



CANCER

IN THE UK 2014

WE ARE
MACMILLAN.
CANCER SUPPORT

State of the nation report
April 2014

#Cancer2014

Cancer in the UK 2014

State of the nation report

Contents

- 4 **Foreword**
- 6 **Executive summary**
- 10 **Outcome 1:** I was diagnosed early
- 14 **Outcome 2:** I understand, so I make good decisions
- 18 **Outcome 3:** I get the treatment and care which are best for my cancer, and my life
- 22 **Outcome 4:** Those around me are well supported
- 26 **Outcome 5:** I am treated with dignity and respect
- 30 **Outcome 6:** I know what I can do to help myself and who else can help me
- 34 **Outcome 7:** I can enjoy life
- 38 **Outcome 8:** I feel part of a community and I'm inspired to give something back
- 42 **Outcome 9:** I want to die well
- 46 **Conclusion**
- 47 **Summary of recommendations**
- 51 **Find out more**
- 53 **References**



Foreword

Every year, as life expectancy improves, more and more people in the UK are diagnosed with cancer. By 2020, almost one in two of us will get cancer in our lifetimes. However, thanks to improvements in diagnosis, treatment and care, we are also living longer with the disease.

In the early 1970s, half of all people with cancer died within one year of diagnosis. Today, this 'median survival' has improved to six years. These changes mean that the two million people living with cancer in the UK today will grow to four million by 2030. Tomorrow's typical cancer patient, if such a person exists, will not look like today's. They will be older and more likely to have another condition as well as cancer, or be living with active cancer as a long-term chronic condition. And they will live with these conditions, and the consequences of their cancer and its treatment, for longer.

Cancer services across the UK will have to adapt to these changes. Earlier diagnosis and intervention; treatment that improves not only survival but also the quality of that survival. Better aftercare to ensure people with cancer remain well and stay out of hospital. End-of-life care that helps people die well, where they want to die.

At Macmillan Cancer Support, we believe that all of these improvements will be good for people with cancer, and will be more cost-effective than the status quo. But as *Cancer in the UK 2014* shows, our health and social care systems in each of the four countries of the UK have so far failed to grasp the true scale of the challenge. All of us have been too slow to react to the dramatic shifts in the nature of cancer. If we don't take action now, the state of cancer care in the UK will reach a crisis point.

In the UK, we know what good care looks like. Indeed, every region of the UK is getting at least something right for local people with cancer. But we are failing to deliver good care consistently.

This report examines the state of cancer in the UK in terms of the nine issues that people affected by cancer have told Macmillan matter most to them. These issues include not only clinical outcomes, but also the impact of cancer on the whole of a person's life.

Looking at these issues, we find that too many people are diagnosed late, shown a lack of compassion during their care, or feel abandoned after treatment to cope with the long-term consequences of cancer alone. Your chance of receiving the treatment that is most likely to cure you often depends on where you live in the UK and on your age. Our survival rates are among the worst in Europe.

For a nation with an NHS that does amazing things every day, it should offend our pride to have such poor cancer outcomes. There are no signs of increased government funding to cope with the growing burden of cancer. More important than money, therefore, is the need for a clear determination in government and across the cancer community to fix the issues we're facing.

As Macmillan's first state of the nation report, *Cancer in the UK 2014* provides a clear wake-up call to our health and social care leaders. By the end of the next Westminster Parliament in 2020, there will be three million people living with cancer in the UK – two-thirds of whom will be aged 65 or over. How will we cope with these growing numbers when we cannot even meet the needs of people today?

Everyone treating, caring for or supporting people with cancer must adapt their way of working, whether in health or in social care, senior managers or frontline staff. Where there are known solutions and services with a strong evidence base, these must be funded and provided.

We need a shift in the focus of resources from hospitals to the community to better support the growing number of people who are surviving cancer but struggling to live active and fulfilled lives. In some areas we need to take more radical action, by redesigning entire cancer care systems or introducing innovative new roles into the health and social care workforce. We also need local government to recognise and act on the most urgent social care needs of people with cancer. And we need health and social care to work together to better support people to manage their condition and take back control of their lives. Most importantly we need a shift in mindset in response to the changing nature of cancer – and we need it now.

Macmillan is working hard to support the growing number of people living with cancer, in partnership with the NHS, local government and many other organisations. As well as developing essential frontline services, we help drive forward innovation and improvements in cancer care systems and policy across the UK. We work with employers to help support people with cancer and those who care for them in their working lives. All of this is still not enough – we need more widespread action.

Each of the four countries in the UK must have a clear, up-to-date cancer plan that sets out what will be done to address the issues raised in this report and how progress will be measured.

Governments and the entire health and social care workforce must recognise the true scale of the challenge presented by cancer. All of us must work in partnership to deliver what people with cancer need. But engaging just these audiences alone will again still not be enough – we must also inspire millions of people across the UK to get involved. Together, we can help people reclaim their lives from cancer and ensure that no-one, irrespective of who they are, where they live, or which cancer they have, faces cancer alone.



Ciarán Devane

Chief Executive
Macmillan Cancer Support

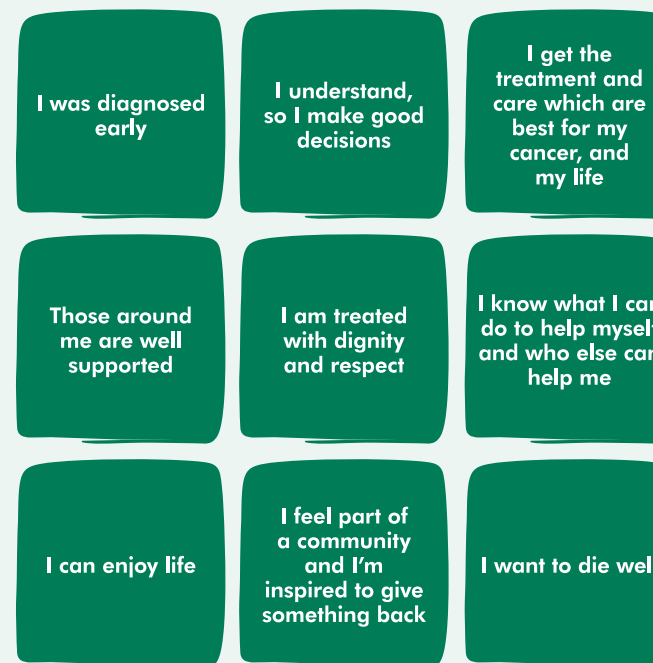
Executive summary

Cancer in the UK 2014, the first in a regular series of state of the nation reports from Macmillan Cancer Support, shows for the first time how the UK is performing on the issues that matter most to people with cancer. We have carried out a comprehensive review of the available evidence and applied it to Macmillan's 'Nine Outcomes' – nine statements that people with cancer have told us they want to be able to say about their cancer experience. It is our vision that every person living with cancer will be able to say that the Nine Outcomes are true for them by 2030.

Macmillan's Nine Outcomes

For each of the Nine Outcomes, shown on the right, we present the following:

- An explanation of what this Outcome means to people with cancer
- A summary of evidence showing current performance against the Outcome for people with cancer in the UK
- An overall assessment of how the UK is faring against the Outcome
- A selection of key facts and figures
- Our recommendations for what should be done to improve the experience of people with cancer
- One example of how Macmillan is helping people with cancer
- A personal story from someone with cancer in the UK showing the real impact cancer has on people's lives



Macmillan is carrying out a wide range of activities to help achieve all Nine Outcomes for people with cancer, but as this report is focusing on the UK's performance as a whole we have selected just one highlight of our work in each area. You can find more details of the featured services and solutions on page 52, along with contact details for key Macmillan people. The facts and figures for each Outcome are presented in a summary format in the main section, with full details explaining which specific groups of people with cancer they refer to included in the references.

State of the nation overview

Over the past few decades the UK has achieved major progress in life expectancy, partly thanks to improvements in diagnosis, treatment, care and survival for serious conditions such as cancer. Significant credit for this should go to the people working in the NHS in all four countries of the UK. However, as *Cancer in the UK 2014* shows, there is still a huge gap we have to bridge in order to deliver Macmillan's Nine Outcomes for people with cancer by 2030. Current performance against each of the Nine Outcomes is simply not good enough.

Tens of thousands of people with cancer are being diagnosed too late, shown a lack of compassion during their care or denied a 'good' death. In some areas, such as early diagnosis and the treatment of older people, international comparisons show the UK lags behind many other European countries.

Our assessment of each of the Nine Outcomes shows that:

1. Too many cancers are only diagnosed once they have reached an advanced stage, which greatly reduces people's chance of survival
2. Many people living with cancer in the UK do not receive the information and support they need to understand what is happening to them and so cannot make informed decisions about their care
3. Too many people – particularly older people – are not given the best possible treatment and care for cancer, reducing their chances of survival, and there are simply not enough clinical nurse specialists to go around
4. People who care for those with cancer or play an important role in their day-to-day lives are missing out on vital support
5. Too often people with cancer are not treated as individuals during treatment and are shown a lack of compassion when at their most vulnerable. NHS leaders must treat patient experience and clinical outcomes with parity of esteem and recognise that both good patient and staff experience are vital for good clinical outcomes
6. Many people with cancer feel abandoned to fend for themselves after their treatment ends and do not know where to turn for help or support
7. Significant numbers of people with cancer experience long-term physical, emotional, financial and work issues, many of which could be improved by better advice and support and increasing physical activity
8. Many people face cancer alone or lack support from their family and friends. We need more social networks and charitable activity such as volunteering and fundraising to help strengthen communities
9. Too many people who die from cancer are denied a 'good' death – they are not able to die in the place of their choosing and experience inadequate control of pain and other symptoms

What Macmillan says should be done

This report sets out a range of specific recommendations, summarised on pages 47–50, that we at Macmillan believe will help deliver the Nine Outcomes for people with cancer in the UK. At a broad level, where there are known solutions and services with a strong evidence base, these must be funded and provided. We need a shift in the focus of resources from hospitals to the community to better support people with cancer in self-managing their condition and leading active and fulfilled lives. And in some areas we need to take more radical action, such as redesigning entire cancer care systems or introducing innovative roles into the health and social care workforce.

‘We need to better support people with cancer in self-managing their condition and leading active and fulfilled lives.’

On a specific level, if national and local health and social care leaders must focus on only the most important issues, we believe the following three priorities will make the biggest difference to people with cancer:

- Delivering cancer outcomes that match the best in Europe – particularly by reducing late diagnosis, investing in care after treatment by delivering the cancer Recovery Package, and addressing the needs of older people
- Ensuring all people with cancer are treated with the highest levels of dignity and respect – particularly by giving patient experience parity of esteem with clinical outcomes, and supporting staff to deliver this
- Improving end-of-life care for people with cancer by delivering free social care for people at the end of their lives and enabling people to spend their final weeks and days in the place of their choice

Each UK country must have a clear, up-to-date cancer plan that sets out what is being done and what will be done to address these three priorities and other issues raised in this report, as well as stating how progress will be measured. Unless cancer remains a specific priority in the NHS today and in the future, and unless we continue to redesign and improve cancer care systems and services, there is a danger that the state of cancer in the UK will fall into crisis.

How Macmillan is helping

As the UK's leading cancer care charity, Macmillan Cancer Support plays a major role in supporting the growing number of people living with and beyond cancer, in partnership with the NHS, local government and other organisations. In 2013 we supported 1.8 million people with cancer, 529,000 carers and 2.9 million friends and family of people with cancer¹. Throughout this report we give examples of some of the specific ways we are helping deliver the Nine Outcomes.

Our work can be summarised into four main areas:

- Promoting evidence-based policies, services and solutions that we know make a difference to ensure they are implemented for everyone with cancer across the UK
- Developing more services and support in the community and at home
- Influencing the design of cancer care systems and pathways to make them more patient-centred and integrated, helping to develop the roles, skills and teamwork of the health and social care workforce, and helping people with cancer take control and be supported to help themselves
- Inspiring millions of people in the UK to get involved in improving the lives of people affected by cancer by volunteering their time, organising a fundraising event, donating money or just simply supporting other people

We are already working with many people in each of the UK countries, including health and social care leaders, service providers, policy makers, health and social care professionals and employers. We urge any others who want to improve cancer care and support in the UK to get in touch – please see page 51 for our contact details.

I was diagnosed
early

Outcome 1: **I WAS DIAGNOSED EARLY**

What 'I was diagnosed early' means to people with cancer

- I was aware of the signs and symptoms of cancer and knew where to seek medical help
- My cancer was diagnosed at an early stage, giving me the best chance of survival
- I was diagnosed by the most appropriate health service for my cancer, ideally via a referral by my GP or a screening programme
- If my cancer comes back or spreads, this is also detected at an early stage and by the most appropriate health service
- I was seen as soon as necessary after my diagnosis by a hospital doctor
- My diagnosis was communicated to me clearly and sensitively

Key insights

- Poor one-year survival
- Too many people diagnosed via A&E
- Variation in GP referrals

‘I was diagnosed early’

People have a better chance of surviving cancer and having fewer long-term complications if the disease is caught early. The UK, however, performs poorly on early diagnosis compared with many other developed countries. Part of the issue is that we do not have comprehensive data on stage of cancer at diagnosis, so we have to rely on imperfect measures such as one-year survival or the way in which people are diagnosed. One study comparing the UK to five other countries with similar health systems and levels of wealth found the UK has the lowest one-year survival rates for colorectal, lung, breast and ovarian cancer². Other research shows one in four cancers in England are diagnosed via an emergency admission, rather than through another clinical pathway such as screening or GP referral. This rises to half of all cases of pancreatic cancer and almost two-thirds of brain or central nervous system cancer, and increases with age for all cancer types.

People diagnosed via an emergency admission are on average around twice as likely to die within a year of diagnosis as those diagnosed via an urgent GP referral³.

There are three key factors that affect early diagnosis: first, people’s level of awareness of signs and symptoms and how quickly they report them to their GP or other health professional, or how many people take up available screening; second, how quickly

and accurately GPs refer people for further investigation; and third, how quickly people receive care and treatment once they have been referred for investigations.

Government mass media campaigns to raise awareness of signs and symptoms of cancer, and to encourage people to visit their GP if they have concerns, appear to have a positive impact. The *Be Clear on Cancer* campaign for lung cancer that ran in England in May and June 2012 was associated with 700 additional diagnoses, a shift towards diagnosis at an earlier stage and 300 more people receiving surgery⁴. A campaign run as part of Scotland’s *Detect Cancer Early* programme in February and March 2012 led to an 8% increase in the proportion of women who said they self-examined their breasts⁵. But people’s awareness of signs and symptoms still remains too low.

