



# THE C WORD

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

How we react  
to cancer today

July 2017

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# FOREWORD

As a Macmillan Nurse, I'm often in the room when a patient is told they have cancer. The main reaction I see from patients is shock. For many, this is very swiftly followed by fear.

As someone who helps people through cancer, I know it can be very tough hearing these words. Many of us have lost people to cancer and one in two of us will get cancer in our lifetime, so its presence in our society is certain<sup>i</sup>.

Our latest research has shown us that cancer is the disease people in the UK fear most<sup>ii</sup>, and for one in ten people, it's their biggest fear of all<sup>iii</sup>.

It doesn't have to be this way. Cancer is a complex disease and it's important we don't trivialise the impact it has had on many people's lives and loved ones. But if we understood more about what it means to be diagnosed with cancer today, we would be more prepared for it to become part of our future.

The fact is that cancer is almost always life-changing, but it isn't always life-ending. More and more people are living longer after cancer and many of those with cancer that cannot be cured are now able to maintain a good quality of life for several years. With the right support, many people with cancer can carry on being parents, grandparents, friends, colleagues, neighbours. Their life with cancer is still their life – the important things aren't just swept away by their diagnosis. Life shouldn't have to grind to a halt just because you've been diagnosed with cancer. Seeing friends, supporting family, and finding a way to pay the bills are still important to people, even if you're living with a terminal diagnosis.

If one in two people will get cancer in their lifetime, every family in the UK is likely to face the disease at some point. As this report shows receiving a cancer diagnosis is as common a 'life milestone' as getting married or being awarded a degree. Therefore, we all need to be better informed about what a diagnosis means. And this starts in that very room, when a person is first told they have cancer.

Macmillan wants the 2.5 million people who are already living with cancer<sup>iv</sup> and those who will receive a diagnosis in the future, to understand that with the right information and the right support from the point of diagnosis, life with cancer, can still be life.



**Fiona Charman**  
Macmillan Nurse

# CANCER IN THE UK TODAY

Every day around 1,000 people across the UK will find out that they have cancer<sup>v</sup> and it's now estimated that half of all people will receive a cancer diagnosis at some point in their lives. People are also twice as likely to survive at least 10 years after being diagnosed with cancer than they were at the start of the 1970s. Then, just one in four (24%) people survived at least 10 years. This rose to around one in three (34%) by the start of the 1990s and is predicted to be one in two (50%) for those diagnosed at the start of the 2010s<sup>vi</sup>.

While the majority of people diagnosed with cancer in the UK (65%) are aged 65 or over, this still means one in three people (35%) are under 65 when they are diagnosed<sup>vii</sup>.

- Over 2,000 children and teenagers are diagnosed with cancer each year.
- Over 10,000 people are diagnosed with cancer in their 20s and 30s each year.
- Over 60,000 people are diagnosed with cancer in their 40s and 50s each year.

**In 2015, there were around 360,000 people diagnosed with cancer in the UK:**

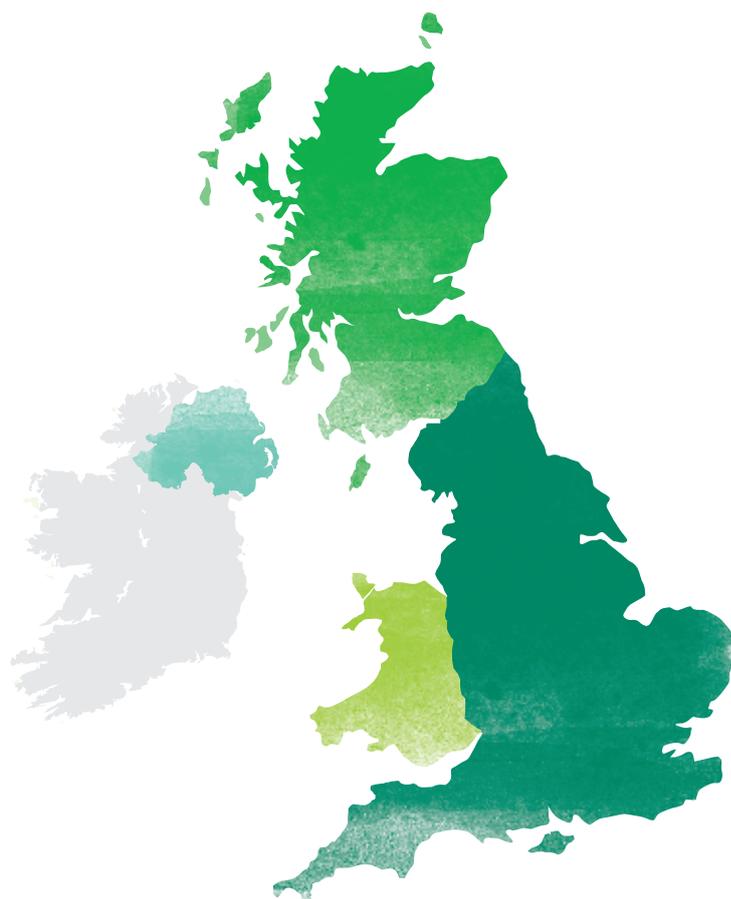
**299,923 people** in England<sup>vii</sup>.

