

Hidden Heartache

The untold story of bowel cancer



beatingbowelcancer.org



01. Welcome

Every 15 minutes someone is diagnosed with bowel cancer. As the support and campaigning charity for everyone affected by bowel cancer, we commissioned this landmark research project to help shine a spotlight on the impact of bowel cancer on patients, and their families and friends.

This report reveals moving diaries from those living with bowel cancer and the issues faced by family and friends. We know that bowel cancer doesn't just affect those going through the disease, but also hits hundreds of thousands of family members and friends hard.

Bowel cancer might be a dark cloud hanging over people, but with the right support and information, we can help relieve fears and anxieties. We want to be here for everyone affected by bowel cancer – whether they're going through it themselves or supporting someone who is.

In this report you can read first-hand what patients and families are facing and we hope you will support us so we can be here for all patients, and their families and friends, into the future.

Mark Flannagan, Chief Executive of Beating Bowel Cancer

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“

Although I do make light of it, I am not frightened of dying and I am not frightened of cancer what I am frightened of is living the way I am and that is what they don't prepare you for.”

– Natty, 55, patient who currently has bowel cancer.

02. Introduction

Abandoned, helpless and with nowhere to turn are just some of the words used by patients and their families and friends to describe the impact of bowel cancer.

Every year in the UK more than 41,000 people are diagnosed with bowel cancer and it's the second biggest cancer killer.¹ But if diagnosed early, more than nine in ten people survive.² With survival rates improving, we need better support for people with bowel cancer before, during and after treatment.

This ground-breaking new study shows the hidden heartache of bowel cancer for the first time. Almost 700 patients, family and friends took part in our research, sharing with us the often harrowing details of their experience of living with bowel cancer.

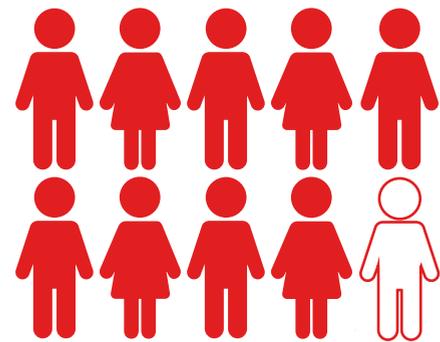
The report highlights good practice, but also shows that more needs to be done. Our study reveals that for many, the shadow of the illness is never far away and, above all, they need support and help; be it talking to others in a similar position or talking to experts.

We asked a number of patients and family members to keep a diary and this was painfully revealing, with spouses and close relatives struggling to cope.

Shockingly, 7% of patients and 15% of family and friends reported that they have no one to speak to.

One of the recurring themes from the study is that feelings of helplessness, panic and isolation can be all-consuming.

This is why it's so important that patients, families and friends get the emotional and psychological support and the information they need.



more
than **9** in **10**

survive
if diagnosed

early

1. Cancer Research UK, Bowel Cancer Statistics. Available at: <http://www.cancerresearchuk.org/health-professional/bowel-cancer-statistics> [Accessed: 23 Feb 2016].

2. Cancer Research UK, *Bowel cancer survival by stage at diagnosis*, December 2014

“ I didn’t sleep at all. I just lay with my mind racing. My world is totally different, out of control, and the near and distant future is all a mystery.”

Patricia, 65, patient who currently has bowel cancer.

03. The impact of bowel cancer

3.1 **Never far away...**

For patients, family and friends bowel cancer is constantly on their mind – its shadow rarely goes away.

Lives become consumed by bowel cancer, both through the illness itself, and the conversations that tend to revolve around it; little else is discussed.

With thoughts and discussion about cancer never far away, being around others who are not aware of their bowel cancer can give patients a sense of relief, and a break from being ill.

“

Bowel cancer is never off my mind.”

- Kerry, 48, daughter-in-law of patient who currently has bowel cancer.

The craving and savouring of normality was something many patients, and family and friends, talked about.



Helen's diary

Because I haven't lost any of my hair, none of my neighbours know there is anything wrong with me. So I had a very lovely and normal evening with nobody knowing and everyone just discussing life, work and what's been on TV recently.