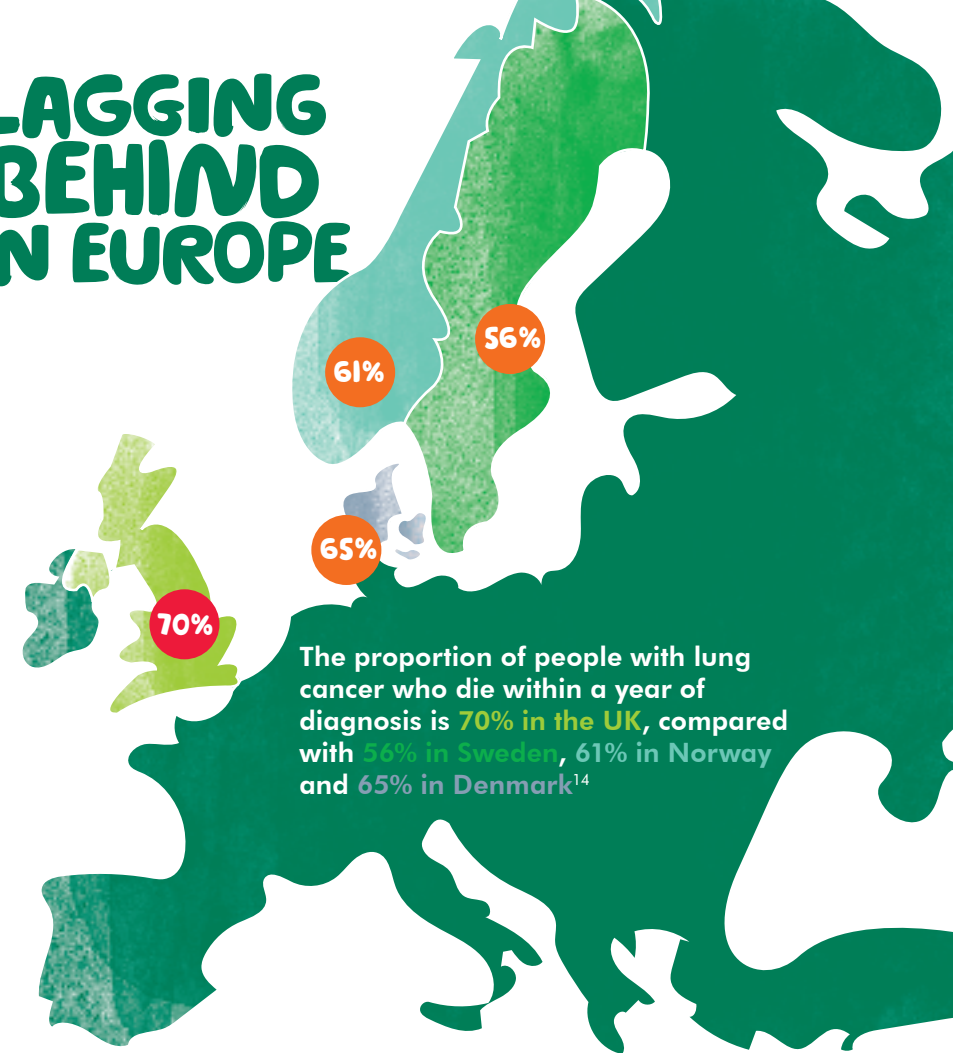
With regards to screening, UK screening programmes are undoubtedly saving lives, but uptake varies significantly with levels of deprivation. In south-east London, women from the most affluent areas are 24% more likely to accept their first breast screening invite than women from the most deprived areas⁶, and in Scotland, people from the most affluent areas are 50% more likely to take part in bowel cancer screening⁷.

In terms of GP referrals, while three in four (73%) people with cancer diagnosed via their GP are referred for investigations after only seeing their GP once or twice,

some people have five or more appointments before being referred⁸. One study reported a six-fold variation in GPs’ individual referral practices⁹. The urgent ‘two-week-wait’ referral pathway works well for people whose symptoms meet the criteria, but those with less specific symptoms often experience delays. At Macmillan we believe the current referral options available to GPs contribute to the delays in diagnosis experienced by some people. In addition, not all diagnostic tests and investigations are available in all areas, and waiting times vary.

We must do more to raise people’s awareness of cancer signs and symptoms, improve uptake of screening, support GPs to improve the referral process and ensure the right resources and processes are in place to support early diagnosis.

LAGGING BEHIND IN EUROPE



I was diagnosed early

Too many cancers are only diagnosed once they have reached an advanced stage, which greatly reduces people's chance of survival

The facts

- One in three (32%) people with cancer die within a year of diagnosis¹⁰, suggesting for many their cancer is diagnosed too late. This varies widely by cancer type and by where you live in the UK, and the UK often performs poorly against other comparable countries
- One in four people with cancer are diagnosed via an emergency admission, and those diagnosed this way are on average around twice as likely to die within a year of diagnosis as those diagnosed via an urgent GP referral¹¹
- More than three-quarters of people with lung cancer are not diagnosed until the cancer has spread beyond their lungs¹², making it much harder to treat. One in five people with lung cancer die within just one month of diagnosis¹³

What Macmillan says should be done

- **Better referrals:** NHS leaders must tackle regional variations in the clinical pathways used to diagnose people with cancer, and GP practices should use the best available clinical decision support tools to help diagnose people earlier
- **Better data:** Cancer registries and hospitals must ensure stage at diagnosis is recorded for every person with cancer in the UK, and the NHS needs to use this data to improve performance
- **Cancer leads:** All commissioning groups and health boards should have dedicated cancer leads


One way Macmillan is helping



'I'm using a clinical decision support tool that Macmillan has developed with GPs to help identify cancer warning signs and diagnose people earlier. It has helped me to review patients at higher risk of cancer and identify who needs additional tests.'

Dr Pawan Randev, Macmillan GP, north-west London

GPs across England and Wales are using the tool, which integrates with their existing IT systems and focuses on five cancer types including hard-to-detect cancers such as ovarian and pancreatic cancer.



'I was experiencing weight loss and serious stomach problems but every time I went to my GP they put it down to irritable bowel syndrome (IBS) or depression because I'd lost my mum.

It wasn't until I collapsed and went back to the doctor again, this time to a locum, that I was referred immediately for hospital tests. A few days later I was given the devastating news that I had stage 3 bowel cancer.

Because I was diagnosed so late I had to have very aggressive chemotherapy. I'm now in remission but I've been left with ongoing muscle pain and 'chemo brain'.

Sonia, 38, from Manchester

I understand,
so I make good
decisions

Outcome 2:

I UNDERSTAND, SO I MAKE GOOD DECISIONS

What 'I understand, so I make good decisions' means to people with cancer

- I received the information and support I needed to understand the type of cancer I have
- I understand my treatment options, the potential consequences of treatment, and any medical procedures that I have had and am going to have
- I am supported to make decisions about my medical care and treatment
- I am informed about the wider impacts of cancer on my life and the sources of support available to me
- I am supported to make decisions about the non-medical aspects of my cancer and its impact

Key insights

- Variation between and within UK countries
- Lack of investment in local information and support services
- Lack of time and skills among health and social care professionals

‘I understand, so I make good decisions’

Supporting people with cancer to make informed decisions about their treatment and care should be a priority for all cancer services. It leads to improved patient engagement and patient safety, a better patient experience and lower healthcare costs¹⁵.

There is also growing evidence that it leads to improved clinical outcomes. For example, women who have continued to take tamoxifen as a follow-up treatment for breast cancer, helping to reduce the risk of the cancer coming back, are 14% more likely to say they were told about the possible side-effects in advance compared with women who stopped taking the drug¹⁶. For people to be able to make informed decisions, health and social care professionals must provide personalised, easy-to-understand information as well as any support that people need to process and act on the information. However, how this is done varies a great deal across the UK, as does the quality of what is provided.

Information and support for people with cancer in the UK is strongest in Scotland, where there is a clear framework and strategy for supported access to information. More progress is needed in Wales in particular, where, despite the fact that good patient information is a commitment in national policy, currently there is no central information strategy to make it a reality.

There is also a great deal of variation within each of the UK countries. Many hospitals have no centralised budget for patient information, and the proportion of people who said they received easy-to-understand written information about their cancer varies from 44% to 81% across hospitals trusts and health boards in England and Wales¹⁷.

Aside from regional and national variations, there are several other challenges in this area. Many health and social care professionals do not have the time or the necessary skills to assess what people’s information and support needs are, particularly for groups with complex needs such as those with learning disabilities or who do not have English as their first language. Some professionals are also reluctant to signpost people to other sources of information or support, or fail to recognise that they should be doing so.

Providing information on more sensitive topics such as sexual issues or end-of-life care can be particularly challenging.

The quality of the information available to people with cancer is also highly variable. The Information Standard, an independent certification scheme, is helping to drive up the quality of patient information for many health conditions but it is voluntary and currently only used in England.

There is far too much poor-quality information produced by individual health and social care providers, leading to a poor patient experience and unnecessary and wasteful duplication.

There are promising centralised initiatives that enable health professionals and patients to create a personalised information package in Scotland and through information prescriptions in England but it is not clear how widely these services are being used.

We must start to see the provision of information and support as a service for people with cancer in its own right¹⁸. People need help to take more control of the decisions that will affect their treatment and care. Personalised, high-quality patient information and ensuring staff have the time and skills to support people to interpret and use this information are both essential for this process.

MORE SUPPORT, BETTER INFORMED²²

I understand,
so I make good
decisions

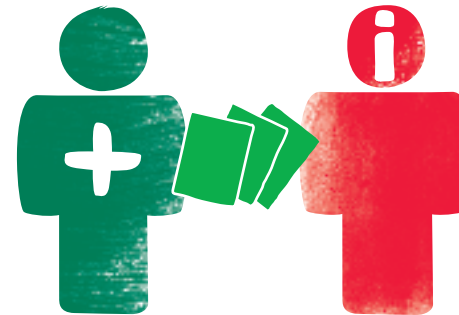
Many people living with cancer in the UK do not receive the information and support they need to understand what is happening to them and so cannot make informed decisions about their care

The facts

- One in four (24%) people living with cancer say they have little or no control over decisions about their care and treatment; of this group, three in five (59%) say more information, or better communication from professionals, would make them feel more in control¹⁹
- Around one in five people with cancer who ask hospital doctors or ward nurses important questions can't understand the answers they are given²⁰
- One in four (25%) people with cancer do not fully understand the potential side-effects of treatment²¹

What Macmillan says should be done

- **Better information:** All people affected by cancer should be offered high-quality, personalised information about the condition and their support and treatment options, including the short-term and long-term consequences of treatment
- **More local services:** Local health and social care leaders should ensure that people affected by cancer can access and are offered local, high-quality, face-to-face cancer information and support services
- **Improved communication:** Health and social care leaders must make information needs assessment and communication skills a higher priority in service plans and training, to ensure professionals identify what information people with cancer need and provide appropriate support



People who are assigned a clinical nurse specialist in hospital are **49%** more likely to be given easy-to-understand written information about the type of cancer they have.

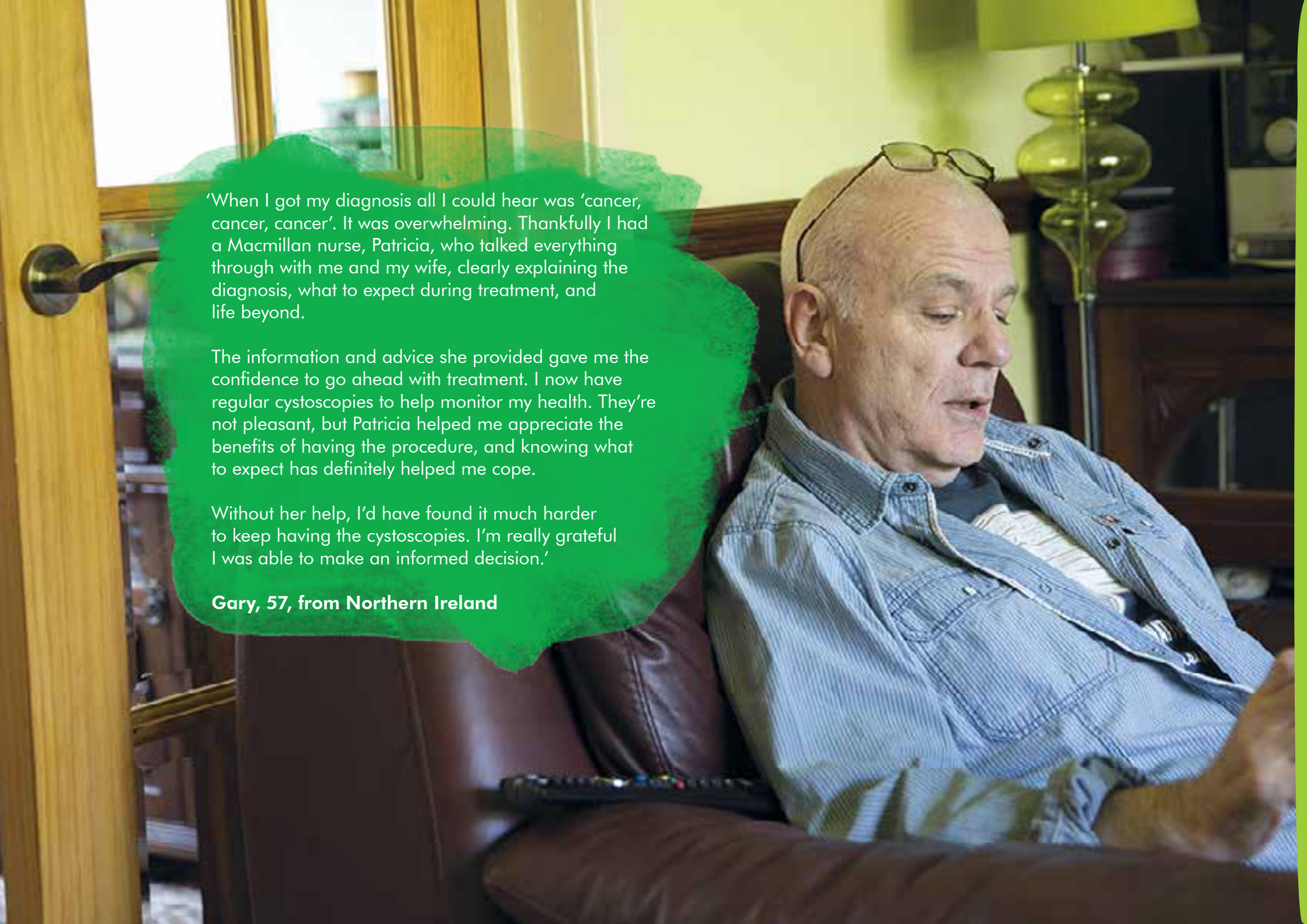
One way Macmillan is helping



'We provide high-quality, easy-to-understand information for people affected by cancer via our Macmillan nurses, information and support services, Macmillan Support Line, website and many other sources.'