**31,467 people** in Scotland<sup>viii</sup>.

**19,088 people** in Wales<sup>vi</sup>.

**9,256 people** in Northern Ireland<sup>x</sup>.

This is the latest official data available and predictions show that **today the number will already be over 365,000 a year**<sup>xi</sup>



Slightly more men are diagnosed with cancer each year than women (51% vs 49%). Four cancer types – breast, prostate, lung and bowel – account for over half (53%) of all new cases of cancer each year. And the rate of cancer varies across the UK. Within England, for example, people in the North-East of England are almost 10% more likely to be diagnosed with cancer each year than people in London<sup>xii</sup>. There will be several reasons for this, including differences in lifestyle and levels of deprivation.

Better screening, quicker referrals and advances in treatment mean that a cancer diagnosis is now a moment that is frequently not life threatening, but nearly always life-changing.

Survival rates do vary depending on the cancer type but many cancers can be treated successfully.

For example, the latest five-year survival rate in England is over 80% for people diagnosed with breast, prostate, melanoma of the skin, Hodgkin lymphoma, thyroid, or testicular cancer, but less than 15% for lung and liver cancer, and just 6-7% for mesothelioma and pancreatic cancer<sup>xiii</sup>.

But we shouldn't simply rely on increasing survival rates if we are to try and change the way we perceive cancer. It's crucial that patients don't simply survive but are supported to live their lives as best they can. Life shouldn't have to grind to a halt just because you're managing cancer at the same time as the school run, your mortgage, your relationships.

We want to support people to be as prepared as possible for a cancer diagnosis. We want them to know what to expect from treatment, and to understand what support is available so they can live their lives, from the moment they are diagnosed, through treatment and into the future.

## Cancer: A common life milestone

Latest figures show there are:

- Over 70,000 more new cases of cancer each year in the UK than new marriages<sup>xxxv</sup>.
- Almost 50,000 more new cases of cancer each year in England and Wales than women giving birth to their first child<sup>xxxvi</sup>.
- A similar number of undergraduate degrees awarded each year in the UK<sup>xxxvii</sup>, compared with new cases of cancer.

In addition, more than 1.2 million people have been diagnosed with cancer under the age of 65 in the past 10 years, including more than 340,000 diagnosed in their 20s, 30s and 40s<sup>xxxviii</sup>.

# THE C-WORD — HOW WE REACT TO CANCER



‘Cancer has changed a lot since the 1970s, but still the harrowing images and memories we all have of our mothers, fathers and grandparents who had the disease, have left an indelible mark. Back then, for many, cancer was simply incurable or left them with little semblance of their previous life. Often a very visual disease, people also have experience of hair loss and scars. The imagery and language around cancer can be so pervasive – we talk in terms of metaphors of invasion and of warriors battling the disease.’

‘It’s important to remember that we are still living with the language and memories of yesterday’s cancer. Today is a different and more complicated story.’

## **Professor Jane Maher, Joint Chief Medical Officer Macmillan Cancer Support**

Despite advances in cancer treatment and care, the ‘C-word’ still holds a uniquely commanding place in society’s mind. The stories of yesterday’s cancer patients have left a collective legacy behind, often forcing us to see cancer in binary terms – cure or die.

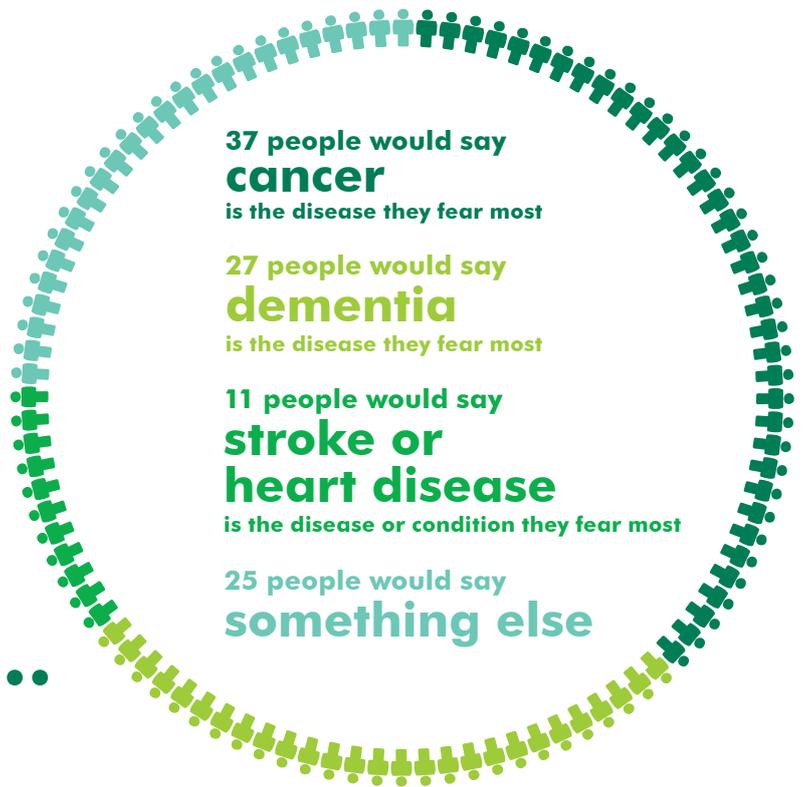
When compared to diseases including Alzheimer’s, multiple sclerosis (MS), and Parkinson’s disease, new research from Macmillan Cancer Support reveals that cancer is the most feared disease today<sup>xiv</sup>.

Not only do people fear it more than other serious long-term and often debilitating conditions, but for one in 10 people, cancer is their greatest fear of all – for these people, they were more afraid of getting cancer than the death of a loved one, terrorism and even being murdered.

In light of these new figures, it may not be so surprising that when faced with a cancer diagnosis, around one in four people (26%) still immediately thought they were going to die when they were told they had the disease<sup>xv</sup>.