43, patient who currently has bowel cancer

With the confirmation of the diagnosis, patients face the reality that their life may be cut short, and they have very little control over it.

Their sense of mortality increases and they feel almost in a state of suspension as they wait to see what happens.

For family and friends, they are constantly watching what their loved one is going through and have to consider the possibility of a future without them.

“

Receiving your diagnosis is frightening, you suddenly become aware of your own mortality and you think “I am going to die”.

No one can really prepare you for the news.”

- Christine, 56, patient who currently has bowel cancer.

These feelings of despair and anguish can be worse at night, when people struggle to control their thoughts and have no one to talk to.

Whilst some patients' sleep is unaffected, many others struggle to sleep through the night. For many, physical or emotional pain is never far away. Nights can be long and lonely.

Even when considering a situation where the all-clear has been given, the prospect of the cancer returning is never far away for the majority of patients (76%) and many (43%) of the family and friends.

76
percent

of patients are still worried about their cancer returning

43
percent

of family and friends do too

Patricia's diary



I had a very unsettled night; mind in overdrive. I didn't sleep at all, I just lay with my mind racing, thinking about all I have been through in the past six years.

The misdiagnosis, the treatments, the operations, the effect it all has had on myself, my husband, my family and friends, and my lifestyle. My world is totally different, out of control and all a mystery in the near and distant future. I don't have many times like this, but it is a necessary safety valve where I try to put all into perspective. Who do I turn to in the middle of the night? Why... myself of course!

65, patient who currently has bowel cancer.

3.2 The impact on family, friends and relationships

As with most conditions attention tends to focus on the patient but our study found that family and friends often need support, in some cases as much as the patient themselves.

For both patients and family and friends the condition can put serious strain on relationships, particularly with partners.

Some find they are disagreeing more, and others are short of quality time.

However for some, the support received from the people they are closest to has helped improve pressured relationships.

“

I look at my husband and think that it's so unfair he is going through this, he is the best daddy and husband there is. I wonder why him? Why us? How can I find the strength to help him through it?"

- 40, wife of patient who currently has bowel cancer.



“

My best friend Andrea and her daughter were there... She's been great since I've been ill. She's really caring and texts me all the time to check I'm okay and if I need anything. The support of friends and family has helped so much over the last 6 months since I was diagnosed.”

- Sophie, 32, patient who currently has bowel cancer.

04. Meeting support needs

4.1 Supporting patients

The extent of support patients receive when living with the condition has a significant impact on their quality of life.

Patients were broadly positive about the extent to which their support/care/information needs are being met at various stages of the condition with patients feeling most confident during treatment (85%), when understanding treatment and treatment options (82%) and initially after diagnosis (77%).

After treatment, confidence is lower. 65% feel their needs are being met when dealing with the after-effects of bowel cancer, dropping to 60% in the first few weeks after treatment, and then 57% in the first year after treatment has ended.

However most tellingly, only 39% of patients felt that their needs were met before their diagnosis when they did not know what was wrong.

65
percent

of patients feel their needs are being met when dealing with after-effects

39
percent

of patients felt their needs were being met before their diagnosis

“ In my case, I would have liked some form of counselling or emotional support after the treatment had finished, particularly after my stoma removal.”

61, patient who had bowel cancer in the past.

4.2 Supporting family and friends

While it is only right to focus on supporting people with bowel cancer, it's vital not to forget family and friends.

Family and friends are less confident and know less about where to obtain support and information than patients at every stage of the journey. 66% feel their needs are being met during treatment; 60% when understanding treatment and treatment options; 55% when dealing with after effects.

In the first few months after treatment this falls to 33%; 32% in the first year after treatment and 31% prior to diagnosis.