Sharon Clarke, Macmillan Information and Support Manager, County Armagh

Our written information is based on the latest evidence, is highly accessible and is developed with input from people affected by cancer.

A man with glasses on his head, wearing a blue button-down shirt, is sitting in a brown leather chair. He is looking down and to the right. The background shows a wooden door frame and a lamp with a green shade. A large, irregular green shape is overlaid on the left side of the image, containing white text.

'When I got my diagnosis all I could hear was 'cancer, cancer, cancer'. It was overwhelming. Thankfully I had a Macmillan nurse, Patricia, who talked everything through with me and my wife, clearly explaining the diagnosis, what to expect during treatment, and life beyond.

The information and advice she provided gave me the confidence to go ahead with treatment. I now have regular cystoscopies to help monitor my health. They're not pleasant, but Patricia helped me appreciate the benefits of having the procedure, and knowing what to expect has definitely helped me cope.

Without her help, I'd have found it much harder to keep having the cystoscopies. I'm really grateful I was able to make an informed decision.'

Gary, 57, from Northern Ireland

I get the treatment and care which are best for my cancer, and my life

Outcome 3:

I GET THE TREATMENT AND CARE WHICH ARE BEST FOR MY CANCER, AND MY LIFE

What 'I get the treatment and care which are best for my cancer, and my life' means to people with cancer

- My medical needs in relation to my cancer and its treatment (including ongoing issues after my cancer treatment) are met with the best treatment and care available
- I start treatment as soon as necessary
- My pain and discomfort is minimised
- I know that services and my care are well co-ordinated and designed around me and my needs
- I only go to hospital when necessary

Key insights

- Low rates of surgery for some cancer types and delays in treatment
- Poorer outcomes for older people with cancer
- Too much focus on treating the disease rather than caring for the whole person

‘I get the treatment and care which are best for my cancer, and my life’

The NHS has made significant improvements in cancer treatment and care over the past few decades. By 2020, around one in three (36%) people with breast or prostate cancer will ultimately die from the disease, down from around two in three (67%) in the early 1990s²³. However, we have not seen anything like these improvements in other cancer types.

The five-year survival rates for pancreatic and lung cancer have increased by less than five percentage points since the 1970s and remain below 10%²⁴. Even in cancers with a good prognosis, such as breast or prostate, surviving does not necessarily mean living well. And our performance in the UK compared with other developed countries is simply not good enough, particularly for older people. If you’re aged 75 or over and get diagnosed with lung, stomach or kidney cancer in the UK, your chances of surviving at least five years are lower than in Eastern Europe²⁵.

Too many people with cancer in the UK are not given the best possible treatment and care. For example, surgery is overall the most effective treatment for cancer. For people with early-stage non-small cell lung cancer, surgery offers the best chance of a cure. Yet we carry out less surgery for lung cancer in the UK than in other European countries, the proportion of people who receive surgery varies widely across the UK, and rates of surgery decline sharply with age²⁶.

People are dying sooner as a result. If rates of surgery for lung cancer across England increased to match the top fifth of areas, around 10% of deaths from lung cancer could be delayed²⁷.

After surgery, radiotherapy is the next most effective treatment for cancer. However, in 2010, the amount of radiotherapy delivered in England was only enough to meet two-thirds of the overall estimated need²⁸. Too many radiotherapy centres are failing to perform enough treatment using modern techniques that can reduce the consequences of treatment, many radiotherapy machines are too old, and there aren’t enough radiotherapy staff in the NHS to meet demand. With regards to cancer drugs, people in the UK are less likely to receive the newest cancer drugs than people in many other developed countries²⁶.

There are also worrying signs about how quickly people are accessing all types of cancer treatment, as a significant number of hospitals across the UK are still failing to meet their targets to start treatment within 62 days of GP referral and the number of NHS foundation trusts in England that are failing to meet the target is higher now than at any point in the past two years²⁹.

This is the picture for some of the basics of cancer treatment, and it’s highly unlikely we are performing well on the more holistic aspects of care. The support of specialist nursing staff is essential for people with cancer, yet around one in eight people will not be assigned a clinical nurse specialist in hospital³⁰.

Too many women with breast cancer are still not being offered reconstructive surgery following a mastectomy. Many people with cancer require palliative care before their condition is officially considered terminal, yet access is patchy. Most lymphoedema care is only available in breast cancer services or hospices, despite the condition affecting people with many types of cancer. And there are very few specialist services set up to support people with the long-term consequences of cancer and its treatment.

There are also concerns that we may be over-treating in some cases, such as early-stage breast cancer and slow-growing prostate cancer, or towards the end of life when intensive treatment may affect people’s quality of life. These are just some of the many examples of where we must improve treatment and care for people with cancer, regardless of their age or where they live in the UK.

I get the treatment and care which are best for my cancer, and my life

Too many people – particularly older people – are not given the best possible treatment and care for cancer, reducing their chances of survival, and there are simply not enough clinical nurse specialists to go around

The facts

- A shocking postcode lottery exists for some treatments that offer the best clinical outcome, such as surgery for lung cancer³¹ (see infographic), which means your chance of survival can depend simply on where you live
- The UK lags behind most comparable countries when it comes to cancer survival, particularly for older people. We have some of the worst five-year survival rates for cancer among people aged 75 or over in Europe³², suggesting too many older people are assessed for treatment on their age alone and not their general fitness
- Every year at least 20,000 people living with cancer lack the support of a clinical nurse specialist while in hospital³⁰

What Macmillan says should be done

- **Clinical nurse specialists:** The NHS must increase access to clinical nurse specialists for people with cancer, particularly for urological, skin, head and neck and rarer cancers, and in both hospitals and the community, to ensure people have the best possible experience of care and are able to access all available support
- **Improved access to treatment:** NHS leaders must tackle postcode lotteries to ensure all people living with cancer in the UK receive the care and treatment that offers the best clinical outcomes, regardless of where they live
- **Age-friendly care:** We must eliminate the barriers that stop older people being able to access treatment. All decisions about treatment and care must be based on an individual's fitness, not their chronological age, and we must re-examine how well social care services are meeting the needs of older people with cancer

SURVIVAL UP..

1971-72

1 YEAR

2007

5.8 YEARS

The time from diagnosis by which half of all people with cancer have died and half have survived (median survival)³³

...BUT POSTCODE LOTTERIES REMAIN

Variation in proportion of people with non-small cell lung cancer who receive surgery, based on 2012 cancer networks in England and Wales³¹

- 15-20%
- 21-25%
- 26-30%
- 31-35%




One way Macmillan is helping



'We fund cancer nurses and innovative health and social care professional roles, within hospitals and increasingly in the community, to help more people receive the best possible care.'

Jacqui Graves, Head of Health and Social Care, Macmillan Cancer Support

Macmillan has funded more than 7,500 health and social care professionals, including nurses, GPs, support workers and pharmacists.



'I'd agreed to have chemotherapy for my breast cancer, but when I went to see the consultant he threw every negative at me about the treatment. He said I might never be the same again and that it might not work anyway. I came out of the appointment and burst into tears. Because of what he said I changed my mind and decided not to go ahead with the chemotherapy after all.

I asked him later why he'd been so negative, and he said: 'You're 60, not 30. At 30 you'd have more life in front of you'. I'm still alive, but I just wish I'd been treated based on my general health, not my age. I also had to seek out my own support after I was diagnosed, as my oncology department did not initially offer any to me.'

Susan, 66, from Warwickshire

Those around
me are well
supported

Outcome 4:

THOSE AROUND ME ARE WELL SUPPORTED

What 'Those around me are well supported' means to people with cancer

- My carer(s) receives the support they need personally (a carer meaning a friend or family member who, without being paid to do so, looks after someone with cancer who couldn't manage without this support)
- My carer(s) is supported to provide me with care
- My family and friends are emotionally, practically and financially supported to deal with the impact of my cancer
- My employer and colleagues receive the information and support they need to help me remain in or return to work if I want to

Key insights

- People who care for those with cancer not being identified as carers
- Lack of emotional and practical support for carers, including when they have lost their loved one
- Employers unaware how best to support people with cancer and their carers

‘Those around me are well supported’

Many people with cancer rely on those around them in their day-to-day lives to provide a range of vital care and support, from loved ones who act as informal carers to employers who help employees with cancer to maintain their working lives. There are more than one million people estimated to be caring for someone with cancer in the UK, and providing this care often has a substantial impact on this group.

Almost half (46%) of those who care for someone with cancer say caring affects their mental health, and one in six (13%) say it causes physical health issues such as sleep and digestive problems³⁴. More than 50,000 people in the UK are estimated to give more than 35 hours of care a week on top of a full-time job³⁵, while almost 240,000 are carrying out vital medical tasks such as administering pain relief or managing catheters³⁶. And if the person with cancer dies, there is a dearth of bereavement support available.

Overall, people caring for those with cancer provide care worth £14.5bn a year³⁷, yet despite this they face a significant lack of support from government and health and social care services. Half of people caring for those with cancer get no support whatsoever and just one in 20 (5%) receive the Carer’s Allowance benefit or have received a formal Carer’s Assessment³⁴.

One of the main reasons for this lack of assessment and support is that those who care for people with cancer are not recognised as carers, either by themselves, or by the health and social care professionals involved in the care of their loved one; more than a third (36%) of people who were with the person they care for at the time they were diagnosed were not asked by a health professional if they would be providing care³⁸. As a result people who care for someone with cancer are potentially missing out on much-needed practical, emotional and financial help.

In England, the Government’s commitment as part of the Care Bill to produce statutory guidance that sets out the responsibility of the NHS to identify carers is an encouraging sign, but will require robust guidance that is put into action.

Caring for someone with a serious health condition can have a significant financial impact. Just under half (46%) of people currently caring for someone with cancer are in full-time work³⁵, and many have to reduce the number of hours they work. Although carers can request flexible working, not all will be granted it and there is no statutory carers’ leave in the UK. Added to this, recent changes to the UK welfare system are seriously affecting many carers.

One of the eligibility criteria for Carer’s Allowance is that the person being cared for must be receiving a relevant disability benefit, and as fewer people are being

deemed eligible for disability benefits, fewer carers are entitled to Carer’s Allowance.

As our population continues to age and more people get cancer, there will also be more people caring for someone with cancer, some as well as working and raising a family. Many carers will themselves be older and more likely to have cancer too, or other long-term health conditions.

Our health and social care services will increasingly rely on the contribution of family and friends of people with cancer and we must do more to ensure they in turn are supported to provide this care and maintain their own health and wellbeing.

Employers also need more support, as many are not aware of their legal responsibilities towards people with cancer or those who care for them, or do not realise that cancer can be a long-term condition with implications beyond the end of treatment. Family and friends who do not provide care can also be affected by someone’s cancer diagnosis, as can the children of those with cancer, and also require support.

Those around
me are well
supported

People who care for those with cancer or play an important role in their day-to-day lives are missing out on vital support

The facts

- Half of people who care for those with cancer (51%) say the word 'carer' does not describe them
- Half of carers of people living with cancer (49%) do not get any support at all, and only 5% receive a formal assessment of their needs from local government⁴⁰
- Many employers don't know how best to support employees with cancer – almost half (46%) of people who were working when diagnosed say their employer did not discuss sick pay, flexible working or making reasonable adjustments⁴¹

What Macmillan says should be done

- **Increased collaboration to identify carers:** Healthcare providers must work with local authorities to formally identify, assess and support people who care for those with cancer
- **Better support for carers:** Health and social care services must work together to ensure carers receive the emotional and practical support they need, including advice on benefits, finances and continuing with employment
- **Support for employers:** Employers must provide better support for employees with cancer and those who care for them, including fulfilling their legal obligations regarding making reasonable adjustments

HIDDEN HEALTHCARE SUPPORT³⁶

Around **240,000** people in the UK are performing **vital healthcare tasks** such as infection control and changing dressings for a relative or friend with cancer



This represents around **ONE IN FIVE** of the estimated **1.1 million** people currently caring for someone with cancer

OVER HALF

of carers providing healthcare tasks are doing so **without information, instructions or training** from a health professional³⁹


One way Macmillan is helping



'The Macmillan Support Line signposts carers to the wide range of information and support available from Macmillan and other sources, such as local authorities.'

Charlotte Argyle, Carers Support Programme Manager, Macmillan Cancer Support

The Macmillan Support Line is staffed by cancer specialists who offer practical, medical, emotional and financial support. In 2013 around one in eight callers – more than 7,000 people – said they were a carer for someone with cancer.

A man with grey hair and glasses, wearing a light blue button-down shirt, is sitting and reading a magazine. The magazine has a green cover with the word 'Hello' visible. In the background, there is a lamp with a white shade and a framed picture on a shelf.

'I wasn't qualified or prepared to care for my wife when she became unwell and I worried constantly about whether what I was doing was right. I have been caring for her for over two years, but not a single person working in the NHS has asked me if I have taken on this role or offered me any information on what support there is for me as a carer.

Caring full-time has put a real strain on me emotionally and financially and I've had to cope with it alone.'

Joe, 62, from Kent, who cares for his wife

I am treated
with dignity
and respect

Outcome 5:

I AM TREATED WITH DIGNITY AND RESPECT

What 'I am treated with dignity and respect' means to people with cancer

- I am treated as an individual, not just as a set of symptoms
- Professionals communicate with me clearly and sensitively
- Professionals give me privacy where appropriate and possible
- My feedback is sought and my concerns are acted upon
- I am treated with care and compassion by the health and social care professionals looking after me, and by any other professional or organisation I interact with in relation to my cancer including my employer, financial institutions and benefits services

Key insights

- Large variations in patient experience
- Too many people with cancer feeling patronised or humiliated
- Good staff experience associated with good patient experience

‘I am treated with dignity and respect’

Overall, the majority of people with cancer receive good, compassionate care from the NHS. However, as the Francis Report highlighted in its response to the Mid-Staffordshire care scandal, there has been a sub-culture within parts of the NHS that has repeatedly compromised patient safety, experience and quality of care.

There are still too many people with cancer who are not treated with dignity and respect throughout their time as a patient, and patient experience in general varies too much between hospitals and between people with different types of cancer.

The results of the third national cancer patient experience survey for England, published in August 2013, showed that while half of NHS hospital trusts made improvements compared with the previous year, a third made no improvements and some showed a decline in performance⁴².

Across England and Wales, the proportion of people who rated their overall care in hospital as excellent or very good varies from 64% to 96%⁴³. We do not know the picture for Scotland and Northern Ireland yet; Northern Ireland has now launched its first national cancer patient experience survey with results due later in 2014, but Scotland does not yet have a regular, cancer-specific survey.

