

**WE ARE
MACMILLAN.
CANCER SUPPORT**

**CURED
— BUT AT
WHAT
COST?**

Long-term consequences
of cancer and its treatment
July 2013

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Foreword

There are more than two million people living with cancer in the UK today, but not all of them are living well. Cancer and its treatment often leaves a gruelling physical and mental legacy for many years afterwards. It begs the question – do we really understand the true cost of being cured?



In recent years Macmillan Cancer Support has been revealing the changing nature of cancer with startling milestone figures. In 2011, we showed that more than four in 10 of us would get cancer. In 2012, our research found that the number of people living with cancer would double to four million over the next 20 years. And in 2013, we highlighted that by 2020, while almost one in two people will get cancer in their lifetime, almost four in 10 of those will not die from it.

While it is clearly good news that more people are surviving cancer, progress can be a double-edged sword. *Cured – but at what cost?* reveals another vital aspect of the changing cancer story. At least one in four of those living with cancer – around 500,000 people in the UK – face poor health or disability after cancer treatment.

Many cancer patients will complete their primary treatment and return, more or less, to the same level of health and wellbeing that they enjoyed before their diagnosis. But a significant proportion 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 or bone problems, or a second cancer. And the consequences of cancer and its treatment can affect much more than just a person's physical or mental health. Some patients become isolated from friends or family, or are unable to continue working, causing financial difficulties as well as further isolation. For these patients, a cure comes with a heavy and often unexpected cost.

Of course, it is not just those given an 'all-clear' who are affected. Many of the two million living with cancer today are still undergoing primary treatment, or are living with incurable disease. We are not focusing on the acute side-effects of treatment in this report, or on end-of-life needs, but we do not forget the additional burden they represent. Nor is this an issue restricted to older patients in poor health: a high proportion of those who were treated for cancer as children or young adults can face the long-term consequences of treatment, such as heart problems or second cancers, for the rest of their adult life.

Some may be alarmed by the sheer scale of the problem, but this too is a double-edged sword. It sounds daunting, but it shows the Government and the NHS that we must take action, particularly if we are to cope with the increased demand for services. Many healthcare professionals underestimate the long-term consequences of cancer and its treatment, and some can feel uncomfortable talking about something for which they may feel partly responsible. We must overcome this. Revealing the scale of the problem also shows people experiencing these issues that they are not alone and I hope will encourage them to seek information and support. The current low profile of long-term consequences of cancer and its treatment means some of those affected are reluctant to report them, particularly if they feel grateful to be free of cancer.

With more and more people living after cancer treatment, this issue is only going to get bigger. We need action from health professionals, commissioners and policy makers to ensure that up-to-date treatment

and evidence-based services are available to prevent unnecessary disability. All patients should already receive information about potential long-term consequences before and after treatment, but they should also be given a holistic needs assessment, care plan and treatment summary once it is complete. This should include clear information about potential long-term effects for GPs, so they in turn can carry out proactive cancer care reviews. Local and national commissioners must ensure good care is available for all and specialist services are provided for those in particular need. Most importantly, patients should feel able to ask for help if they are experiencing any physical or emotional issues after treatment.

It is good that we are curing more people of cancer. But we have to recognise 'not dying' is not the same as 'being well'. No one should face the often severe long-term effects of cancer alone. And if we can gather better evidence and build more responsive services, no one will.