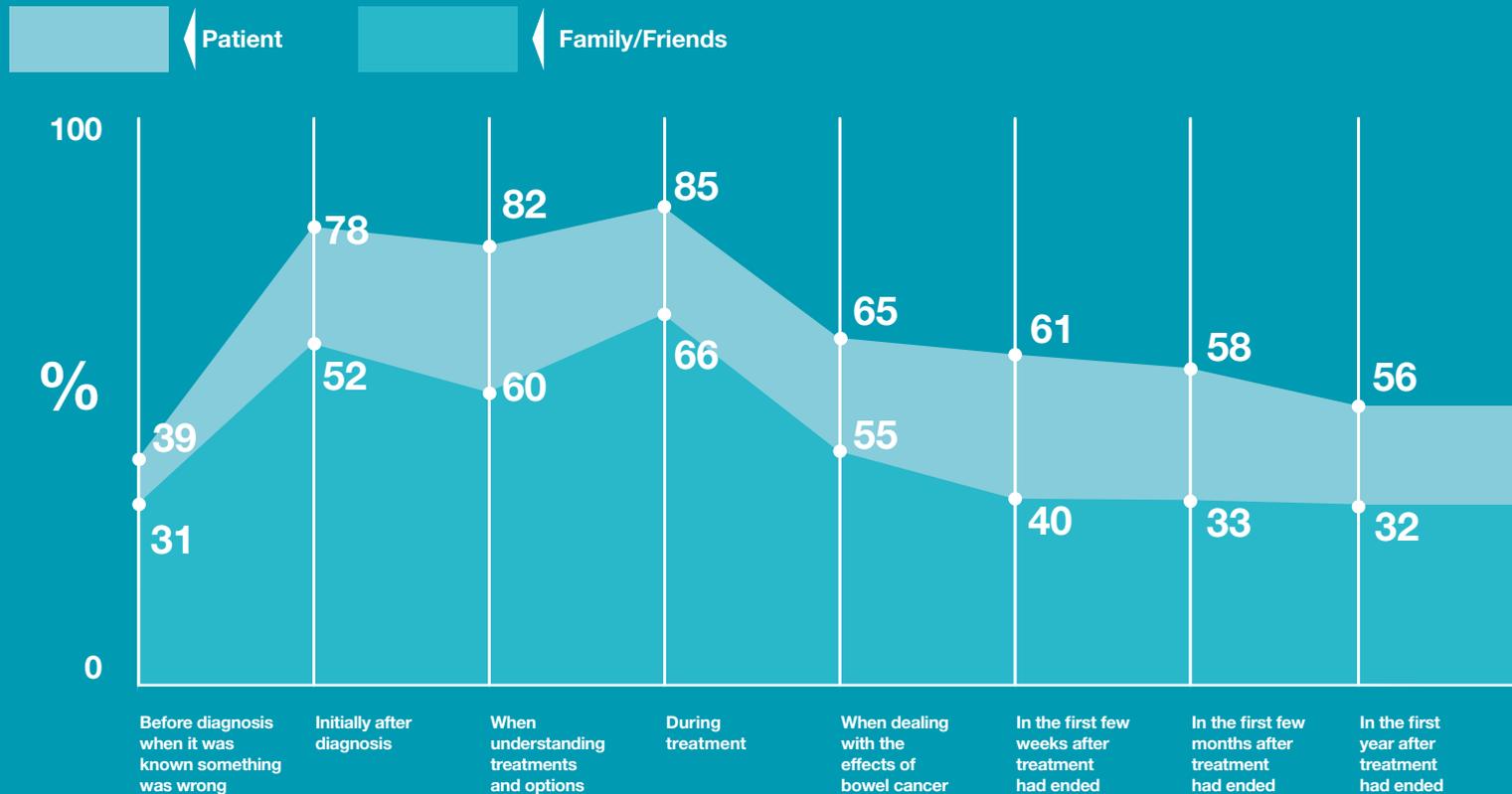
Perhaps most shocking of all, only 27% of family and friends felt their information and support needs were met after the death of their friend or relative.

“

I would like a forum for those of us bereaved by bowel cancer. When my husband died, I felt like that had to be the end of my relationship with the forum and I was suddenly totally alone.”

– 40, wife of someone who died from bowel cancer.

Percentage of people who felt their needs were met...



