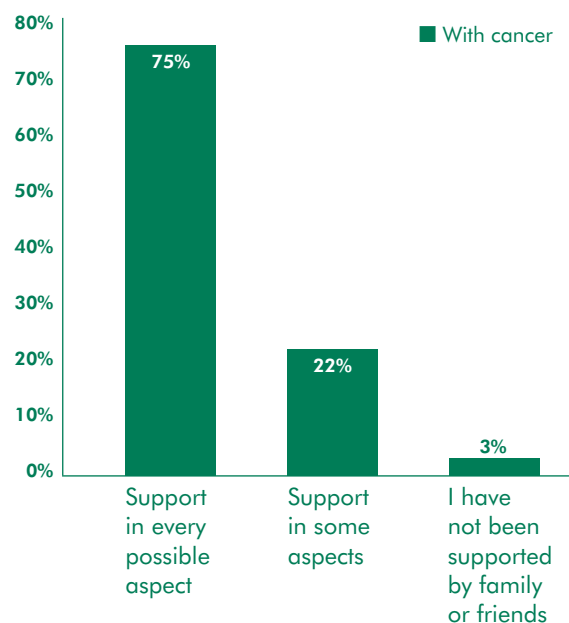
- Nearly everyone (95%) feels that they put the needs of the person with cancer above their own needs (**Figure 5.3**, page 15)
- Almost a quarter (24%) feel abandoned (**Figure 5.3**, page 15)
- Six in ten (61%) people who need and want information, advice and support on the emotional aspects of a cancer diagnosis, do not receive it (**Figure 2.2**, page 9)
- Two thirds (67%) experience anxiety (**Figure 4.3**, page 13)
- Eight in ten (85%) people who experience anxiety do not receive information, advice, support or treatment for it (**Figure 4.4**, page 13)
- Four in ten (42%) experience depression (**Figure 4.3**, page 13)
- Three quarters (75%) of people who experience depression do not receive information, advice, support or treatment for it (**Figure 4.5**, page 13)
- Over a third of people (36%) feel that their relationship with the person who has cancer, and with family and friends, is put under 'enormous strain' (**Figure 5.3**, page 15)

- Nearly a quarter (23%) say they experience difficulties in their relationship with their husband, wife or partner (**Figure 5.1**, page 14)
- Nine in ten (90%) feel they have to remain strong for the person with cancer (**Figure 5.3**, page 15)

We also asked people with cancer about the needs of, and levels of support provided by, their carer, family members and friends:

- Only one in five (21%) feel that the needs of the person/people caring for them are met by health and social care services (**Figure 4.2**, page 12)
- Three quarters (75%) say that their family and friends provide support in every respect (**Figure 6.1**)

Figure 6.1
Which of the following best describes the level of support your friends and family provides throughout the cancer journey?