Other survey data show one in five (21%) people with cancer felt patronised by hospital staff and one in seven (15%) felt humiliated by nurses⁴⁴. Seven percent felt like dropping out of treatment early because of the way hospital staff dealt with them⁴⁵. Dignity is particularly an issue for older, vulnerable people with cancer.

While these figures highlight areas of concern, it is also important to use objective measures of patient experience – asking people whether a specific thing happened rather than how they felt about their care and experience. For example, four in 10 (42%) people with cancer in England and Wales say not all doctors and nurses asked them what name they would prefer to be called while they were staying in hospital, and this varies across hospital trusts and health boards from 16% to 72%⁴³. Using objective measures is important because these issues have a big impact on people’s experience and highlight tangible areas where improvements can be made. We also need more data, both subjective and objective, on the experiences of hard-to-reach groups in particular.

At the root of the issue is that too many health and social care providers fail to recognise that patient experience is just as important as clinical outcomes and patient safety, or that dignity and privacy are basic human rights. Delivering patient experience is still considered a ‘soft’ skill that falls to nursing staff.

There is growing evidence that good patient experience is in fact intrinsically linked to good clinical outcomes, and also that good staff experience is associated with good patient experience. More than half of hospital trusts where staff suffer the lowest levels of discrimination are ranked in the top 20% for overall patient experience, whereas none of the trusts where staff suffer the most discrimination appear in the top 20%⁴⁶.

All organisations across the NHS and government must take decisive steps to deliver a better patient experience as soon as possible. There is still much more to be done to raise people’s expectations about what a good experience is and to empower them to drive change, and to effectively build and strengthen a common culture of compassion. And while most of the focus in this area rightly concentrates on health and social care services, people with cancer must also be treated with dignity and respect by all other professionals and organisations they interact with in relation to their condition.

I am treated
with dignity
and respect

Too often people with cancer are not treated as individuals during treatment and are shown a lack of compassion when at their most vulnerable. NHS leaders must treat patient experience and clinical outcomes with parity of esteem and recognise that both good patient and staff experience are vital for good clinical outcomes

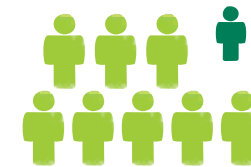
The facts

- At one in five hospitals, a third of people with cancer did not receive enough emotional support from staff while an outpatient or day case⁴⁷
- Four in 10 (42%) people living with cancer say not all doctors and nurses asked them what name they would prefer to be called by while they were staying in hospital⁴³
- Almost a fifth (19%) of people with cancer felt treated as a 'set of symptoms' rather than a person, while one in six (17%) said doctors spoke to them as if they weren't there⁴²

What Macmillan says should be done

- **National surveys:** All countries in the UK should have regular, cancer-specific patient experience surveys that cover hospital, primary, community and social care
- **Support for frontline staff:** NHS leaders must ensure all frontline staff have the training and support they need to prioritise care and compassion as well as excellent clinical treatment in their day-to-day role
- **Staff experience:** NHS leaders must recognise that good staff experience is essential for good patient experience and provide support for staff mental and physical wellbeing

HAPPY STAFF, HAPPY PATIENTS



ONE IN NINE

hospital staff have experienced discrimination in the past 12 months⁴⁸



MORE THAN 50%

of hospital trusts in which staff report experiencing the lowest levels of discrimination appear in the **top 20%** of trusts for overall patient experience⁴⁶

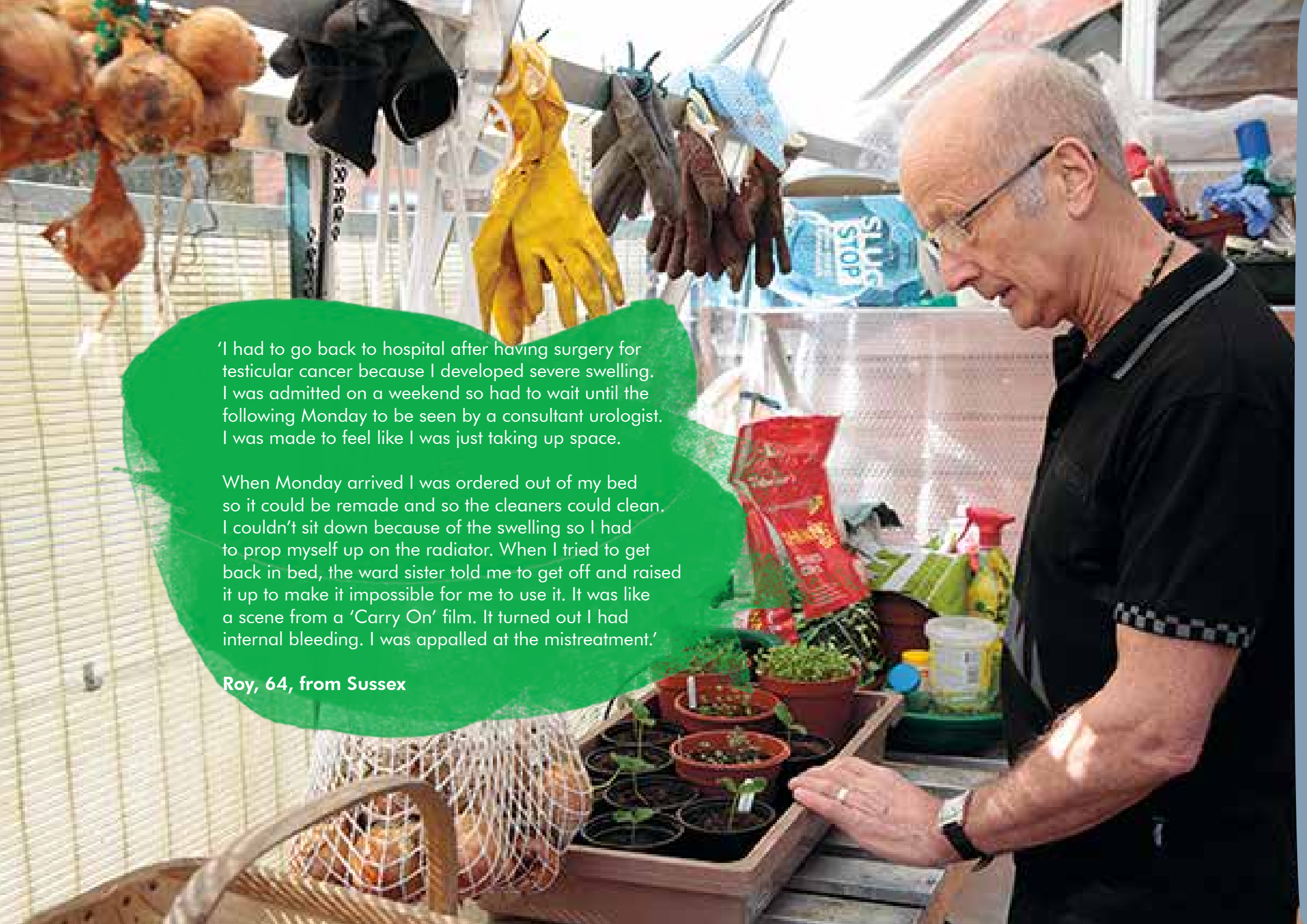
One way Macmillan is helping



'We've developed a guide for the NHS to help improve the relationship between staff and patients. The Macmillan Values Based Standard[®] will improve the aspects of patient experience that patients and staff say are most important.'

Jagtar Dhanda, Head of Inclusion,
Macmillan Cancer Support

The Macmillan Values Based Standard[®] sets out eight behaviours that will improve patient experience and includes input from over 300 healthcare staff and people with cancer.



'I had to go back to hospital after having surgery for testicular cancer because I developed severe swelling. I was admitted on a weekend so had to wait until the following Monday to be seen by a consultant urologist. I was made to feel like I was just taking up space.

When Monday arrived I was ordered out of my bed so it could be remade and so the cleaners could clean. I couldn't sit down because of the swelling so I had to prop myself up on the radiator. When I tried to get back in bed, the ward sister told me to get off and raised it up to make it impossible for me to use it. It was like a scene from a 'Carry On' film. It turned out I had internal bleeding. I was appalled at the mistreatment.'

Roy, 64, from Sussex

I know what I can
do to help myself
and who else can
help me

Outcome 6:

I KNOW WHAT I CAN DO TO HELP MYSELF AND WHO ELSE CAN HELP ME

What 'I know what I can do to help myself and who else can help me' means to people with cancer

- I am supported so that I can manage my condition when I'm at home
- I know who to contact for support at any point following my cancer diagnosis
- I know what to do to improve my health and wellbeing and I am supported to do so

Key insights

- Outdated follow-up system
- Lack of support after treatment
- Need for more support to help people self-manage

‘I know what I can do to help myself and who else can help me’

Over the past few decades the nature of cancer has changed. Advances in diagnosis and treatment have meant that many people who previously would have died soon after diagnosis are now living with active cancer as a long-term condition for many years, while many more others are effectively cured but experience long-term consequences of the cancer and its treatment.

The NHS, however, has been slow to adapt. A significant proportion of people with cancer continue to experience unmet needs for months or even years after treatment ends, including depression, anxiety and fatigue. Half of those who need support after treatment do not get enough from health and social care services, and more than half are not certain who to contact if they have a concern related to their cancer⁴⁹. Almost one in three (32%) people with cancer who experience loneliness and have completed treatment say they felt most isolated or lonely after their initial treatment ended⁵⁰.

One of the main factors contributing to these issues is that the follow-up system for most people with cancer is still based on the now-outdated view that if someone’s initial cancer treatment was successful, their need for care and support ended once they were discharged from hospital, and that the best form of follow-up was for people to see their cancer specialist every six months for five years.

This one-size-fits-all approach does not properly target help to those who need it or support people to manage their condition themselves. For those living with cancer as a long-term condition or with long-term consequences of the disease or its treatment, taking an active role in managing their own care and maintaining a healthy lifestyle can enhance their quality of life.

As the number of people diagnosed with and surviving cancer is increasing year-on-year the traditional follow-up model is putting more and more pressure on hospitals, becoming more expensive to deliver, and risks overloading cancer specialists as the need for follow-up continues to grow. There is also often a lack of communication between a person’s cancer specialist and their GP, and a failure to give people enough information about the treatment they have received, what to expect afterwards, what they can do to help themselves and what support is available in their local community. As an example of this, only one in five people with cancer are offered a written care plan or assessment after treatment⁴³.

The National Cancer Survivorship Initiative in England has drawn on the lessons learned from other long-term conditions such as diabetes to develop a new model of aftercare called the Recovery Package, to better support people with cancer across the UK, particularly after treatment ends.

The key elements of this package are explained in more detail on the following page and should ensure that someone with

cancer has their full range of needs identified and assessed, that they are supported to manage their own condition as much as possible, made aware of available support services in the community, and that their GP has the information they need to provide ongoing support.

The cost of delivering the Recovery Package should be addressed by implementing a more sophisticated model of follow-up care that uses risk stratification to tailor care according to people’s needs and ability to self-manage. However, while there has been encouraging progress so far in parts of the UK, the Recovery Package is not yet being provided across the UK. In some areas, specific elements of the package may already be available, but not as part of a complete package and not always for all people with cancer. In some cases, people with cancer are not taking an active role in managing their own care when the advice and support is available to enable them to do so. It is important that more health and social care leaders integrate the Recovery Package into their local cancer services.

I know what I can do to help myself and who else can help me

Many people with cancer feel abandoned to fend for themselves after their treatment ends and do not know where to turn for help or support

The facts

- Around half (53%) of people living with cancer have one or more moderate or severe unmet needs, such as depression, anxiety or tiredness, six months after the end of treatment⁵¹
- More than half (58%) of people living with cancer are not certain who to contact if they have a concern related to their condition⁵²
- Only one in five (22%) people with cancer are offered a written assessment or care plan after treatment⁴³

What Macmillan says should be done

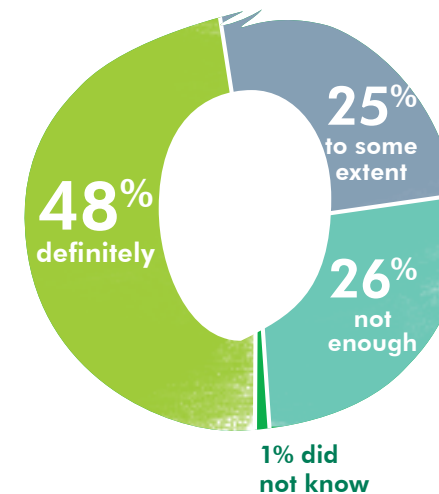
Recovery Package: To better support people with cancer after treatment ends, everyone diagnosed with cancer in the UK should receive a cancer Recovery Package. This should include:

- Holistic Needs Assessments (identifying their physical, emotional, financial and other needs) and care plans at key points during treatment and recovery
- A Treatment Summary, completed at the end of treatment and sent to the person with cancer and their GP
- A Cancer Care Review, completed six months after treatment by the person's GP or practice nurse, to discuss their needs, possible long-term consequences of treatment and what they can do to help themselves
- An education and support event such as a Health and Wellbeing Clinic, to help people work towards supported self-management and a healthy lifestyle, including physical activity and directing them to support available in their local community

LACK OF SUPPORT AFTER TREATMENT⁵³

Half of people who needed support after treatment did not definitely receive enough from health and social care services

Following your initial cancer treatment, have you been given enough care and help from health and social services?