83%

of patients

Know where to obtain information and support about bowel cancer

71%

of family and friends

78%

of patients

Are confident when talking to other people about bowel cancer

57%

of family and friends

4.3 What's getting in the way?

Both patients, family and friends, often experience the same barriers accessing the right information and support.

Negative information

People finding and being overwhelmed by the negative information, particularly when searching the internet.

“

Getting lost or scared in Google.”

- 51, patient who currently has bowel cancer.

Fear of what they might find out

What they might find out was given as a reason for not accessing information and support.

“

Fear, embarrassment, depression.”

- 43, daughter of patient who currently has bowel cancer.

Embarrassment

Embarrassment is a barrier that is there throughout, be it when discussing symptoms or later on when dealing with the side-effects.

“

I find discussing my sex life difficult with other people. I believe that most people do. It is a subject which I must get to grips with.”

- Patricia, 65, patient who currently has bowel cancer.

Difficult to get time off work

People need time off work to meet healthcare professionals and others offering support and this isn't always straightforward.

“

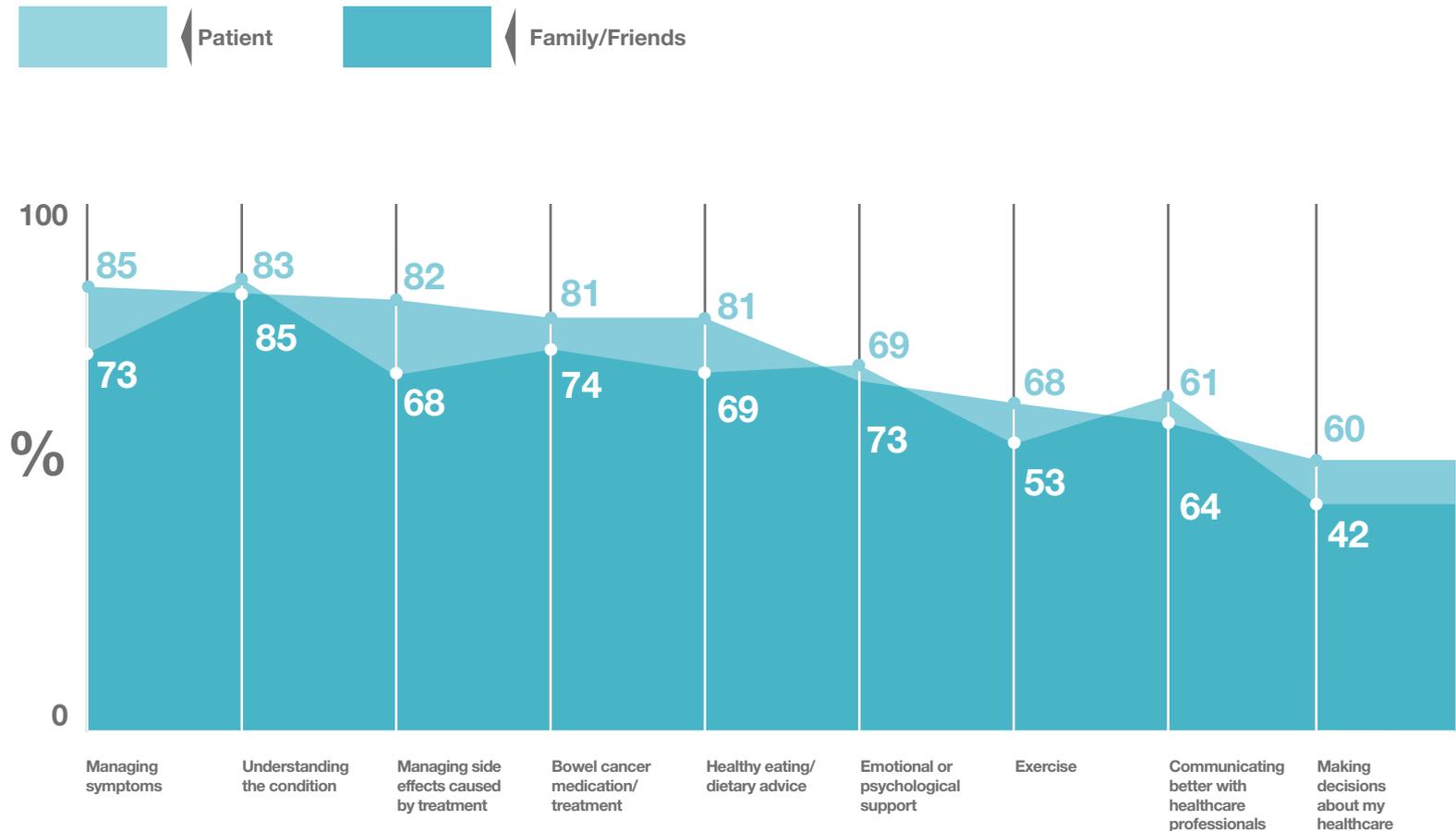
Not all employers will allow paid time off from work to meet with professionals.”