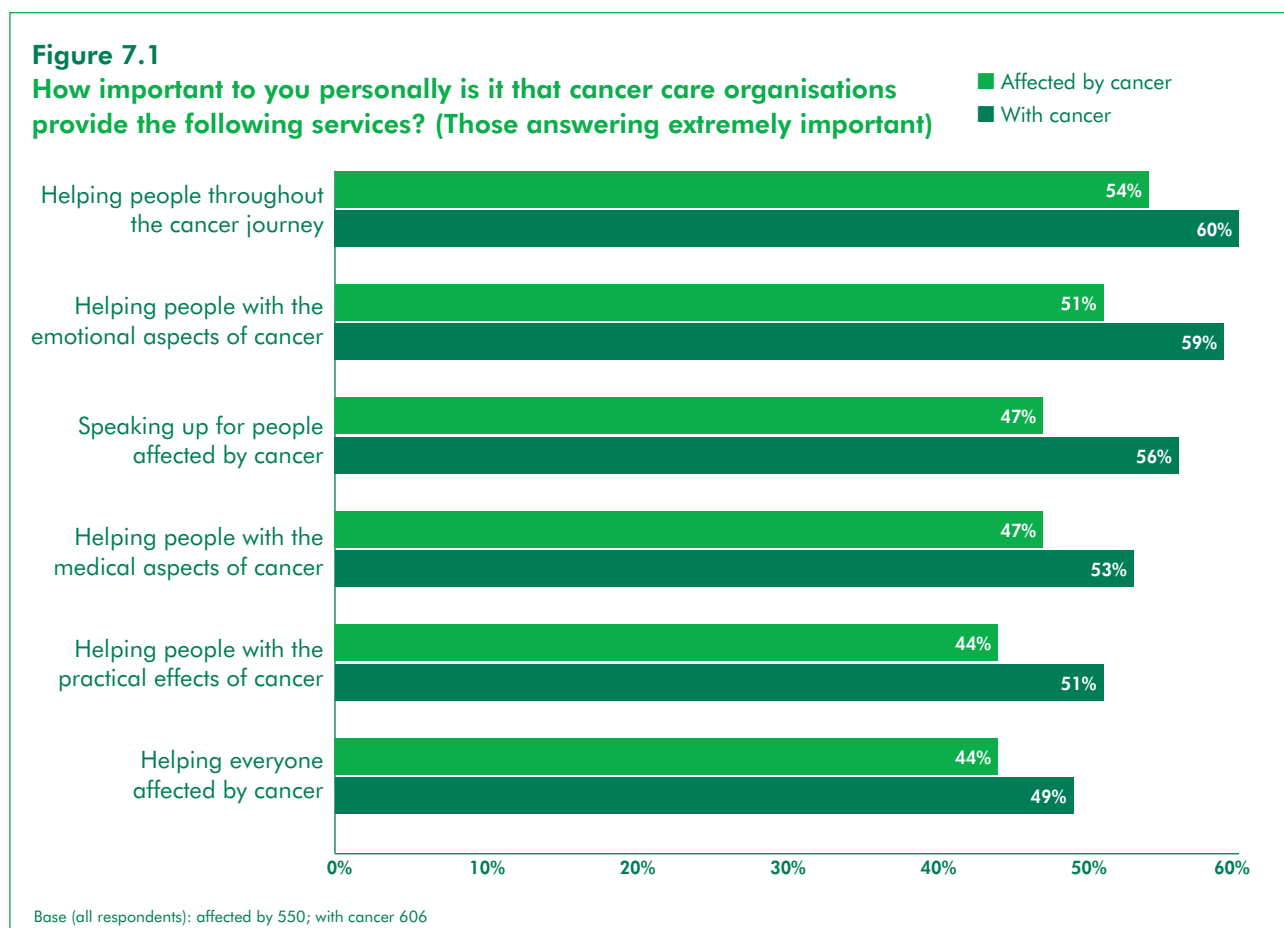


Base (all respondents): with cancer 606

What people expect from cancer care organisations

As **Figure 7.1** shows, Macmillan's report finds that people with and affected by cancer think it's 'extremely important' that cancer care organisations consider the emotional and practical needs that follow a cancer diagnosis:

- Nearly six in ten people with cancer (59%) and half of people affected by cancer (51%) believe it is 'extremely important' that cancer care organisations help people with the emotional aspects of cancer
- Half of people with cancer (51%) and four in ten people affected by cancer (44%) believe it is 'extremely important' that cancer care organisations help people with the practical effects of cancer