And it's not just those given the diagnosis; loved ones, colleagues, and friends also have this response to the 'Big-C'. Over half of people who have known someone who's had cancer within the past five years thought the person was going to die when they found out they had the disease<sup>xvi</sup>.

## If the UK was 100 people...



Of people who've known someone with cancer<sup>xvii</sup>:

- More than half (56%) thought that person would die
- Around half (47%) thought they would lose their hair
- Nearly two thirds of people (61%) were surprised when they found out because the person hadn't looked ill.

For people who've had a cancer diagnosis<sup>xviii</sup>:

- Almost one in four (23%) thought their life was over when they found out their diagnosis
- Nearly two thirds (64%) were worried about the impact on their family and friends
- One in five (21%) were worried people would treat them differently
- Nearly half (46%) were scared of having treatment.

But the reality is that almost everyone living with cancer (90%) says they are still living their life as normally as possible.

- Around half of people who've had cancer (52%) say cancer has not changed who they are
- Only one in seven people with cancer (14%) worry they are letting their family down
- Three in four people with cancer (75%) do not feel they are any less able to be there for their friends
- Only around one in five people recently diagnosed with cancer (20%) report losing their hair<sup>xix</sup>.



**More than four in five people with cancer (85%) do not want cancer to define them**

# The impact of fear when someone receives a diagnosis

The paralysing effect of hearing the word 'cancer' can't be underestimated. The common reaction people have at the moment the news is broken speaks volumes about the way we view this disease.

Just under half (45%) of people said it was 'the worst news imaginable', and 42% said it didn't feel real – it felt like a bad dream. One in three people (34%) say they were in a daze and couldn't take anything in<sup>xx</sup>.

According to the UK's four national Cancer Patient Experience Surveys, around one in four cancer patients did not fully understand the explanation of what was wrong with them<sup>xxi</sup>.

People's reactions to hearing they have cancer are understandable and only natural considering it is the most feared disease today. But it's important that long-held misperceptions around what a cancer diagnosis means don't stop cancer patients getting the information and support they need.

If people are to keep living their lives as normally as possible, we need to reduce this fear and help people understand their situation holistically – from their treatment options and possible side effects, to the support they might need financially or with their care.

'When they told me I had cancer, everything stopped. All I could think was that this can't be happening to me. I've got three children, I can't cope. I just assumed it was a death sentence. I cried for six weeks.'

**Diane, 48, from Gloucestershire, diagnosed with breast cancer in 2015**

'One thing that has never changed over the years is how someone reacts when you tell them they have cancer. People still instantly ask themselves, 'am I going to die?' People have much more information when they are diagnosed nowadays, but they are often in 'life and death' mode which means many do not actually take in the information. It is so important for people to have a specialist nurse there to explain what happens next after this life-changing moment.'

**Professor Jane Maher, Joint Chief Medical Officer  
Macmillan Cancer Support**

The strength of the association between cancer and death is so strong that it even impacts the work of Macmillan Nurses.

Forty years ago, the initial nurse posts that Macmillan funded were almost exclusively geared toward palliative care to meet the needs of the time. As a result, there is still trepidation from some patients who come into contact with a Macmillan Nurse today, fearing they solely provide end of life care. In reality, for decades Macmillan Nurses have been providing support as Clinical Nurse Specialists across the whole cancer experience, from the moment someone is diagnosed, through treatment and beyond.

'I was introducing myself to a patient after his diagnosis had just been confirmed when he saw my badge and said "You are a Macmillan Nurse!" He hastily turned around and left the department. I was baffled. It transpired that he had associated 'Macmillan Nurse' with people who were 'imminently dying or having a bad time' and as such did not want anything to do with me as that would imply he was in such a situation. I spent a long time talking about Macmillan roles and the support they offered. He asked many questions and was satisfied that a Macmillan Nurse didn't mean "the end".'

**Marina Soya-Bongay**  
**Macmillan Lung Cancer Clinical**  
**Nurse Specialist**



# Life with cancer is still life

A staggering 90% of people with cancer say they are still living their lives as normally as they can. This shows that most people with cancer are carrying on and focusing on what is important to them – life. Nearly nine in ten (85%) of people with cancer do not want cancer to define them<sup>xxii</sup>.

When you're diagnosed with cancer, some of your priorities may change but what's fundamentally important to you will most likely remain. The very things that make up who you are don't have to go away just because you're undergoing treatment.

'I was working two jobs and BMX biking in my free time, but when I started lacking energy and bruising strangely my GP referred me for blood tests. I was stunned to be told I had cancer. All I could think was that it was all over for me. Turns out I'm now in remission after the great support of my healthcare team, family, friends and Macmillan. I've been back on my bike, keeping it safe and taking things slow. It's a real target to get back to where I was.'

**Matt, 22, from Cornwall,  
diagnosed with leukaemia in 2013**



**35% of people say their cultural background**



**44% of people say their career**



**63% of people say their hobbies**



**89% of people say their personality**



**92% of people say their family<sup>xxiv</sup>**

**So what do people with cancer say was important to their personal sense of identity before they were diagnosed?<sup>xxiii</sup>**

Macmillan understands that when someone has cancer, these parts of their life – family, friends, careers, hobbies – are still important, if not more so. That's why it's vital that when someone is diagnosed with cancer, there is support available to help them get on with their life, no matter how cancer affects them. Life with cancer doesn't have to stop a mum from being a mum, or a runner from being a runner, or a friend from being a friend.