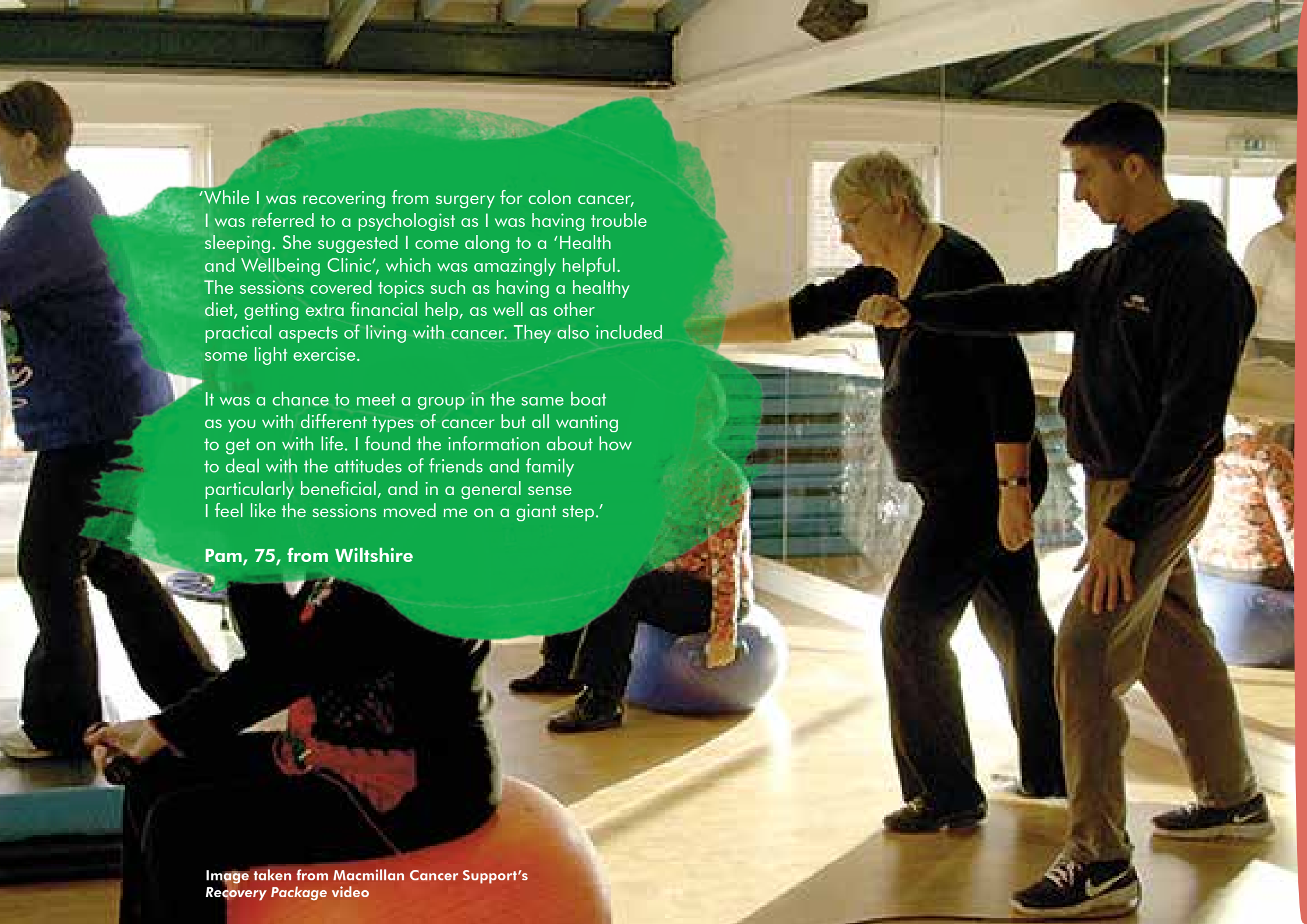
One way Macmillan is helping



'We're helping to roll-out a cancer 'Recovery Package' to improve the follow-up care and support that people with cancer receive after treatment.'

Nicola Cook, Senior Macmillan Development Manager for North West England and the Isle of Man

The Recovery Package was developed and tested by the National Cancer Survivorship Initiative (NCSI), a partnership between Macmillan and NHS England.



'While I was recovering from surgery for colon cancer, I was referred to a psychologist as I was having trouble sleeping. She suggested I come along to a 'Health and Wellbeing Clinic', which was amazingly helpful. The sessions covered topics such as having a healthy diet, getting extra financial help, as well as other practical aspects of living with cancer. They also included some light exercise.

It was a chance to meet a group in the same boat as you with different types of cancer but all wanting to get on with life. I found the information about how to deal with the attitudes of friends and family particularly beneficial, and in a general sense I feel like the sessions moved me on a giant step.'

Pam, 75, from Wiltshire



Outcome 7: **I CAN ENJOY LIFE**

What 'I can enjoy life' means to people with cancer

- My emotional well-being is the best it can be, all things considered
- I can enjoy the best quality of life for as long as possible and do things I love doing, where possible
- I do not live in financial hardship as a consequence of my cancer

Key insights

- High proportion of people with unmet physical and emotional needs following cancer treatment
- Many people hit by the financial cost of cancer
- Need for more support to help people stay in or return to work

‘I can enjoy life’

Having cancer and undergoing treatment has a significant impact on quality of life for most people with cancer in the UK. The effects can spread into all aspects of someone’s life and persist for some time after treatment ends. Cancer will inevitably have some impact on people’s health and wellbeing. However, the issues are made worse because our health and social care services are designed to focus on the initial treatment rather than ongoing care.

The most immediate impact of cancer is usually on people’s physical and mental health and wellbeing. A significant proportion of people with cancer will experience a wide range of distressing long-term problems, such as bowel or urinary incontinence, crippling fatigue or sexual difficulties. Some will face an increased risk of heart disease or osteoporosis⁵⁴, and more than one in three (38%) are anxious or depressed⁵². These issues are often worse for people who lack emotional or social support.

Overall at least one in four people with cancer – representing around 500,000 people living with cancer in the UK today – will face disability or poor health after treatment⁵¹.

The other issues that also affect people’s quality of life often stem from these physical and emotional difficulties. Four out of five (83%) people with cancer are hit by the financial cost of the disease, which averages around £570 a month for those affected.

Overall 85% of people spend more money each month on things like travelling to appointments or increased day-to-day costs, while three in 10 (30%) experience a loss of income as they have to stop working or reduce their hours⁵⁵. Many of those who are hit by the cost of cancer find it a constant struggle to pay their bills or are falling behind with payments, and financial worries can worsen people’s mental health and social isolation.

In many cases the loss of income caused by people being less able to work could potentially be avoided if people received more support to stay in employment. In addition to the financial aspect, working has significant benefits for people’s self-esteem, and can help people with cancer with their recovery and rehabilitation, as well as maintaining social connections and a sense of normality and control. Currently, however, almost half of those who are working when diagnosed have to make changes to their working lives, with around four in 10 of these changing jobs or leaving work altogether⁵⁶.

If people are unable to work, they need to be able to rely on the safety net of the welfare system.

Thanks to Macmillan, people awaiting, undergoing or recovering from gruelling cancer treatment should be placed into the Support Group for Employment and Support Allowance, where support is unconditional without the need for a stressful face-to-face assessment. However, we are still hearing too many stories about those with

serious physical and emotional difficulties experiencing severe delays when applying for Personal Independence Payment.

The wide range of impacts that cancer can have on people’s quality of life shows just how important it is to carry out holistic needs assessments, as described in the previous section of this report, as well as give people with cancer the right advice and support. Many of the physical, emotional and social challenges people with cancer face can be reduced if people are able to stay physically active, so this is one area that we must prioritise if we are to improve people’s quality of life and help them reclaim their lives from cancer.

I can enjoy life

Significant numbers of people with cancer experience long-term physical, emotional, financial and work issues, many of which could be improved by better advice and support and increasing physical activity

The facts

- At least one in four people face disability or poor health after cancer treatment⁵¹
- More than one in three people living with cancer (38%) are anxious or depressed⁵²
- Almost one in three people with cancer lose an average £860 a month because they are unable to work or have to cut down their hours, while six in seven see their monthly spend increase by an average £270 a month⁵⁷

What Macmillan says should be done

- **Physical activity:** Health and social care professionals must promote the benefits of physical activity to people with cancer, and local authorities need to provide appropriate schemes to help deliver long-lasting behaviour change
- **Specialist work support:** We need the UK governments' departments for work and health to support the employment of people with cancer and other long-term health conditions, such as via improved availability and access to vocational rehabilitation support, and employers must also provide better support to those affected by cancer
- **Benefits support and advice:** The UK government must ensure people with cancer are fully supported by the welfare system. This includes assessing their claims for Personal Independence Payments fairly and promptly and ensuring they are not forced into work-related activity to receive Employment and Support Allowance, as well as ensuring they can access advice and support when needed and are protected from further cuts to welfare spending

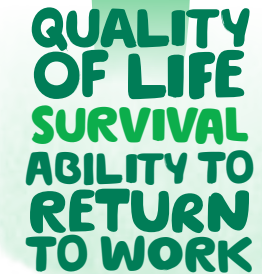
GET ACTIVE, FEEL GOOD

The effects of increasing physical activity in people living with cancer:

**FATIGUE
ANXIETY
DEPRESSION
RECURRENCE**



**QUALITY
OF LIFE
SURVIVAL
ABILITY TO
RETURN
TO WORK**



One way Macmillan is helping



'I manage a walking scheme that supports England's Walking for Health programme, the largest network of health walks in the UK. Our walks help people with cancer to lead a more active lifestyle. The walks are free, friendly, short and at a pace that most people with cancer can safely enjoy.'

Lorraine Rasmussen, coordinator for the Walk4Life scheme in County Durham

Macmillan is supporting people with cancer to achieve healthier, more active lifestyles through sustainable behaviour change, such as via Walking for Health and other walking partnerships and physical activity schemes.



'During the chemotherapy for my throat cancer, I became very weak. I started having problems eating and drinking, and I lost six-and-a-half stone in just three months. When my treatment finished I couldn't even walk. I became very depressed and for a time stopped all visitors.

I was referred to Wendy, a Macmillan occupational therapist, and Kathy, a Macmillan physiotherapist. Together they helped me walk again. They took me around the garden with my walking frame, then out on the pavement and gradually we went further and further.

It was thanks to them that I was able to go on a cruise with my wife Pat, where I celebrated my 70th birthday. We've since been able to have other holidays to France and Spain. I'm back to a more healthy weight, and I can take Pat to get her hair done and go and see my mates again.'

David, 74, from South Wales

I feel part of
a community
and I'm
inspired to give
something back

Outcome 8:

I FEEL PART OF A COMMUNITY AND I'M INSPIRED TO GIVE SOMETHING BACK

What 'I feel part of a community and I'm inspired to give something back' means to people with cancer

- I know where there are other people like me who I can turn to
- I do not feel alone in any aspect of my cancer journey
- I know what opportunities are available for me to get involved with voluntary organisations and services
- The contribution I make to my community and people affected by cancer is valued

Key insights

- Too many people with cancer facing isolation and loneliness
- People affected by cancer want to give back, but opportunities for them to do so are not universally available or easy to access
- Volunteers play a major role in supporting people affected by cancer

'I feel part of a community and I'm inspired to give something back'

Despite the fact that cancer will affect nearly everyone in the UK one way or another, it is still an isolating condition. Almost one in four people with cancer in the UK will lack support from family or friends during their treatment or recovery⁵⁸ and one in five will experience loneliness following their diagnosis⁵⁹.

Isolation can have a significant impact on people's health and wellbeing: people with cancer who experience loneliness are almost eight times more likely to eat a poor diet than those who aren't lonely and almost five times more likely to have not left the house for days⁵⁹. Many people with cancer do receive support from their family, friends, colleagues and neighbours, and a significant minority of people with cancer draw support from a community specifically related to their cancer – around one in 10 are members of an online community or offline support group¹⁹. But as the figures relating to isolation show, too many people with cancer do not feel connected to people or part of a community that can offer support.

Volunteers and voluntary organisations play a major role in supporting people with unmet practical and emotional needs. Many people in the UK contribute their time or money to charitable causes and gain a great deal of satisfaction in the process.

More than one in four have volunteered in some form in the past 12 months, and around three in four have helped fundraise in their local community⁶¹.

These proportions are similar for people with cancer, but there is still much more to do as a nation to build communities and provide support to those who need it.

Many people with cancer want to give back after receiving support, either with their time or money, and doing so has many benefits. As well as providing social opportunities it can be a life-enhancing activity that boosts people's physical and emotional wellbeing. But there are a range of barriers that stop more people giving back, whether they have cancer or not. This is partly because some parts of the voluntary sector have been slow to adapt in response to changes in UK society and to the recognition that people take action in different ways depending on their demographics and stage of life. Volunteering, for example, has often been the preserve of white, middle-class, middle-aged women, while people with serious health conditions such as cancer have often encountered a protectionist attitude when exploring opportunities to give back.

There are encouraging signs that these barriers are being broken down. Cancer charities such as Macmillan and Breast Cancer Care have invested heavily in online communities, and campaigns such as that coordinated by the Movember Foundation have made effective use of social media to engage male audiences.

Online campaign groups such as 38 Degrees and platforms such as Change.org are engaging a diverse range of audiences to achieve real impact. Specific volunteering schemes have been developed to reach out to younger age groups, such as RockCorps, which offers free concert tickets in exchange for volunteering, and Macmillan's partnership with De Montford University, in which students carry out volunteering as part of their degree. Initiatives such as Macmillan's 'Team Up' pilot in Brighton and our Skype 'buddying' scheme are exploring the use of brief volunteering activities to engage those who lack time for traditional volunteering. However there remains significant room for improvement when it comes to providing opportunities to give back that people from different backgrounds will be interested in, and ensuring that volunteers and others who give back are adequately supported by the organisations they are helping.

I feel part of a community and I'm inspired to give something back

Many people face cancer alone or lack support from their family and friends. We need more social networks and charitable activity such as volunteering and fundraising to help strengthen communities

The facts

- One in five (22%) people living with cancer have felt lonely, or more lonely than before, since they were diagnosed⁵⁹
- People with cancer who are lonely are twice as likely as those who aren't to say they would find or have found support from a volunteer useful⁶⁰
- People with cancer can benefit socially from giving back themselves – for example, four in 10 (40%) people living with cancer have attended a charity social event in the past 12 months⁶¹

What Macmillan says should be done

- **Acknowledge isolation:** Health and social care professionals must recognise that isolation can have a real, negative impact on people's health, and the NHS and local government should prioritise the funding of community services to provide additional emotional support to people with cancer
- **Building volunteering capacity:** Health and social care leaders must invest in practical and emotional support services delivered by volunteers and ensure volunteers have the support and training required to deliver a high-quality service
- **Promote the benefits of giving back:** National and local health and social care leaders should encourage people affected by cancer to directly support the voluntary organisations involved in their care by giving something back as volunteers, fundraisers, campaigners or in other ways and at a time that is right for them

GIVING BACK

How people living with cancer have given back in the previous 12 months⁶¹:



More than

ONE IN FOUR

have volunteered their time



ONE IN FOUR

have hosted a charity social event such as a pub quiz or coffee morning

FOUR IN 10

have attended an event



ALMOST ALL

have donated money to charity


One way Macmillan is helping



'I help recruit volunteers and develop services in my local community, to support people affected by cancer and provide more opportunities for people to give back.'

Nesreen Badiozzaman, Macmillan Direct Volunteering Service Manager – Central Scotland

Our volunteers provide a wide range of help and support for people with cancer, such as giving lifts to medical appointments and picking up prescriptions.



'I found it really hard to return to full-time work after treatment as I experienced bad fatigue. I don't know how I would have coped without the ongoing support of my Macmillan nurse.

My experience of cancer gave me a real understanding of issues faced by cancer patients. I wanted to put this experience to good use, and so I started volunteering at the Macmillan Information and Support Service – it is brilliant that people affected by cancer in the east end of Glasgow can access the support and information they need right on their doorstep.'