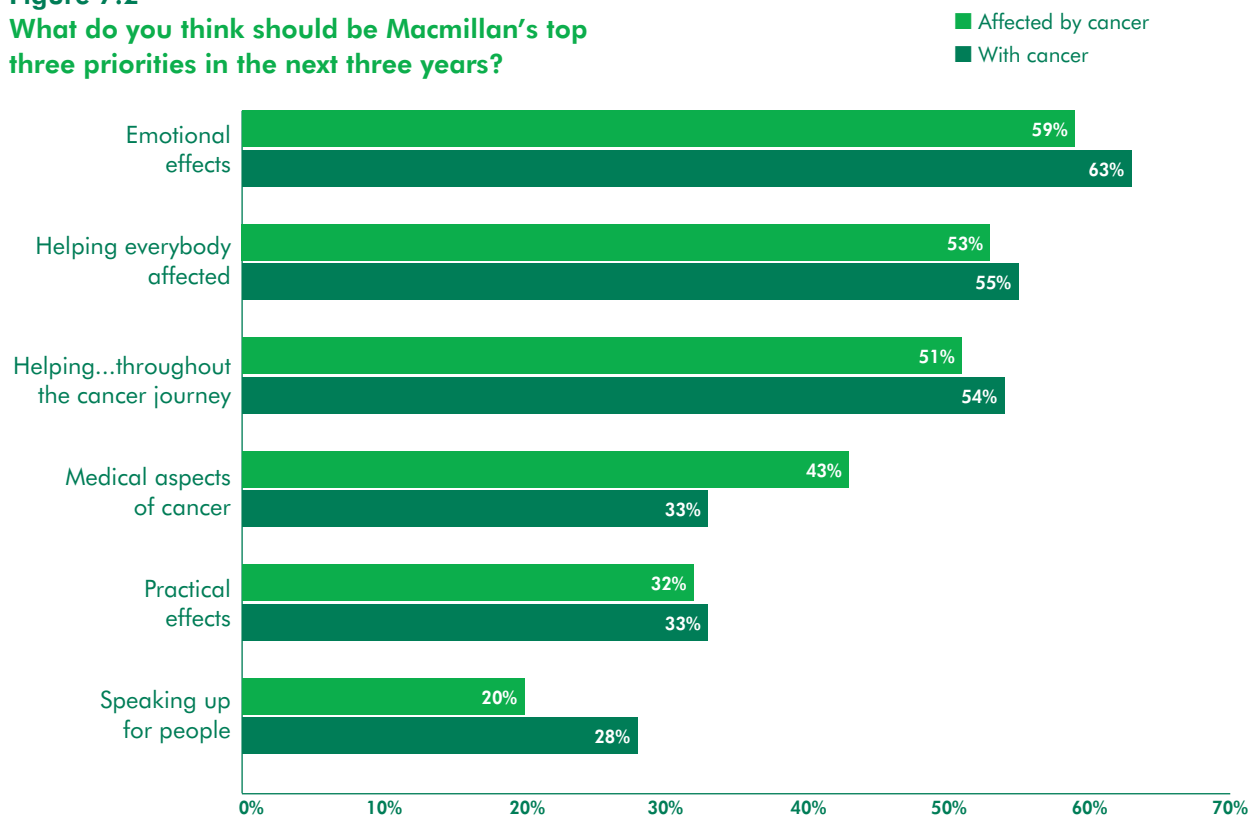


'I think cost should not be an issue in the care and treatment of serious illness. In fact, government should take full responsibility for all illness, why should we rely on charity for something we are entitled to, namely the NHS?'

When asked ‘What do you think should be Macmillan Cancer Support’s top three priorities in the next three years?’:

- Nearly two thirds (63%) of people with cancer and nearly six in ten (59%) people affected by cancer, say helping with the emotional effects should be Macmillan’s top priority (**Figure 7.2**)
- More than half (55%) of people with cancer and half (53%) of people affected by cancer, say helping everybody affected by cancer (**Figure 7.2**)
- Half (54%) of people with cancer and half (51%) of people affected by cancer, say helping people throughout the cancer journey (**Figure 7.2**)

Figure 7.2
What do you think should be Macmillan’s top three priorities in the next three years?



Base (all respondents): affected by 550; with cancer 606

Implications for Macmillan Cancer Support and recommendations to government

The findings of Macmillan's *Worried Sick* research reveal just how devastating and debilitating a cancer diagnosis is on the lives of people with and affected by the disease. The emotional impact of receiving a cancer diagnosis is huge. Coping with this on a day-to-day basis is very difficult. Anxiety and depression among the people who participated in our research is widespread. However, more than this, living with cancer puts a huge strain on family members and partners and this strain has resulted in a quarter of people with cancer experiencing relationship difficulties, with nearly a quarter of those people actually breaking up with their partner (nearly 7% of the total number of people with cancer).

The pattern of cancer treatment has been changing over recent years. Much cancer treatment, such as chemotherapy or radiotherapy, is now given to people during frequent and prolonged outpatient visits to hospital or even at home. This means that much of the burden of living with the physical and emotional after-effects of treatment rests with family members and friends, who often need to take on caring responsibilities. People tell us that the emotional effects of treatment are the most difficult to cope with. However, trying to manage the practical and financial aspects of life around this – housework, childcare, work, caring responsibilities for other family members – is extremely difficult.

Although previous research has revealed some of these issues, we were not prepared for the extent of the difficulties people have reported, such as the impact that cancer has on people's closest relationships.

For many years now, Macmillan has been working to provide the kind of support people and their families and carers need. We have done this through our network of Macmillan professionals, through our information and support services, and through the way we influence government and the health service. But clearly this is not enough. More people need Macmillan's help – we need to develop more services, and get them to people when and where they need them. We are committed to extending the network of our support services so that more people living with cancer can get the help they need, and we will invest more in help and support for people managing their illness outside of hospitals.

We intend to offer every person in the UK living with cancer contact with Macmillan in a way that is appropriate and relevant to them, to help them find the support they need to live with cancer.