This starts with them having a good experience when they are diagnosed.

'Being diagnosed with terminal cancer at the age of 35 was a shock. I assumed it was an older person's disease, not someone who had just had a baby. I had a 15 year old daughter and an eight-month-old baby at the point of diagnosis and, because I could physically manage day to day life most days, I was determined to keep things as normal as possible. Cancer took control of my body but I wasn't about to let it take control of my life. I had no choice but to go back to work because I had a mortgage to pay. People don't realise someone with incurable cancer still needs to pay the bills.'

**Mandy, 42, from Glasgow,  
diagnosed with secondary breast cancer in 2009**



# Diagnosis – the first time you find out you have cancer

There is a range of support available to people when they are diagnosed. Most patients, but currently not all, will be given the name of a Clinical Nurse Specialist (CNS), many of whom are supported by Macmillan.

Macmillan Nurses are experts in cancer care, with expertise in either a type of cancer, such as breast cancer, or a type of treatment such as chemotherapy. Some specialise in specific types of health issue related to cancer or its treatment, such as lymphoedema (limb swelling). As it stands, they can't be there for everyone but we do know that when they are, they make all the difference.

Wherever possible, Macmillan Nurses are in the room when someone is told they have cancer. They're there to support the patient and answer any questions they might have after.

They are typically the main point of contact in the cancer care team throughout a patient's experience to provide support and practical guidance. This can be anything from advice on how to tell your children you have cancer to what to take to treatment.

Research shows that giving patients the name of the CNS in charge of their care is one of the most important factors in ensuring they have a good experience<sup>xxv</sup>.



'The moment someone is diagnosed is life-altering. Before that point, the patient might suspect cancer, but in their head, they're still a healthy person. Once the news is broken, they are in an unknown world of biopsies, scans, needles and treatment. For the GP, consultant or health professional delivering this news, giving that information in the right way is critical. It's important to try and ensure someone is there with the patient but also realise that the patient might not take in everything you say. It's vital that healthcare professionals assess how much a patient has absorbed. Having a clinical nurse specialist - such as a Macmillan Nurse - present during this initial conversation gives the patient a familiar contact for future questions they may think of.'

**Dr Ashling Lillis,  
Specialist Registrar in Acute Internal Medicine**

Patients who have a CNS are:

- More than twice as likely to be given information about financial help or benefits
- Twice as likely to be told how their cancer could affect their work life or education (79% vs 40%)
- 55% more likely to be told about the long-term side-effects of treatment (58% vs 38%)
- 48% more likely to be given written information about their cancer (75% vs 51%)<sup>xxvi</sup>.

We estimate that Macmillan Nurses support over half a million people with cancer every year<sup>xxvii</sup>, so Macmillan has seen first-hand what matters to patients when they first hear they have cancer. Living well with cancer starts the moment you're diagnosed, so it's vital that people have the right information and support available from the beginning.

Patients must be given clear information about their diagnosis, their treatment options, and the potential longer-term impact of that treatment as early as possible. This is so that healthcare professionals and patients can identify areas that might impact their life later in their cancer experience and take steps to reduce this.

They should also be informed about the support that's available, whether that's in relation to their care or the different ways cancer can affect their wider life and wellbeing. This can range from struggling to pay the mortgage because their finances have been hit, to worrying about their relationships as result of a diagnosis. Macmillan supports people and their families through services like the Macmillan Support Line, the online community, and mobile information services. We also run cancer information and support centres around the country which offer a range of support services such as benefits advice, yoga, wig and beauty services, and nutritional advice.

We believe that how and where someone is told they have cancer can make a huge difference. It's best if a family member or friend is present throughout the consultation to offer emotional support and ask questions that might later be helpful for the patient.

Being fully informed and supported from the beginning can help people maintain a sense of control, which can help them live their lives as well as they can following diagnosis.

Macmillan Nurses have supported **almost 5 million cancer patients** over the past 10 years<sup>xxxii</sup>



- Currently, most people **(84%) are told they have cancer in a private face-to-face appointment with a healthcare professional**. However, one in 20 **(5%) are told in front of strangers**, and one in 14 **(7%) are told over the phone or by letter**, when no face-to-face support is available<sup>xxviii</sup>.



## 5% of people are told they have cancer in front of strangers

- **More than one in five people who would like to have family or friends there when they find out they have cancer are not told that this is an option<sup>xxix</sup>**, meaning they miss out on vital emotional support at the point of diagnosis. Family and friends can also help people understand the often-complex information they are being told about their prognosis and treatment options.



‘When a patient is diagnosed, I sometimes see a look in their eyes as if to say ‘life as I know it is over.’ But one of the best things about my role as a Macmillan Nurse is helping to show them that it’s not always the case. This can range from supporting patients through difficult times by helping organise family experiences like weddings and holidays, to providing psychological support and also guidance on where to get help with their finances. We only get one chance in life, so it’s important that we help them live it without regret. I like to remind my patients ‘who they are’ and help them live well.’

**Hollie Watts, Macmillan Nurse**



'A GP with 2,000 patients will typically see around six to eight new cases of cancer each year which means they come across cancer relatively infrequently<sup>xxx</sup>. But when they do, their role is absolutely crucial – from spotting signs and symptoms, to patient referral, to breaking the news. The support GPs provide doesn't end there. No matter how a patient learns they have cancer they can always come back to their GP for support. For many, they are a familiar face in the revolving door of health professionals they meet as they go through tests and treatment. It's vital GPs are equipped not only to spot signs and symptoms of cancer but to recognise their ongoing role in supporting cancer patients with the challenges they face. Macmillan GPs are there to support colleagues to make a difference to people affected by cancer.'