Maureen, 37, from Glasgow, diagnosed with cancer in 2007

I want to die well

Outcome 9: **I WANT TO DIE WELL**

What 'I want to die well' means to people with cancer

- I will die free from symptoms such as pain and fear, and with dignity
- I will die in the place and manner of my choosing
- I will be emotionally and spiritually supported at the end of my life
- My family and friends will be emotionally and spiritually supported at the end of my life and beyond

Key insights

- Lack of choice around place and manner of death
- Inadequate control of pain and other symptoms for people dying at home
- High number of people not receiving social care support at the end of life

'I want to die well'

People are surviving cancer for longer, but every year more and more people are diagnosed with the disease. If we combine the different types of cancer it is now the most common cause of death in the UK⁶². Despite this, too many people with cancer are denied a 'good' death – one where they are able to die in the place and manner of their choosing and with good control of symptoms such as pain.

When asked, most people approaching the end of their lives say that they would prefer to be cared for and die at home, but too few of them are able to do so. For people with cancer, while three in four (73%) would prefer to die at home with the right support⁶³, fewer than a third (30%) do⁶⁴. People with cancer generally receive the best quality of care if they are able to die at home⁶⁵, however there are still significant gaps in care at home that contribute to this not being possible. Many people with a terminal illness end up in hospital because they or their carer lack support with day-to-day tasks⁶⁶. Three in four people with any terminal illness in England do not receive any social care support in the last month of their life, and those who have low levels of social care use in the last year of life are more likely to be admitted to hospital or visit A&E⁶⁷. The majority of healthcare professionals believe the complexity of social care assessments are one of the reasons people do not receive appropriate social care support at the end of life⁶⁸.

Only one in four (24%) of those with cancer who die at home have complete pain relief all of the time in the last three months of life, compared with two-thirds (66%) of those with cancer who die in a hospice⁶⁹. Community nurses provide vital support in people's homes, including pain relief, but fewer than half of GPs in the UK believe people who are terminally ill receive adequate access to care at night and at weekends⁷⁰.

As well as a lack of support for people who want to die at home, overall there is a lack of planning and coordination between different care settings and services. More than one in four (27%) people who recently lost a loved one to cancer say hospital and community services did not work well together during their last hospital admission⁷¹. To give people the best chance of having their wishes about end-of-life care met, their preferences should be set out in an advance or anticipatory care plan and recorded on an end-of-life care register – however whether this happens or not varies across the UK.

We do not fully understand the needs of particular groups of people as they approach the end of their lives, such as those with advanced but incurable cancer, children and young people with terminal illness, or hard-to-reach or vulnerable groups including those with learning disabilities or dementia, or who are homeless.

We also need to explore whether intensive treatment at the end of life reduces the likelihood of people being able to die at home in the UK as it does in the US⁷², and if so how, and we have an incomplete understanding of people's overall experience of care at the end of life.

The family and friends of those who die from cancer also need more support. Almost one in five (18%) recently bereaved carers would have liked some emotional support from someone from a health or social care service or bereavement service but did not receive any⁷¹. We must ensure the right services are in place to help people achieve a 'good death'.

I want to die well

Too many people who die from cancer are denied a 'good' death – they are not able to die in the place of their choosing and experience inadequate control of pain and other symptoms

The facts

- With the right support, three in four (73%) people with cancer would prefer to die at home⁶³, but fewer than a third (30%) are able to do so⁶⁴
- Only 34% of carers of those who died in a hospital from any cause rated the overall quality of care as excellent or outstanding, compared with 53% of those whose loved one died at home⁷³
- More than half (57%) of bereaved cancer carers say their loved one did not have complete pain relief all the time in their last three months of life⁷¹

What Macmillan says should be done

End-of-life care package: Everyone who is approaching the end of their lives with cancer should receive a package of care to help them die in the place and manner of their choosing with as little pain as possible. This care should include:

- Having their preferences for end-of-life care and an advance/anticipatory care plan recorded on an end-of-life care register
- Free social care at the end of life to help with simple day-to-day tasks so people can stay at home for longer
- 24/7 community services, particularly community and palliative care nurses and good GP support, including out-of-hours
- A model of care that incorporates early referral, home-based clinical interventions and close, flexible collaboration between primary care and other community-based services, such as the evidence-based Macmillan Specialist Care at Home model

DENIED THEIR DYING WISH

Where people living with cancer want to die, with the right support⁶³:



73%
at home



27%
elsewhere



<1%
in hospital

Where they actually die⁶⁴:



30%
at home



32%
elsewhere



38%
in hospital

One way Macmillan is helping



'We're trialling the 'Macmillan Specialist Care at Home' end-of-life care model in six areas of England, after our pilot in Midhurst, Sussex showed it gives people dying from cancer more choice and a better experience at the end of their lives.'

Adrienne Betteley, End-of-life Programme Manager, Macmillan Cancer Support

Working in close collaboration with primary care and other service providers, this community-based model allows early involvement of the palliative care team in providing specialist care, such as blood transfusions, in people's homes.



'Our son Neil was frightened of hospitals. After the sarcoma in his leg spread to his lungs, he collapsed and had to be admitted to hospital. The day before he died, at a meeting with his specialists, the Macmillan nurse asked Neil what he wanted. He said he wanted to be at home in his flat. She arranged this and made him comfortable.

Nobody made us aware of the possibility of this sort of care for Neil, and he might not have made it home without this last-minute intervention.'

Tony and Dorothy, both 68, from Lancashire



Conclusion

Every year, more and more people are diagnosed with cancer: by 2020, almost one in two of us will get cancer in our lifetimes⁷⁴. Thankfully, more people are living longer with the disease.

Forty years ago, the median survival time for all cancer types – the time by which half of people with the disease have died – was just one year, and now it is predicted to be nearly six years⁷⁵. Much of the credit for this should go to the people working in the NHS in all four countries of the UK. However, despite these advances, *Cancer in the UK 2014* shows us that there is still a huge gap we have to bridge in order to deliver on the outcomes that matter most to people with cancer.

Although there is much to be proud of in each region of the UK, overall the current performance on cancer in the UK's health and social care systems is simply not good enough. In some areas, such as early diagnosis and the treatment of older people, international comparisons show the UK lags behind much of Europe. Unless cancer remains a specific priority in the NHS now and in the future, and unless we continue to redesign and improve cancer care systems and services, there is a danger that the UK will fall even further behind.

We must take urgent action to implement the things that we know work if we are to prevent the state of cancer in the UK being a source of national shame.

This report sets out a range of specific recommendations, summarised on pages 47–50, that we at Macmillan believe will help deliver better outcomes for people with cancer in the UK. Proven solutions and services must be funded and provided, and resources shifted from hospitals to the community. Where necessary we must take more radical action, such as redesigning entire cancer care systems and pathways or introducing innovative roles into the health and social care workforce. On a specific level, if national and local health and social care leaders must focus on only the most important issues, we believe the following three priorities will make the biggest difference to people with cancer:

- Delivering cancer outcomes that match the best in Europe – particularly by reducing late diagnosis, investing in care after treatment by delivering the cancer Recovery Package, and addressing the needs of older people
- Ensuring all people with cancer are treated with the highest levels of dignity and respect – particularly by giving patient experience parity of esteem with clinical outcomes, and supporting staff to deliver this

- Improving end-of-life care for people with cancer by delivering free social care for people at the end of their life and enabling them to spend their final weeks and days in the place of their choice

Each UK country must have a clear, up-to-date cancer plan that sets out what is being done now and what will be done in the next few years to address the issues raised in this report and how progress will be measured.

Macmillan is already working with many people in each of the UK countries, including health and social care leaders, service providers, policy makers, health and social care professionals and employers. We urge any others who want to improve cancer care and support in the UK to get in touch – you can find our contact details on page 51. Our most powerful weapon in the fight against cancer is people.



Juliet Bouverie

Director of Services and Influencing
Macmillan Cancer Support

Summary of recommendations

At Macmillan we believe the following three priorities will make the biggest difference to people with cancer:

- **Delivering cancer outcomes that match the best in Europe** – particularly by reducing late diagnosis, investing in care after treatment by delivering the cancer Recovery Package, and addressing the needs of older people
- **Ensuring all cancer patients are treated with the highest levels of dignity and respect** – particularly by giving patient experience parity of esteem with clinical outcomes, and supporting staff to deliver this
- **Improving end-of-life care for people with cancer** by delivering free social care for people at the end of their life and enabling them to spend their final weeks and days in the place of their choice

Our specific recommendations against each of the Nine Outcomes are summarised below:

Outcome 1: I was diagnosed early

- **Better referrals:** NHS leaders must tackle regional variations in the clinical pathways used to diagnose people with cancer, and GP practices should use the best available clinical decision support tools to help diagnose people earlier
- **Better data:** Cancer registries and hospitals must ensure stage at diagnosis is recorded for every person with cancer in the UK, and the NHS needs to use this data to improve performance
- **Cancer leads:** All local commissioning groups and health boards should have dedicated cancer leads.

Outcome 2: I understand, so I make good decisions

- **Better information:** All people affected by cancer should be offered high-quality, personalised information about the condition and their support and treatment options, including the short-term and long-term consequences of treatment
- **More local services:** Local health and social care leaders should ensure that people affected by cancer can access and are offered local, high-quality, face-to-face cancer information and support services
- **Improved communication:** Health and social care leaders must make information needs assessment and communication skills a higher priority in service plans and training, to ensure professionals identify what information people with cancer need and provide appropriate support.

Outcome 3: I get the treatment and care which are best for my cancer, and my life

- **Clinical nurse specialists:** The NHS must increase access to clinical nurse specialists for cancer patients, particularly for urological, skin, head and neck and rarer cancers, and in both hospitals and the community, to ensure people have the best possible experience of care and are able to access all available support
- **Improved access to treatment:** NHS leaders must tackle postcode lotteries to ensure all people living with cancer in the UK receive the care and treatment that offers the best clinical outcomes, regardless of where they live
- **Age-friendly care:** We must eliminate the barriers that stop older patients being able to access treatment. All decisions about treatment and care must be based on an individual's fitness, not their chronological age, and we must re-examine how well social care services are meeting the needs of older people with cancer.

Outcome 4: Those around me are well supported

- **Increased collaboration to identify carers:** Healthcare providers must work with local authorities to formally identify, assess and support people who care for those with cancer
- **Better support for carers:** Health and social care services must work together to ensure carers receive the emotional and practical support they need, including advice on benefits, finances and continuing with employment
- **Support for employers:** Employers must provide better support for employees with cancer and those who care for them, including fulfilling their legal obligations regarding making reasonable adjustments.

Outcome 5: I am treated with dignity and respect

- **National surveys:** All countries in the UK should have regular, cancer-specific patient experience surveys that cover hospital, primary, community and social care
- **Support for frontline staff:** NHS leaders must ensure all frontline staff have the training and support they need to prioritise care and compassion as well as excellent clinical treatment in their day-to-day role
- **Staff experience:** NHS leaders must recognise that good staff experience is essential for good patient experience and provide support for staff mental and physical wellbeing.

Outcome 6: I know what I can do to help myself and who else can help me

- **Recovery Package:** To better support people with cancer after treatment ends, everyone diagnosed with cancer should receive a cancer Recovery Package. This should include:
 - Holistic Needs Assessments (identifying their physical, emotional, financial and other needs) and care plans at key points during treatment and recovery
 - A Treatment Summary, completed at the end of treatment and sent to the person with cancer and their GP
 - A Cancer Care Review, completed six months after treatment by the person's GP or practice nurse, to discuss their needs, the possible long-term consequences of treatment and what they can do to help themselves
 - An education and support event such as a Health and Wellbeing Clinic, to help people with cancer work towards supported self-management and a healthy lifestyle, including physical activity and directing them to support available in the local community.

Outcome 7: I can enjoy life

- **Physical activity:** Health and social care professionals must promote the benefits of physical activity to people with cancer, and local authorities need to provide appropriate schemes to help deliver long-lasting behaviour change
- **Specialist work support:** We need the UK governments' departments for work and health to support the employment of people with cancer and other long-term health conditions, such as via improved availability and access to vocational rehabilitation support, and employers must also provide better support to those affected by cancer
- **Benefits support and advice:** The UK government must ensure people with cancer are fully supported by the welfare system. This includes assessing their claims for Personal Independence Payments fairly and promptly and ensuring they are not forced into work-related activity to receive Employment and Support Allowance, as well as ensuring they can access advice and support when needed and are protected from further cuts to welfare spending.

Outcome 8: I feel part of a community and I'm inspired to give something back

- **Acknowledge isolation:** Health and social care professionals must recognise that isolation can have a real, negative impact on people's health, and the NHS and local government should prioritise the funding of community services to provide additional emotional support to people with cancer
- **Building volunteering capacity:** Health and social care leaders must invest in practical and emotional support services delivered by volunteers and ensure volunteers have the support and training required to deliver a high-quality service
- **Promote the benefits of giving back:** National and local health and social care leaders should encourage people affected by cancer to directly support the voluntary organisations involved in their care by giving something back as volunteers, fundraisers, campaigners or in other ways that are in a way and at a time that is right for them.

Outcome 9: I want to die well

- **End-of-life care package:** Everyone who is approaching the end of their lives with cancer should receive a package of care to help them die in the place and manner of their choosing with as little pain as possible. This care should include:
 - Having their preferences for end-of-life care and an advance/anticipatory care plan recorded on an end-of-life care register
 - Free social care at the end of life to help with simple day-to-day tasks so people can stay at home for longer
 - 24/7 community services, particularly community and palliative care nurses and good GP support, including out-of-hours
 - A model of care that incorporates early referral, home-based clinical interventions and close, flexible collaboration between primary care and other community-based services, such as the evidence-based Macmillan Specialist Care at Home model.