We will provide a personalised service for people and their families, giving them information and support and helping them navigate their way through the system. We will also provide opportunities to share experiences with other people living with cancer and to speak to those who have power and influence to improve cancer practice and policy.

Nevertheless, this alone is not enough. We need to influence government to address the needs we have identified and drive up standards in cancer services.

This study provides further evidence for cancer organisations, government and other decision-makers that they must work together to develop a new approach to cancer support.

Macmillan Cancer Support makes the following recommendations:

Recommendation 1: Governments across the UK should develop and/or update Cancer Plans that go beyond treatment of the disease, and address matters that affect the quality of life and wider social needs of people with and affected by cancer throughout their lives

The NHS Cancer Plan for England is an example of the significant progress that can be made to the experience of someone at the start of their cancer journey. People who suspect they have cancer are diagnosed and receive treatment sooner, and mortality rates are therefore falling.

We warmly welcome progress made, yet the current *Cancer Plan* priorities and targets do not fully reflect what people with and affected by cancer actually want. Reducing mortality rates and waiting times is not enough and leads to new challenges that require policy solutions. Our research demonstrates we need a new approach to tackling cancer, which is from the perspective of the person with and affected by cancer, and which looks after the whole person, not just their disease. This starts with a strategy that focuses on prevention, and ends with one that aims to help people with and affected by cancer resume as normal and healthy a life as possible. Or, on the other hand, to make sure that they have the end of life care and support they want. It must also involve co-ordination of care. This would help achieve a seamless provision of health and social care so that people with and affected by cancer do not get lost in, or feel abandoned by, the system.

This joined-up, cross-departmental approach to tackling cancer, where quality of life concerns are central, should form the basis of cancer strategies in each of the nations of the UK.

**Recommendation 2:
The NHS should give greater priority to creating, funding and sustaining services across the UK that address the emotional, practical, information and support needs of people with and affected by cancer**

Our research shows that far too many people with and affected by cancer feel abandoned by health and social services. They also go without the emotional and practical support they need in order to lead as normal life as possible during their cancer experience.

Government policy to provide better supportive and palliative care in England and Wales is in place. In March 2004, the National Institute for Health and Clinical Excellence (NICE) published its *Guidance on Cancer Services*.⁸ Yet the *Guidance* has not been given additional funding by government, and Primary Care Trusts (PCTs) have not given it sufficient priority.

Our research shows that implementation of the NICE *Guidance* is vital and that development of similar supportive and palliative care provision in Scotland and Northern Ireland is as important to cancer patients and carers as the rest of the treatment they receive.

We are concerned that, in the short term, current NHS structural and financial reforms may actually worsen cancer patients' and carers' feeling of abandonment.

**Recommendation 3:
The NHS should carry out regular surveys that measure things that matter most to people with and affected by cancer at all stages of their cancer experience, and not just when they are in hospital. They should also find effective ways of involving people with and affected by cancer so that services become more person-centred**

Macmillan's research will come as a surprise to many policymakers. They assume that people want good treatment and that supportive and palliative care is 'nice-to-have'. Our research shows they are mistaken. There needs to be long-term NHS funding for regular patient surveys and improved ways of involving cancer patients, and those that care for them, in the development and evaluation of cancer services. Only then will cancer services reflect the needs and wants of people with and affected by cancer in the future.

- 1 Department of Health, *The NHS Cancer Plan: A plan for investment, a plan for reform*, London, 2000

Scottish Executive Health Department, *Cancer in Scotland: Action for change*, 2001

Wales and Northern Ireland do not have *Cancer Plans*
- 2 For further information on Macmillan's Better Deal campaign, please visit www.macmillan.org.uk/campaigns
- 3 www.cancerresearchuk.org/aboutcancer/statistics
- 4 Department of Health, *The NHS Cancer Plan: A plan for investment, a plan for reform*, London, 2000
- 5 People with and affected by cancer were asked if they experienced feelings of uneasiness and/or apprehension about future uncertainties (anxiety) or feelings of extreme sadness, guilt and/or despondency (depression). People responding yes will not necessarily have been diagnosed with clinical anxiety or depression.
- 6 Carers UK leaflet, *Facts About Carers*, Carers UK, April 2005
- 7 Carers UK, *Missed Opportunities: The impact of new rights for carers*, Carers UK, 2003

This reported that only 32% of carers had had a carers' assessment while half of carers are not informed of their right to an assessment at the time the disabled person is assessed.
- 8 National Institute for Health and Clinical Excellence (NICE), *Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer*, NICE, March 2004

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