**Dr Rosie Loftus, Joint Chief Medical Officer,  
Macmillan Cancer Support**

Macmillan has a 200-strong GP community. These GPs, who act as clinical cancer leads in their local area, enable access to cancer education for other GPs, support the planning and delivery of cancer services and provide practical support to help GPs recognise and manage people with cancer. As part of their role, they run communication skills training courses, supporting their colleagues to handle important conversations at the point of diagnosis.

'They shuffled me into a side room where the doctors were talking to each other and I was being referred to in the third person. Then someone took me to a back room and I had to try to come to terms with the news. I felt as though they had no idea what to say to me. I was given so much information and so many booklets, but I couldn't understand what they were saying. I couldn't take it all in. The whole experience was very unpleasant and because it was so unexpected, I was given the shocking news alone, without my husband.'

**Tavinder, 38, diagnosed with breast cancer in 2014**

# UNDERSTANDING SIDE EFFECTS AND MAKING CHOICES

After someone is diagnosed, they will need to start thinking about their treatment options. At this early stage, it's important they understand how various treatments might affect them in the future as well as in the short-term.

Survival rates have long been reported by official bodies across the UK, but there have been no equivalent measures of whether people are living well. In England, the NHS is working with patients and carers, as well as charities such as Macmillan, to develop a national metric on quality of life. This will enable better evaluation of long-term quality of life after treatment, which in future can be used to furnish patients at the point of diagnosis with the best information to make the right treatment choice for them. This is key to enabling people to live the life they want to live during and after treatment.

'For many patients diagnosed with prostate cancer, there will be a number of options available to them. They may be given the choice of 'active monitoring' or of surgery or radiotherapy. Recent evidence shows that no option will be better than the other in terms of their chances of living 10 years or more after their diagnosis but may have different effects on their lives. So, in making a choice, it comes down to an individual's personal preference. One patient may be kept up at night worrying about cancer still inside them, another may prefer to avoid a procedure if it could leave them with lasting problems such as incontinence. That's why, at the point of diagnosis, it's vital that patients have the best possible information available to them so that they can make the right choices for them. This should include having a better understanding of the impact their decision may have on their future quality of life.'

**Professor Jane Maher,  
Joint Chief Medical Officer,  
Macmillan Cancer Support**

At the moment, around 625,000 people in the UK are estimated to be facing poor health or disability after treatment for cancer<sup>xxxii</sup>. People can experience crippling fatigue, bowel and urinary incontinence, and sexual difficulties among other issues. The fallout can be far-reaching on their ability to live their life as they wish, affecting their families, finances, relationships, and ability to work. However, if patients have the right information and the right help, they can be supported to manage the consequences of their treatment and limit the impact it could otherwise have on their quality of life.

To ensure people who have had a cancer diagnosis can get this support to help them live their lives, Macmillan worked with the NHS and Department of Health to develop and test a Recovery Package. This is a package of care designed to identify people's needs and make sure they are addressed by stopping them from falling through the gaps between their hospital and their GP and giving those who are able the tools and support they need to take control of their own health.

Taking action so that people can be supported to live as well as possible after their treatment needs to start from the moment they are diagnosed. That is why the first stage of the Recovery Package happens just after diagnosis and before the start of treatment. This gives people an opportunity to record their needs and concerns at the earliest point so they can be signposted to support as soon as possible. We want everyone diagnosed with cancer to have access to the Recovery Package to make sure this happens.

**Taking action so that people can be supported to live as well as possible after their treatment needs to start from the moment they are diagnosed.**



'As far as I was concerned war had been declared between me and cancer and from the very start I needed to have whatever treatment was offered. But there were days when I felt useless and struggling to keep awake and that's when my local Macmillan Information and Support Centre manager helped turned things around for me. He opened my eyes to all the help that was possible and his experience meant he could see what I needed. Knowing I was dealing with people who knew what I was talking about and how I was feeling, was so important. It lifted a weight off me and my partner.'

**Paul, 64, from Leicestershire, diagnosed with prostate cancer in 2012**

# CONCLUSION

Being told that you have cancer can feel like being thrust into the unknown.

But if half of us will receive a cancer diagnosis in our lifetime, it's important that we are all better informed about what to expect if we do one day find out we have cancer.

Cancer is almost always life-changing, but it isn't always life-ending.

Macmillan has supported millions of people through cancer. From our experience, we believe that living well with cancer begins at diagnosis. People should come away from that first appointment feeling informed about their choices and knowing what support is available.

Knowing what to expect can help people to overcome the shock of a diagnosis and manage their lives with cancer. You may have cancer, but you still have a life to lead, friends to see, family who need you, and people to love.

Because life with cancer is still life. Macmillan is here to help people live it.

'I was 22 weeks pregnant with my second child when I was told I had cancer. It was a complete shock as I'd not felt unwell, only a small lump in my neck like a swollen gland. It was tough treatment and even though I had cancer I was still a pregnant woman. My 'oracle', Ian, my Macmillan specialist nurse, helped get me through it by being a constant face, always ready to help with even the simplest of questions, like where to park. I know he'll always be there for us.'

**Kimberley, 33, from Bedfordshire, diagnosed with tonsil cancer in 2014**



# SUPPORT AVAILABLE

## Face to face support

As well as through Macmillan Nurses, patients can access information at Macmillan cancer information services which are in operation throughout the UK, in hospitals, libraries, or shops. They provide practical and emotional support to people recently diagnosed with cancer. For example, a £1.5 million Macmillan Support Centre, part of a new Health and Wellbeing Campus at Altnagelvin Hospital in Northern Ireland, will open in summer 2017, offering a dedicated suite of rooms where people living with cancer can receive counselling, benefits advice, wig and prosthesis fitting, and complementary therapies.