Find out more

Local Macmillan contacts

England

Main contact number:
01904 651 700

General managers:

Central and South West England:

David Crosby
dcrosby@macmillan.org.uk

East Midlands and North of England:

Fay Scullion
fscullion@macmillan.org.uk

London, Anglia and the South East Region:

Carol Fenton
cfenton@macmillan.org.uk

Scotland

Main contact number:
01312 603 720

General manager:

Janice Preston
jpreston@macmillan.org.uk

Wales

Main contact number:
01656 867960

General manager:

Susan Morris
smorris@macmillan.org.uk

Northern Ireland

Main contact number:
02890 708 613

General manager:

Heather Monteverde
hmonteverde@macmillan.org.uk

For a full list of local Macmillan contacts, please visit:

[www.macmillan.org.uk/
servicedevelopmentcontacts](http://www.macmillan.org.uk/servicedevelopmentcontacts)

Macmillan resources

- **Electronic Clinical Decision Support (eCDS) tool:**
www.macmillan.org.uk/earlydiagnosis
- **Information and support services:**
www.macmillan.org.uk/directservices
- **Macmillan Support Line: 0808 808 00 00**
(Monday to Friday, 9am-8pm)
- **Patient Experience Top Tips Guide:**
www.macmillan.org.uk/downloadsandtoolkits
- **Macmillan Values Based Standard®:**
www.macmillan.org.uk/cancerpatientexperience
- **Recovery Package:**
www.ncsi.org.uk/what-we-are-doing/the-recovery-package/survivorship@macmillan.org.uk
- **Physical activity:**
www.macmillan.org.uk/professionalsphysicalactivity
- **Walking for Health:**
www.walkingforhealth.org.uk
- **Work and Cancer Toolkit for employers:**
www.macmillan.org.uk/employersguide
- **Direct Volunteering Service:**
www.macmillan.org.uk/GetInvolved/Volunteervolunteering@macmillan.org.uk
- **Palliative and end-of-life care:**
www.macmillan.org.uk/professionalspalliativecare
- **Time to choose: Making choice at the end of life a reality report:**
www.macmillan.org.uk/timetochoose
- **Summary of the Midhurst Macmillan Community Specialist Palliative Care Service report:**
www.macmillan.org.uk/midhurst
- **Cancer clinical nurse specialists: An evidence review report:**
www.macmillan.org.uk/clinicalnursereview

References

- ¹ Macmillan Cancer Support. End-of-year figures for 2013. To be published in forthcoming 2013 Annual Report.
- ² Coleman MP *et al.* Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995–2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data. *Lancet* 2011; 377: 127–138
[http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(10\)62231-3/fulltext?_eventId=login#tbl2](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(10)62231-3/fulltext?_eventId=login#tbl2)
- ³ Elliss-Brookes L *et al.* Routes to diagnosis for cancer – determining the patient journey using multiple routine data sets. *Br J Cancer* 2012; 107: 1220–1226
<http://www.nature.com/bjc/journal/v107/n8/full/bjc2012408a.html>
- ⁴ Department of Health, Public Health England and NHS England. Letter entitled *February - March 2014 - Be Clear on Cancer symptom awareness campaigns*. December 2013.
<http://www.england.nhs.uk/wp-content/uploads/2013/12/be-clear-cancer.pdf>
- ⁵ Scottish Government. Primer Campaign Impact Evaluation. August 2012.
<http://www.scotland.gov.uk/Topics/Health/Services/Cancer/Detect-Cancer-Early/Campaign-Impact-Evaluation>
- ⁶ Public Health England. Levels of socio economic deprivation affect screening uptake for breast cancer. June 2013.
<https://www.gov.uk/government/news/levels-of-socio-economic-deprivation-affect-screening-uptake-for-breast-cancer>
- ⁷ ISD Scotland. Scottish Bowel Screening Programme.
<http://www.isdscotland.org/Health-Topics/Cancer/Bowel-Screening/> (accessed February 2014)
- ⁸ Royal College of General Practitioners. *National Audit of Cancer Diagnosis in Primary Care*. 2011.
http://www.rcgp.org.uk/policy/rcgp-policy-areas/~/_media/Files/Policy/National%20Audit%20of%20Cancer%20Diagnosis%20in%20Primary%20Care%20Document%20FINAL%20with%20amends%201Dec11%20RW.ashx
- ⁹ Baughan P *et al.* Urgent suspected cancer referrals from general practice: audit of compliance with guidelines and referral outcomes. *BJGP* 2011; 61: e700–e706.
<http://bjgp.org/content/61/592/e700.abstract>
- ¹⁰ Office for National Statistics. Cancer Survival Index for Clinical Commissioning Groups, Adults Diagnosed 1996-2011 and Followed up to 2012,
<http://www.ons.gov.uk/ons/rel/cancer-unit/a-cancer-survival-index-for-clinical-commissioning-groups/adults-diagnosed-1996-2011-and-followed-up-to-2012/index.html> (accessed April 2014)
- ¹¹ Average one-year survival rate for 15 selected cancer types (which includes the 10 most commonly diagnosed in the UK) is 72% for people diagnosed via the two-week-wait route compared with 40% for people diagnosed via an emergency admission. Source: Elliss-Brookes L *et al.* Routes to diagnosis for cancer – determining the patient journey using multiple routine data sets. *Br J Cancer* 2012; 107: 1220–1226
<http://www.nature.com/bjc/journal/v107/n8/full/bjc2012408a.html>

- ¹² Defined as TNM stage III-IV/SEER stage regional or distant. Refers to people diagnosed with lung cancer in two cancer registry areas in England, or Northern Ireland, during 2004-2007. Source: Walters S *et al.* Lung cancer survival and stage at diagnosis in Australia, Canada, Denmark, Norway, Sweden and the UK: a population-based study, 2004–2007. *Thorax* 2013; 68: 551–564 <http://thorax.bmj.com/content/68/6/551/T2.expansion.html>
- ¹³ Macmillan Cancer Support. *Cancer's unequal burden – the reality behind improving cancer survival rates*. April 2014. http://www.macmillan.org.uk/Documents/CancersUnequalBurden_2014.pdf
- ¹⁴ One-year survival for people diagnosed with lung cancer during 2005-2007 is 29.7% in the UK and 43.6% in Sweden. UK figure refers to people diagnosed with lung cancer in England, Wales or Northern Ireland. Source: Coleman MP *et al.* Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995–2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data. *Lancet* 2011; 377: 127–138 [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(10\)62231-3/fulltext?_eventId=login#tbl2](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(10)62231-3/fulltext?_eventId=login#tbl2)
- ¹⁵ Patient Information Forum. *Making the Case for Information*. May 2013. <http://www.pifonline.org.uk/wp-content/uploads/2012/09/PiF-Case-for-Information-full-report-FINAL-Sept2013.pdf>
- ¹⁶ Kahn *et al.* Patient centered experiences in breast cancer predicting long-term adherence to tamoxifen use. *Med Care* 2007; 45: 431–439
- ¹⁷ Cancer Patient Experience Survey 2013, England. Cancer Patient Experience Survey 2013, Wales. England results are based on responses from patients with a cancer diagnosis who were discharged from hospital between 1st September and 30th November 2012 from 155 NHS trusts in England. Wales results are based on responses from patients with a cancer diagnosis who were discharged from hospital between 1st September 2012 and 31st March 2013 from six health boards and one trust in Wales
- ¹⁸ Patient Information Forum. *Making the Case for Information*. May 2013. <http://www.pifonline.org.uk/wp-content/uploads/2012/09/PiF-Case-for-Information-full-report-FINAL-Sept2013.pdf>
- ¹⁹ Macmillan Cancer Support/YouGov online survey of 3,007 UK adults who have or have had cancer. Fieldwork was undertaken between 5th and 27th December 2013. Survey data has been weighted to be representative of the wider cancer population (cancer prevalence) in the UK by age, gender, nation and cancer type.
- ²⁰ Defined as those who needed an explanation of side effects who said the side effects were not explained to them, or the explanation was only understandable to some extent. Refers to patients who received treatment for cancer between 1st September and 30th November 2012 from 155 NHS trusts in England. Source: Cancer Patient Experience Survey 2013, England. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/301-2013-national-cancer-patient-experience-survey-programme-national-report/file>

- ²¹ Defined as those who had important questions to ask a doctor or ward nurse and who only got answers they could understand some of the time, rarely or never. Refers to patients who had had an operation or stayed overnight in hospital for cancer care between 1st September and 30th November 2012 from 155 NHS trusts in England. Source: Cancer Patient Experience Survey 2013, England. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/301-2013-national-cancer-patient-experience-survey-programme-national-report/file>
- ²² In England, 12% of people are not given the name of a clinical nurse specialist (CNS) while in hospital, and 74% of those who were given the name of a CNS were given easy-to-understand written information about the type of cancer they had, compared with 49% of those who were not given the name of a CNS. In Wales 66% of those who were given the name of a CNS were given easy to understand written information about the type of cancer they had, compared with 47% of those who were not given the name of a CNS. Weighted averages of these figures show across England and Wales 73% of those who were given the name of a CNS were given easy to understand written information about the type of cancer they had, compared with 49% of those who were not given the name of a CNS. England figures are based on a survey of cancer patients who were discharged from hospital between 1st September and 30th November 2012 from 155 NHS trusts in England, who said they needed written information on these subjects. Wales figures are based on a survey of cancer patients who were discharged from hospital between 1st September 2012 and 31st March 2013 from six Health Boards and one Trust in Wales, who said they needed written information on these subjects. Sources: Cancer Patient Experience Survey 2013, England. Cancer Patient Experience Survey 2013, Wales.
- ²³ Macmillan Cancer Support. *Cancer mortality trends for top four cancers: 1992–2020*. December 2013. <http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchsummaries/Mortalityratesexecutivesummary.pdf>
- ²⁴ Cancer Research UK. Cancer survival statistics for common cancers. <http://www.cancerresearchuk.org/cancer-info/cancerstats/survival/common-cancers/> (accessed February 2014)
- ²⁵ The relative five-year survival rate for people diagnosed with stomach, colon, rectal, lung, prostate, breast, ovarian or kidney cancer, or non-Hodgkin's lymphoma, in the UK or Ireland is lower than the overall European average. The rate for people diagnosed with stomach, kidney, lung or ovarian cancer in the UK and Ireland at 75 or over is worse than the average rate of any other individual European region. Refers to people diagnosed with cancer during 2000–2007. Source: De Angelis *et al.* Cancer survival in Europe 1999–2007 by country and age: results of EURO-CARE-5—a population-based study. *Lancet Oncology* 2013; [http://dx.doi.org/10.1016/S1470-2045\(13\)70546-1](http://dx.doi.org/10.1016/S1470-2045(13)70546-1)
- ²⁶ Health and Social Care Information Centre. National Lung Cancer Audit: 2013. <http://www.hscic.gov.uk/searchcatalogue?productid=13406&q=title%3a%22Lung+cancer%22&infotype=0%2fAudit&sort=Relevance&size=10&page=1#top> (accessed February 2014)
- ²⁷ Riaz SP *et al.* Variation in surgical resection for lung cancer in relation to survival: Population-based study in England 2004–2006. *EJC* 2012; 48: 54–60 <http://www.ejccancer.com/article/S0959-8049%2811%2900508-9/abstract>
- ²⁸ Department of Health. *Radiotherapy Services in England 2012*. Figure is based on the difference between the estimated demand (48,035 attendances per million head of population) and actual activity recorded (32,981 attendances per million head of population), pg 24. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213151/Radiotherapy-Services-in-England-2012.pdf

- ²⁹ Monitor. Performance of the foundation trust sector for quarter three 2013/14 http://www.monitor.gov.uk/sites/all/modules/fckeditor/plugins/ktbrowser/_openTKFile.php?id=45624; Welsh Government. NHS Wales cancer waiting times: Quarter ending 31 December 2013. <http://wales.gov.uk/docs/statistics/2014/140219-nhs-cancer-waiting-times-quarter-december-2013-en.pdf>; Scottish Government. Cancer waiting times <http://www.scotland.gov.uk/About/Performance/scotPerforms/partnerstories/NHSScotlandperformance/CancerwaitingtimesStandard>; Northern Ireland Executive. Cancer waiting times. <http://www.northernireland.gov.uk/index/media-centre/news-departments/news-dhssps/news-dhssps-080114-publication-of-the.htm>
- ³⁰ Twelve percent of patients said they had not been given the name of a clinical nurse specialist who would be in charge of their hospital care. Refers to patients who received treatment for cancer between 1st September and 30th November 2012 from 155 NHS trusts in England. Source: Cancer Patient Experience Survey 2013, England. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/301-2013-national-cancer-patient-experience-survey-programme-national-report/file>. The 12% figure was then applied to 170,000,
- the estimate of the number of patients admitted to hospital each year in England for their first definitive cancer treatment. Source: Department of Health provider-based cancer waiting times for Q4 2012-2013 for patients undergoing first definitive treatment (all cancers) within 31 days or more than 31 days from diagnosis. The quarterly figures have been multiplied to arrive at an annual figure. <http://transparency.dh.gov.uk/cancer-waiting-times>. Please note: a patient may have more than one primary cancer for which they received treatment within the same 12 months and hence may be double counted. Admitted figure includes ordinary admissions and day cases in addition to patients admitted for an overnight stay.
- ³¹ Health and Social Care Information Centre. National Lung Cancer Audit: 2013. <http://www.hscic.gov.uk/searchcatalogue?productid=13406&q=title%3a%22Lung+cancer%22&infotype=0%2fAudit&sort=Relevance&size=10&page=1#top> (accessed February 2014) Variations persist after adjusting for age, sex, socioeconomic status, stage of disease and general health (performance status)
- ³² The relative five-year survival rate for people diagnosed with stomach, colon, rectal, lung, prostate, breast, ovarian or kidney cancer, or non-Hodgkin's lymphoma, in the UK or Ireland is lower than the overall European average.
- The rate for people diagnosed with stomach, kidney, lung or ovarian cancer in the UK and Ireland at 75 or over is worse than the average rate of any other individual European region. Refers to people diagnosed with cancer during 2000-2007. Source: De Angelis *et al.* Cancer survival in Europe 1999-2007 by country and age: results of EURO-CARE-5—a population-based study. *Lancet Oncology* 2013; published online Dec 5. [http://dx.doi.org/10.1016/S1470-2045\(13\)70546-1](http://dx.doi.org/10.1016/S1470-2045(13)70546-1)
- ³³ Macmillan Cancer Support. *Living after diagnosis: Median survival times*. November 2011. <http://www.macmillan.org.uk/Documents/AboutUs/Research/Newsroom/LivingAfterCancerMedianCancerSurvivalTimes.pdf> (accessed March 2014)
- ³⁴ Macmillan Cancer Support. *More than a million*. January 2012. http://www.macmillan.org.uk/Documents/Cancerinfo/Ifsomeoneelsehascancer/More_than_a_million.pdf
- ³⁵ Macmillan Cancer Support. '50,000 employees have a second full-time job as cancer carers' press release. November 2012. http://www.macmillan.org.uk/Aboutus/News/Latest_News/50,000EMPLOYEEESHAVESECONDFULL-TIMEJOBASCANCERCARERS.aspx