- 59, patient who currently has bowel cancer.

4.4 More support and information

Patients, family and friends are keen to get support across a broad range of issues related to bowel cancer with much of the focus on symptoms, the condition itself, things that might alleviate side-effects, as well as emotional and psychological support, and help dealing with healthcare.

Percentage of people want support in...



05. Someone to talk to

Talking is an important outlet for patients and family and friends alike, enabling them to cope with the burden of diagnosis, treatment and life after treatment.

Most people in our study turn to partners, friends and healthcare professionals, but worryingly 7% of patients and 15% of family and friends said that they don't speak to anyone.

“

Having the most wonderful, caring, supportive family and friends, and NHS professionals they have all helped me to stay positive.”

– Martin, 62, patient who currently has bowel cancer.

“

Talking to my husband openly and telling him how I feel really helps. I'm so glad we have the relationship we have to be able to do this.”

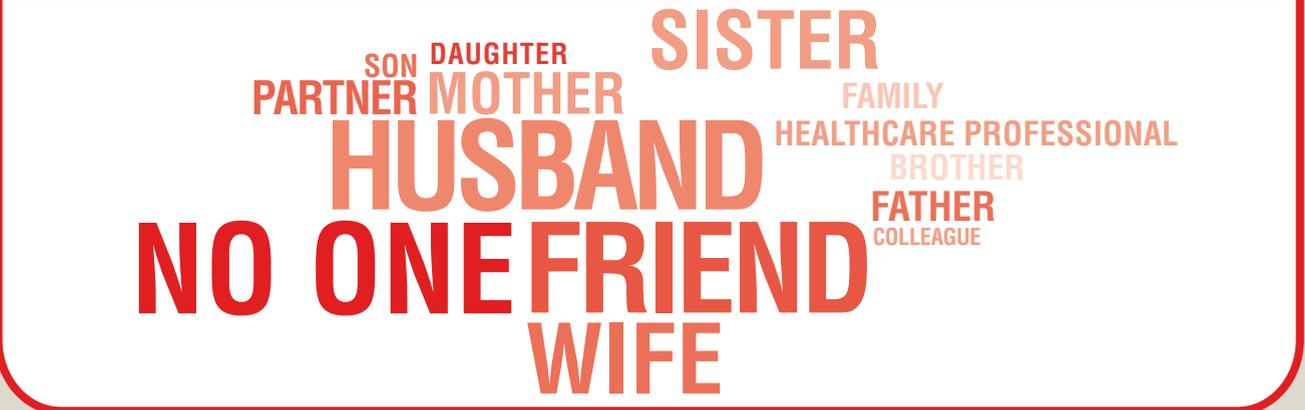
– Claire, 39, wife of patient who currently has bowel cancer.

Who is the one person you talk to about bowel cancer the most?

Patients



Family and friends



5.1 Beating Bowel Cancer

As well as talking to others, many people have found Beating Bowel Cancer to be an important source of information, support and advice with 62% of patients and 50% of family and friends having had some form of contact.

What is clear from our study is that people want more information, support and advice, be it from healthcare professionals, charities or other people who have been through or are going through the same experience.

People are looking for support groups and contact with others with similar experiences including face-to-face.