To reach as many communities as possible, Macmillan also runs four mobile information services and two mobile information pods. In 2016, they reached almost 116,000 people in town halls, shopping centres and car parks across England, Scotland and Wales<sup>xxxii</sup>.

## Online

For those who want to talk to others who have been diagnosed, Macmillan's Online Community is a space where people affected by cancer can get peer support from each other around the clock, sharing their advice and providing support. In 2016, more than 900,000 people visited the online community, which now has 120,000 members<sup>xxxiii</sup>.

Macmillan's website has a number of pages dedicated to information for those who have recently been diagnosed.

## On the phone

The Macmillan Support Line, staffed by trained experts, is there to provide a range of practical, clinical, financial and emotional support. This can include help with complex issues such as welfare claims, help with fuel bills or simply providing an opportunity to chat through what their doctor just told them.

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- i Macmillan estimate based on; Maddams J, Utley M, Møller H. *Projections of cancer prevalence in the United Kingdom, 2010-2040*. Br J Cancer 2012; 107: 1195-1202. (Scenario 1 presented here) Forman D, et al. *Cancer prevalence in the UK: results from the EUROPREVAL Study*. *Annals of Oncology*. 2003. 14: 648–654; Office for National Statistics; Information Services Division (ISD) Scotland; General Registrar Office Scotland; Welsh Cancer Intelligence and Surveillance Unit; Northern Ireland Cancer Registry; Northern Ireland Statistics and Research Agency.
- ii Macmillan Cancer Support/ ICM online survey of 2,096 UK adults. Fieldwork undertaken 22nd-24th March 2017. Survey results are weighted to be representative of the UK population. When asked which condition or disease people most feared getting themselves, 37% said cancer was their top fear, compared with 27% who said dementia/Alzheimer’s disease. When asked which condition or disease people most feared their family or friends getting, 38% said cancer and 27% said dementia/Alzheimer’s disease.
- iii As ref ii. When asked what was people’s greatest fear of all, 10% of people chose cancer over a range of other options including the death of a loved one, terrorism and being murdered. 3% of people selected ‘other’ and 18% said they did not have any major fears.
- iv Macmillan estimate based on; Maddams J, Utley M, Møller H. *Projections of cancer prevalence in the United Kingdom, 2010-2040*. Br J Cancer 2012; 107: 1195-1202. (Scenario 1 presented here) Forman D, et al. *Cancer prevalence in the UK: results from the EUROPREVAL Study*. *Annals of Oncology*. 2003. 14: 648–654; Office for National Statistics; Information Services Division (ISD) Scotland; General Registrar Office Scotland; Welsh Cancer Intelligence and Surveillance Unit; Northern Ireland Cancer Registry; Northern Ireland Statistics and Research Agency.
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- viii ISD Scotland. *Cancer statistics – Annual incidence*. <http://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/All-Types-of-Cancer/> (accessed April 2017).

- ix Welsh Cancer Intelligence and Surveillance Unit. Cancer incidence in Wales. <http://www.wcisu.wales.nhs.uk/cancer-incidence-in-wales-1> (accessed March 2017).
- x Northern Ireland Cancer Registry. All cancers – Incidence, prevalence and survival statistics: 1993-2015. [http://qub.ac.uk/researchcentres/nicr/FileStore/OfficialStats2015/INCIDENCEFINALOUTPUTS/Filetoupload,746089\\_en.xls](http://qub.ac.uk/researchcentres/nicr/FileStore/OfficialStats2015/INCIDENCEFINALOUTPUTS/Filetoupload,746089_en.xls) (accessed March 2017).
- xi As ref v.
- xii Office for National Statistics. Cancer registration statistics, England: 2014. May 2016. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancerregistrationstatisticsengland/2014> (accessed March 2017)  
The rate of new diagnoses for all cancers ranges from 584.4 per 100,000 people in London and 585.2 in the East of England, to 637.7 in the North East of England – a difference of around 9%.
- xiii Office for National Statistics. Cancer survival in England: Patients diagnosed between 2010 and 2014 and followed up to 2015. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalinenglandadultsdiagnosed/2010and2014andfollowedupto2015#5-year-survival> (access March 2017).
- xiv As ref ii.
- xv Macmillan Cancer Support/YouGov survey of 2,005 UK adults with a previous cancer diagnosis. Fieldwork was undertaken between 20th - 29th March 2017. The survey was carried out online. The figures have been weighted and are representative of the UK population of those living with cancer.
- xvi Macmillan Cancer Support/ ICM online survey of 2,096 UK adults. Fieldwork undertaken 22nd-24th March 2017. Survey results are weighted to be representative of the UK population.
- xvii As ref xvi.
- xviii As ref xv.
- xix Macmillan Cancer Support/YouGov survey of 1,011 adults with a previous cancer diagnosis. Fieldwork was undertaken between 10th and 17th December 2015. The survey was carried out online. The figures have been weighted and are representative of the living with cancer population.
- xx Macmillan Cancer Support/YouGov online survey of 1,020 UK adults with a previous cancer diagnosis. Fieldwork was undertaken between 5th and 14th October 2016. The survey was carried out online. The figures have been weighted and are representative of the UK living with cancer population.