- ³⁶ Macmillan Cancer Support/YouGov online survey of 2,004 UK adults either currently caring for someone with cancer, or who have cared for someone with cancer within the last three years. Fieldwork was undertaken between 6 – 16th September 2013. Survey data has been weighted to the known age and gender profile of UK cancer carers (using 2011 Macmillan Cancer Support/Ipsos MORI ‘More than a Million’ research), and to be nationally representative by region. Survey results show that 22% of carers perform healthcare tasks for those they care for. This percentage has been applied to the estimated total number of carers in the UK to arrive at a population estimate of 240,000. The estimated total number of carers is derived from Macmillan Cancer Support/Ipsos MORI research in 2011 that found that 2.1% of the UK population aged 15+ were currently caring for someone with cancer. Converted to a population estimate (using ONS 2010 Mid Year Population estimates) this equates to 1,080,000 adults aged 15+.
- ³⁷ Estimated annual economic value based on the estimated number of cancer carers in England and data on the number of hours of unpaid care they provide each week, multiplied by a unit cost for replacement care. Estimated number of cancer carers in England and data on the number of hours of unpaid care provided taken from Macmillan Cancer Support and Ipsos MORI research conducted in 2011. (http://www.macmillan.org.uk/Documents/Cancerinfo/Ifsomeoneelsehascancer/More_than_a_million.pdf) Unit cost of £18 an hour for replacement care is based on 2011 NHS Information Centre data. This estimate follows the same method as the 2011 Carers UK/University of Leeds paper which estimated the annual economic value of all UK carers at £119 billion http://www.carersuk.org/media/k2/attachments/Valuing_carers_2011___Carers_UK.pdf
- ³⁸ Macmillan Cancer Support/YouGov online survey of 2,004 UK adults either currently caring for someone with cancer, or who have been providing care within the last three years. Fieldwork was undertaken between 6 – 16th September 2013. Survey data has been weighted to the known age and gender profile of UK cancer carers (using 2011 Macmillan Cancer Support/Ipsos MORI ‘More than a Million’ research), and to be nationally representative by region. Survey results found that 29% of carers (n=558) were with the person with cancer when they were diagnosed by a health professional.
- ³⁹ Macmillan Cancer Support/YouGov online survey of 2,004 UK adults either currently caring for someone with cancer, or who have cared for someone with cancer within the last three years. Fieldwork was undertaken between 6 – 16th September 2013. Survey data has been weighted to the known age and gender profile of UK cancer carers (using 2011 Macmillan Cancer Support/Ipsos MORI ‘More than a Million’ research), and to be nationally representative by region. Survey results show that 22% of carers perform healthcare tasks for those they care for. This percentage has been applied to the estimated total number of carers in the UK to arrive at a population estimate of 240,000. The estimated total number of carers is derived from Macmillan Cancer Support/Ipsos MORI research in 2011 that found that 2.1% of the UK population aged 15+ were currently caring for someone with cancer. Converted to a population estimate (using ONS 2010 Mid Year Population estimates) this equates to 1,080,000 adults aged 15+.
- ⁴⁰ Macmillan Cancer Support. *More than a million*. January 2012. http://www.macmillan.org.uk/Documents/Cancerinfo/Ifsomeoneelsehascancer/More_than_a_million.pdf
- ⁴¹ Macmillan Cancer Support/YouGov online survey of 2,217 UK adults living with cancer. Fieldwork was conducted between 5th – 17th June 2013. Survey results are unweighted.
- ⁴² Cancer Patient Experience Survey 2013, England. Results are based on responses from patients with a cancer diagnosis who were discharged from hospital between 1st September and 30th November 2012 from 155 NHS trusts in England.

- ⁴³ Cancer Patient Experience Survey 2013, England. Cancer Patient Experience Survey 2013, Wales. England results are based on responses from patients with a cancer diagnosis who were discharged from hospital between 1st September – 30th November 2012 from 155 NHS trusts in England. Wales results are based on responses from patients with a cancer diagnosis who were discharged from hospital between 1st September 2012 – 31st March 2013 from six health boards and one trust in Wales.
- ⁴⁴ Macmillan Cancer Support/YouGov online survey of 2,217 UK adults living with cancer. Fieldwork was conducted between 5th – 17th June 2013. Survey results are unweighted. Results here are based on the 455 people diagnosed within the last two years who had a stay of one or more nights in hospital during their cancer treatment.
- ⁴⁵ Macmillan Cancer Support/YouGov online survey of 2,142 UK adults living with cancer. Fieldwork conducted 26th November – 14th December 2012. Survey results are unweighted. Results presented are based on the 358 people diagnosed within the last two years who had a stay of one or more nights in hospital during their cancer treatment.
- ⁴⁶ The relationship between cancer patient experience and staff survey results, Picker Institute Europe (30 July 2013). Picker Institute Europe was commissioned by Macmillan Cancer Support to investigate the relationship between the results for the Cancer Patient Experience Survey (CPES) and the NHS Staff Survey. The data was from the 2011 CPES and the 2011 NHS Staff Survey. For the full results please visit <http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/ReportCPES-StaffexperienceP2709v4.pdf>. Additional analysis by Picker Institute Europe shows that 52% of hospital trusts where staff suffer the lowest levels of discrimination (top 20% for question KF38 on the 2011 NHS Staff Survey: % staff experiencing discrimination at work in last 12 months) are ranked in the top 20% for overall patient experience (question 70 in the CPES: patient's rating of care 'excellent' or 'very good'), whereas none of the trusts where staff suffer the most discrimination (bottom 20% for question KF38) appear in the top 20% for overall patient experience.
- ⁴⁷ Cancer Patient Experience Survey 2013, England. Results are based on responses from patients with a cancer diagnosis who were discharged from hospital between 1st September and 30th November 2012 from 155 NHS trusts in England.
- ⁴⁸ NHS England/Picker Institute Europe. National NHS Staff Survey 2013. Key Finding 28. Percentage of staff experiencing discrimination at work in the last 12 months <http://www.nhsstaffsurveys.com/Page/1019/Latest-Results/Staff-Survey-2013-Detailed-Spreadsheets/>
- ⁴⁹ Department of Health. *Quality of life of cancer survivors in England*. 2012. Results are based on responses of 3,300 people between 1 and 5 years from diagnosis with breast, colorectal or prostate cancer or non-Hodgkin's lymphoma (NHL) from three participating cancer registries (West Midlands, East of England and Thames)

- ⁵⁰ Macmillan Cancer Support and Ipsos MORI research into isolation and loneliness amongst people affected by cancer. Research methodology: Online survey of 1,065 UK adults who have ever been diagnosed with cancer. Fieldwork took place between 12th – 30th September 2013. 1,000 interviews were carried out using Ipsos MORI's Online Access Panel, with an additional 65 sourced from Macmillan's contacts in Scotland, Wales and Northern Ireland. Survey data has been weighted by gender, age and nation using 2008 cancer prevalence estimates. 15 telephone and 5 face-to-face depth interviews with people living with cancer, to explore their experiences in more detail. The research found that 22% of people living with cancer (238 out of the 1,065 survey sample) have been lonely since their cancer diagnosis, or more lonely than they were before. Research findings amongst those who are lonely are therefore based on 238 people. Of this group, 76% had completed treatment, and of these, 32% reported feeling most lonely or isolated either immediately after their initial treatment ended or sometime after
- ⁵¹ Macmillan Cancer Support. *Throwing light on the consequences of cancer and its treatment*. July 2013. <http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/throwinglightontheconsequencesofcanceranditstreatment.pdf>
- ⁵² Department of Health. *Quality of life of cancer survivors in England*. 2012. Results are based on responses of 3,300 people between 1 and 5 years from diagnosis with breast, colorectal or prostate cancer or non-Hodgkin's lymphoma (NHL) from three participating cancer registries (West Midlands, East of England and Thames)
- ⁵³ Department of Health. *Quality of life of cancer survivors in England*. 2012. Results are based on responses of 3,300 people between 1 and 5 years from diagnosis with breast, colorectal or prostate cancer or non-Hodgkin's lymphoma (NHL) from three participating cancer registries (West Midlands, East of England and Thames). Half of patients (48%) said they did not require any help or support after treatment.
- ⁵⁴ Macmillan Cancer Support. *Throwing light on the consequences of cancer and its treatment*. July 2013. <http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/throwinglightontheconsequencesofcanceranditstreatment.pdf>
- ⁵⁵ Macmillan Cancer Support. *Cancer's hidden price tag media exec summary*. April 2013. <http://www.macmillan.org.uk/Documents/AboutUs/Newsroom/Cancers-Hidden-PriceTag-exec-summary-April-2013.doc>
- ⁵⁶ Macmillan Cancer Support. *Making the shift: Providing specialist work support to people with cancer*. March 2013. <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/WorkingThroughCancer/Making-the-shift-specialist-work-support-for-people-with-cancer.pdf>
- ⁵⁷ Macmillan Cancer Support. *Cancer's Hidden Price Tag: Revealing the costs behind the illness*. April 2013. <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Costofcancer/Cancers-Hidden-Price-Tag-report-England.pdf>
- ⁵⁸ Macmillan Cancer Support. *Facing the fight alone*. February 2013. http://www.macmillan.org.uk/Documents/AboutUs/MAC13970_Isolated_cancer_patients_media_reportFINAL.pdf

- ⁵⁹ Macmillan Cancer Support and Ipsos MORI research into isolation and loneliness amongst people affected by cancer. Research methodology: Online survey of 1,065 UK adults who have ever been diagnosed with cancer. Fieldwork took place between 12 – 30 September 2013. 1,000 interviews were carried out using Ipsos MORI's Online Access Panel, with an additional 65 sourced from Macmillan's contacts in Scotland, Wales and Northern Ireland. Survey data has been weighted by gender, age and nation using 2008 cancer prevalence estimates. 15 telephone and 5 face-to-face depth interviews with people living with cancer, to explore their experiences in more detail. The research found that 22% of people living with cancer (238 out of the 1,065 survey sample) have been lonely since their cancer diagnosis, or more lonely than they were before. Research findings amongst those who are lonely are therefore based on 238 people.
- ⁶⁰ Macmillan Cancer Support and Ipsos MORI research into isolation and loneliness amongst people affected by cancer. Research methodology: Online survey of 1,065 UK adults who have ever been diagnosed with cancer. Fieldwork took place between 12 and 30 September 2013. 1,000 interviews were carried out using Ipsos MORI's Online Access Panel, with an additional 65 sourced from Macmillan's contacts in Scotland, Wales and Northern Ireland. Survey data has been weighted by gender, age and nation using 2008 cancer prevalence estimates. 15 telephone and 5 face-to-face depth interviews with people living with cancer, to explore their experiences in more detail. The research found that 22% of people living with cancer (238 out of the 1,065 survey sample) have been lonely since their cancer diagnosis, or more lonely than they were before. Research findings amongst those who are lonely are therefore based on 238 people.
- ⁶¹ Macmillan Cancer Support and GfK research into people's charitable behaviour. Telephone survey of 1,098 UK adults. Fieldwork carried out June 2012. Survey data weighted by gender and age to be representative of UK population. Results not published externally.
- ⁶² Cancer Research UK. Cancer deaths compared with other causes of death in the UK. <http://www.cancerresearchuk.org/cancer-info/cancerstats/mortality/all-cancers-combined/#Cancer4> (accessed March 2014)
- ⁶³ Macmillan Cancer Support. February 2010 online survey of 1,019 UK adults living with cancer. Survey results have not been weighted.
- ⁶⁴ Office for National Statistics. Place of death for cancer patients 2012, England and Wales – personal communication.
- ⁶⁵ Office of National Statistics. Quality of care at the end of life varies with cause and place of death. July 2013 <http://www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/2012/sty-care-at-the-end-of-life.html>
- ⁶⁶ Macmillan Cancer Support. *Time to choose: Making choice at the end of life a reality*. October 2013. <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Endoflife/TimeToChoose.pdf>
- ⁶⁷ Nuffield Trust. Understanding patterns of health and social care at the end of life. October 2012. http://www.nuffieldtrust.org.uk/sites/files/nuffield/121016_understanding_patterns_of_health_and_social_care_full_report_final.pdf (accessed March 2014)
- ⁶⁸ Macmillan Cancer Support/ICM online survey of 155 UK health professionals who treat people living with cancer (55 GPs, 50 oncologists, and 50 cancer clinical nurse specialists). 97% of healthcare professionals agreed that the complexity of, and the time it takes to complete, social care needs assessments was an important barrier preventing patients receiving appropriate social care at the end of life. Fieldwork conducted September 2012. Survey results are unweighted.

- ⁶⁹ Additional analysis for cancer specific data from National Bereavement Survey (VOICES), 2012
<http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-313468> (personal communication from ONS)
- ⁷⁰ Marie Curie Cancer Care. Survey commissioned by Marie Curie with Doctors.net.uk (DNUK) and conducted by DNUK's research division medeConnect Healthcare Insight. Respondents were recruited from the Doctors.net.uk membership. Responses were collected from 1,003 regionally representative GPs in the UK. The survey fieldwork was conducted over the period 22nd – 28th January 2014.
http://www.mariecurie.org.uk/ImageVaultFiles/id_1941/cf_100/Marie-Curie-calls-for-around-the-clock-care-for-te.PDF
- ⁷¹ Additional analysis for cancer specific data from National Bereavement Survey (VOICES), 2012
<http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-313468>
- ⁷² Wright *et al.* Associations between palliative chemotherapy and adult cancer patients' end of life care and place of death: prospective cohort study. *BMJ* 2014; 348: g1219
- ⁷³ Macmillan Cancer Support. *Time to choose: Making choice at the end of life a reality*. October 2013.
<http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Endoflife/TimeToChoose.pdf>
- ⁷⁴ Macmillan Cancer Support. *Cancer mortality trends: 1992–2020*. May 2013.
<http://www.macmillan.org.uk/Documents/AboutUs/Newsroom/Mortality-trends-2013-executive-summary-FINAL.pdf> (accessed March 2014)
- ⁷⁵ Macmillan Cancer Support. *Living after diagnosis: Median survival times*. November 2011.
<http://www.macmillan.org.uk/Documents/AboutUs/Newsroom/LivingAfterCancerMedianCancerSurvivalTimes.pdf> (accessed March 2014)
- ⁷⁶ Central Office of Information. Extent and causes of international variations in drug usage. July 2010.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216249/dh_117977.pdf

Notes

When you have cancer, you don't just worry about what will happen to your body, you worry about what will happen to your life. At Macmillan, we know how a cancer diagnosis can affect everything and we're here to support you through. From help with money worries and advice about work, to someone who'll listen if you just want to talk, we'll be there. We'll help you make the choices you need to take back control, so you can start to feel like yourself again.

No one should face cancer alone. For support, information or if you just want to chat, call us free on **0808 808 00 00** (Monday to Friday, 9am–8pm) or **visit macmillan.org.uk**

Cancer in the UK 2014

State of the nation report

Printed using sustainable material. Please recycle.
Macmillan Cancer Support, registered charity in England and Wales (261017),
Scotland (SC039907) and the Isle of Man (604). MAC14909