5.2 Most useful support

For many, family and friends are the key provider of support, hope and relief.

Patients seemed thankful for the help and support that their family and friends have provided during and after their treatment, and reliant on it.

Patients, family and friends see support groups and forums (both face-to face and online) as vital in helping people understand what they're going through.

Support and help from medical professionals – consultants, nurses and doctors – is crucially important in providing confidence and reassurance.

“

Talking to others who have had or have bowel cancer.”

- 54, patient who had bowel cancer in the past.

“

My consultant surgeon, his expertise, care and compassion. He put me at ease and explained everything clearly.”

- 58, patient who had bowel cancer in the past.



“

My partner's husband died of bowel cancer 20 years ago. There were no early tests then, and by the time they had found it it was too late. It has spread too far and he died. She's been able to help me coming to terms with how good it is they caught it early.”

- Ian, 69, patient who had bowel cancer in the past.

Claire's diary



I am really lucky to have some great friends which I met through NCT classes when pregnant with my first.

We usually chat about schools, child behaviour and do some good old proud mummy bragging but this has recently altered as they want to know how Russ is and how I am, how we are coping etc. which is totally understandable and lovely that they care and want to support us but I miss conversations which aren't about radiotherapy next steps and coping. I need normality, in fact I crave it. I am constantly wondering if we will have it again or if this is our new normality.

I wish I could find a local support group of other spouses with cancer and preferably with children who understand the need for normality and also a little of how I am feeling.

39, wife of patient who currently has bowel cancer.

Bob's diary



This evening the nausea had subsided and I enjoyed my evening meal. I had a long telephone conversation with a good friend who had bowel cancer six years ago and has given me tremendous support since my initial diagnosis in 2013.

Bob, 61, patient who currently has bowel cancer.

5.3
Emotional
support for
family and friends

Whilst patients are rightly the focus of all concerned with bowel cancer, our study has shown that family and friends need support, particularly emotional support to cope with what they're going through.

We spoke to Jim whose father was diagnosed with bowel cancer five years ago and died recently.

“

It has made me quite depressed and anxious. I regret so much over the last couple of years and had built up so much emotion inside. It can affect you a great deal but at the time you don't realise how it is affecting you. The doctor told me about a therapist and counsellors who could talk to me about bereavement and the whole package.”

We also spoke to Colin whose wife died of bowel cancer some years ago.

“

They had a bereavement group.... It was for people who had lost partners, husbands, wives or friends. That was a great help. I also went for one-to-one counselling and that lasted about 6 months.”

Help us ease the heartache of bowel cancer

As this report shows, bowel cancer can have a devastating impact on everyone involved; not only on the patient themselves, but their family and friends too. With the right support and information, we can help ease the heartache, but we can only do it with your help.

Support us

We are a charity that relies entirely on voluntary donations as well as gifts in Wills and we need you to help us continue our vital work. **Text ACHE16 £5 to 70070** to donate and help ease the hidden heartache of bowel cancer.

Visit our website to make a donation at **beatingbowelcancer.org**

Share your story

Post your message of support and share your experience on our Hidden Heartache Message Wall by visiting **beatingbowelcancer.org**

We're here for you

If you're worried about bowel cancer or need a shoulder to lean on, talk to us.

Call our nurses on: **020 8973 0011** or email: **nurse@beatingbowelcancer.org**

Visit our online forum: **beatingbowelcancer.org/forum**

We won't give up until everyone affected by bowel cancer gets the support they need. Please help ease the heartache of bowel cancer. Thank you.



Natty, 55, patient who currently has bowel cancer.

Beating Bowel Cancer is the support and campaigning charity for everyone affected by bowel cancer.

When bowel cancer hits, it can be hard to know where to turn and it's natural to have lots of questions and concerns.

That's why we run the UK's only nurse-led specialist helpline, which people call a 'lifeline'.

Whatever the situation, we'll always listen and be supportive.

Contact our nurses on 020 8973 0011 or email nurse@beatingbowelcancer.org.

beatingbowelcancer.org

Produced in partnership with:

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