xxi National Cancer Patient Experience Survey. England, 2015: <http://www.ncpes.co.uk/index.php/reports/national-reports/2489-cpes-2015-national-report-pdf/file>.  
Scotland, 2015: <http://www.gov.scot/Resource/0050/00501127.pdf>.  
Wales, 2013: <https://www.qualityhealth.co.uk/resources/surveys/welsh-cancer-experience-survey/2013-welsh-cancer-epperience-survey/walescancer-patient-experience-reports-english-language-versions/527-wales-cancer-patient-experience-surveynational-report-2013/file>  
Northern Ireland, 2015: <https://www.qualityhealth.co.uk/resources/surveys/northern-ireland-cancer-patient-experience-survey/northern-ireland-cancerpatient-experience-survey-1/2015-northern-ireland-cancer-patient-experience-survey/northern-irelandcancer-patient-experience-survey-reports/702-2015-ni-cancer-patient-experience-survey-all-trusts-report/file>

At time of writing 73% of respondents to the 2015 England National Cancer Patient Experience survey said 'that they completely understood the explanation of what was wrong with them'. In the 2015 Northern Ireland Cancer Patient Experience survey 73% said they completely understood the explanation of what was wrong with them. In the 2015 Scottish CPES 75% said they completely understood the explanation of what was wrong. In the 2013 Welsh CPES 75% of patients said they completely understood the explanation of what was wrong. All other respondents understood some of it, or did not understand the explanation.

xxii As ref xv.

xxiii Respondents were asked 'To what extent were the following important to your personal sense of identity, before your cancer diagnosis? By sense of identity we mean what makes you feel like 'you' and/or helps to define you as an individual.' The question was asked separately for each of the following factors: My personality, My job career, My relationship, My family, My cultural background, Keeping fit or playing sports, My hobbies, The clothes I wear and My physical appearance. Figures presented here are the net important responses (Very important and Fairly important) for select questions.

xxiv As ref xv.

xxv National Cancer Patient Experience Survey. England, 2014: <https://www.qualityhealth.co.uk/resources/surveys/national-cancer-experience-survey/2014-national-cancer-patient-experiencesurvey/2014-national-cancer-patient-experience-survey-national-reports/6-88-2013-national-cancer-patientexperience-survey-national-report-pdf/file>  
Wales, 2013: <https://www.qualityhealth.co.uk/resources/surveys/welsh-cancer-experience-survey/2013-welsh-cancer-eperience-survey/walescancer-patient-experience-reports-english-language-versions/527-wales-cancer-patient-experience-surveynational-report-2013/file>  
Northern Ireland, 2015: <https://www.qualityhealth.co.uk/resources/surveys/northern-ireland-cancer-patient-experience-survey/northern-ireland-cancerpatient-experience-survey-1/2015-northern-ireland-cancer-patient-experience-survey/northern-irelandcancer-patient-experience-survey-reports/702-2015-ni-cancer-patient-experience-survey-all-trusts-report/file>

xxvi National Cancer Patient Experience Survey. England, 2014: <https://www.qualityhealth.co.uk/resources/surveys/national-cancer-experience-survey/2014-national-cancer-patient-experiencesurvey/2014-national-cancer-patient-experience-survey-national-reports/6-88-2013-national-cancer-patientexperience-survey-national-report-pdf/file>  
Wales, 2013: <https://www.qualityhealth.co.uk/resources/surveys/welsh-cancer-experience-survey/2013-welsh-cancer-eperience-survey/walescancer-patient-experience-reports-english-language-versions/527-wales-cancer-patient-experience-surveynational-report-2013/file>

Northern Ireland, 2015: <https://www.qualityhealth.co.uk/resources/surveys/northern-ireland-cancer-patient-experience-survey/northern-ireland-cancerpatient-experience-survey-1/2015-northern-ireland-cancer-patient-experience-survey/northern-irelandcancer-patient-experience-survey-reports/702-2015-ni-cancer-patient-experience-survey-all-trusts-report/file>. Figures shown are for the England survey. Similar results are shown in the Wales and Northern Ireland surveys.

- xxvii Macmillan Cancer Support. Annual report, 2015. May 2016. [http://www.macmillan.org.uk/\\_images/macmillan-cancer-support-annual-report-2015\\_tcm9-287545.pdf](http://www.macmillan.org.uk/_images/macmillan-cancer-support-annual-report-2015_tcm9-287545.pdf) (accessed April 2017).
- xxviii Macmillan Cancer Support/YouGov. Total sample size was 1,020 people with a previous cancer diagnosis. Fieldwork was undertaken between 5th and 14th October 2016. The survey was carried out online. The figures have been weighted and are representative of the living with cancer population. 5% of respondents said they were told ‘face-to-face by a healthcare professional in a hospital ward, waiting room or other public area, with other people I didn’t know nearby’, which we have expressed as being told in front of strangers.
- xxix National Cancer Patient Experience Survey. England, 2015: <http://www.ncpes.co.uk/index.php/reports/national-reports/2489-cpes-2015-national-report-pdf/file>. Scotland, 2015: <http://www.gov.scot/Resource/0050/00501127.pdf>. Wales, 2013: <https://www.qualityhealth.co.uk/resources/surveys/welsh-cancer-experience-survey/2013-welsh-cancer-epperience-survey/walescancer-patient-experience-reports-english-language-versions/527-wales-cancer-patient-experience-surveynational-report-2013/file> Northern Ireland, 2015: <https://www.qualityhealth.co.uk/resources/surveys/northern-ireland-cancer-patient-experience-survey/northern-ireland-cancerpatient-experience-survey-1/2015-northern-ireland-cancer-patient-experience-survey/northern-irelandcancer-patient-experience-survey-reports/702-2015-ni-cancer-patient-experience-survey-all-trusts-report/file>. Of patients who felt it necessary to bring a family member or friend with you 21% were not told this was an option in Scotland and Northern Ireland. This rose to 28% for people responding in Scotland, with 28% saying they had not been told they could bring a family member or friend with you.
- xxx Rubin G et al. *The expanding role of primary care in cancer control*. The Lancet Oncology 2015; 16: 1231 –1272. [http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(15\)00205-3/fulltext](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(15)00205-3/fulltext)
- xxxi *Cured but at what cost? Long-term consequences of cancer and its treatment*, July 2013, p1, [http://www.macmillan.org.uk/documents/aboutus/newsroom/consequences\\_of\\_treatment\\_june2013.pdf](http://www.macmillan.org.uk/documents/aboutus/newsroom/consequences_of_treatment_june2013.pdf).
- xxxii Internal data. We estimate that our nurses supported 4.6m cancer patients between 2007-2016.
- xxxiii Internal data.
- xxxiv Internal data.

- xxxv In 2014 in the UK there were 289,841 marriages and 361,216 cancers diagnosed (excluding non melanoma skin cancer). This includes 252,222 marriages registered in England and Wales (Office for National Statistics <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/marriagecohabitationandcivilpartnerships/datasets/marriagesinenglandandwales2013>); 29,069 weddings in Scotland. (National Records of Scotland <https://www.nrscotland.gov.uk/files//statistics/time-series/marriage-2016/mt-1-marriages-1855-to-year-current.xlsx>). 8,550 weddings in Northern Ireland (Northern Ireland Research and Statistics Agency <https://www.nisra.gov.uk/sites/nisra.gov.uk/files/publications/marriages-LGD2014-2008-2015.xls>). 299,856 cancers diagnosed in England in 2014 (Office for National Statistics. 2017 <https://www.ons.gov.uk/file?uri=/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/cancerregistrationstatisticscancerregistrationstatisticsengland/2015/cancerregistrations2015final22.05.2017.xls>). In Wales, there were 19,826 cancers diagnosed in 2014 (Welsh Cancer Intelligence and Surveillance Unit <http://www.wcisuwales.nhs.uk/opendoc/302629>). In Scotland, there were 32,366 cancers diagnosed in 2014 (ISD Scotland [https://www.isdscotland.org/Health-Topics/Cancer/Publications/2017-04-25/i\\_cancer\\_all\\_types.xls](https://www.isdscotland.org/Health-Topics/Cancer/Publications/2017-04-25/i_cancer_all_types.xls)). In Northern Ireland there were 9,168 cancers diagnosed in 2014 (N. Ireland Cancer Registry <https://www.qub.ac.uk/research-centres/nicr/FileStore/OfficialStats2015/INCIDENCEFINALOUTPUTS/Filetoupload,746088,en.xls>).
- xxxvi There were 271,050 live births in England and Wales in 2015 where the mother was known to have had zero previous births and 319,011 cancers diagnosed (excluding non-melanoma skin cancer) in England and Wales in 2015. Based on Office for National Statistics. Birth by parents' characteristics, 2015. November 2016. <https://www.ons.gov.uk/file?uri=/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/datasets/birthsbyparentscharacteristics/2015/birthsbyparentscharacteristics2015v2.xls> 299,923 cancers diagnosed in England in 2015 (Office for National Statistics. 2017 <https://www.ons.gov.uk/file?uri=/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/cancerregistrationstatisticscancerregistrationstatisticsengland/2015/cancerregistrations2015final22.05.2017.xls>). In Wales there were 19,088 cancers diagnosed in 2015 (Welsh Cancer Intelligence and Surveillance Unit <http://www.wcisuwales.nhs.uk/opendoc/302629>).
- xxxvii Higher Education Statistics Agency (HESA). <https://www.hesa.ac.uk/data-and-analysis/students/qualifications> Figure refers to number of undergraduate degrees awarded at third-class level or higher.
- xxxviii Sum of cancer diagnosis (excluding non-melanoma skin cancer) between 2015 and 2006 in people aged 0 to 64 and 20 to 49. Based on Welsh Cancer Intelligence and Surveillance Unit <http://www.wcisuwales.nhs.uk/opendoc/303205>. Personal correspondence (June 2017) with the N. Ireland Cancer Registry which is funded by the Public Health Agency. ISD Scotland [https://www.isdscotland.org/Health-Topics/Cancer/Publications/2017-04-25/i\\_cancer\\_all\\_types.xls](https://www.isdscotland.org/Health-Topics/Cancer/Publications/2017-04-25/i_cancer_all_types.xls). Extract from CancerStats and Office for National Statistics. 2017 <https://www.ons.gov.uk/file?uri=/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/cancerregistrationstatisticscancerregistrationstatisticsengland/2015/cancerregistrations2015final22.05.2017.xls>. This work uses data provided by patients and collected by the NHS as part of their care and support.

# Notes

You may have cancer, but you are still you. Macmillan is here to help you get on with your life no matter what. We can give you the practical, emotional, and genuinely personal support you need to hold on to who you are and what's important to you.

From the moment you're diagnosed, for as long as you need us, you can lean on Macmillan. Call us free on **0808 808 00 00** or visit **macmillan.org.uk**

Life with cancer is still life – we'll help you live it.

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Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Also operating in Northern Ireland. July 2017. MAC16768.

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