Ciarán Devane

Executive summary

- The impact of having cancer does not always end when treatment finishes.
- At least 500,000 people in the UK are facing poor health or disability after treatment for cancer¹ – approximately one in four (25%) of those who have been diagnosed with cancer at some point in their lives.
- The long-term consequences of cancer and its treatment include both physical and mental effects, such as chronic fatigue, sexual difficulties, mental health problems, pain, urinary and gastrointestinal problems, and lymphoedema (persistent tissue swelling caused by fluid retention).
- Many of these problems can persist for at least 10 years after treatment² and can be significantly worse than those experienced by people without cancer.
- Certain treatments for cancer also increase the risk of other serious long-term conditions such as heart disease, osteoporosis or a second cancer^{3,4,5}.
- The impact of cancer and its treatment affects much more than just health and wellbeing. The wider implications include social isolation, financial worries caused by disruption to work, and the potential impact on education and future prospects for those who are treated for cancer as children or young adults.
- Some consequences of cancer and its treatment can be reduced with simple interventions, while more complex issues will require specialist services.
- Ways to improve the lives of those affected by the consequences of cancer and its treatment include the National Cancer Survivorship Initiative (NCSI) Recovery Package, specialist late-effects services and helplines, physical activity programmes, improved patient information, public toilet access schemes, and improved data collection, coding and research.
- Patients should recognise that they are not alone if they are experiencing long-term effects following treatment, and speak to their healthcare team for advice and support.

Long-term consequences of cancer and its treatment

Each year, around 325,000 people are diagnosed with cancer in the UK⁶. The majority will receive treatment with surgery, radiotherapy, chemotherapy or other treatments, either alone or in combination.

For many patients, treatment is very successful. Around half of those diagnosed with cancer today will live for at least 10 years after diagnosis. For some cancers, such as melanoma and testicular cancer, the figure is higher than four in five⁷. More than one in three people who have had cancer (35%) will now ultimately die from another cause, increasing to 38% by 2020⁸. But for many people, the impact of having cancer does not end after their treatment finishes.

No current cancer treatment can avoid damaging healthy cells to some extent, and this damage may lead to long-term physical and mental consequences. While researchers aim to develop new treatments that can better target cancerous cells, new therapies do not always achieve any significant reduction in the overall prevalence of long-term consequences^{9,10}. It is highly unlikely we will be able to eliminate the risks associated with having treatment in our lifetimes. And every year more and more people are being diagnosed with cancer and potentially exposed to the long-term effects of the disease and its treatment.

Despite the severity of this issue, until now we have had little understanding of just how many people are affected and in what ways. Now, for the first time, Macmillan has used the best information available to estimate the extent of the long-term consequences of cancer and its treatment among people living with cancer in the UK. We present the key findings on the next page, and examine the issue in more depth for health professionals, commissioners and researchers in our publication *Throwing light on the consequences of cancer and its treatment*.

Prevalence of long-term consequences



At least **500,000** people in the UK are facing poor health or disability after treatment for cancer – approximately one in four (25%) of those who have been diagnosed with cancer at some point in their lives¹¹.

The long-term consequences of cancer and its treatment include both physical and psychological effects. Using published data combined with expert opinion, we estimate¹² that:



At least **350,000** people living with and beyond cancer are experiencing chronic fatigue¹³



Around **350,000** are having sexual difficulties¹⁴



Around **240,000** are living with mental health problems, which can include moderate to severe anxiety or depression, and post-traumatic stress disorder (PTSD)¹⁵



At least **200,000** are living with moderate to severe pain after curative treatment¹⁶



Around **150,000** are affected by urinary problems such as incontinence¹⁷



Around **90,000** are experiencing gastrointestinal problems, including faecal incontinence, diarrhoea and bleeding¹⁸



Up to **63,000** are experiencing lymphoedema (persistent tissue swelling caused by fluid retention, usually in the arms or legs)¹⁹

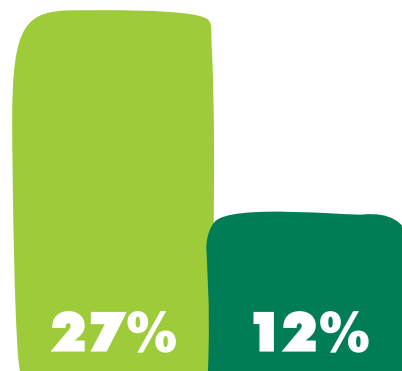
These problems may only emerge months after treatment, and some can persist for at least 10 years²⁰.



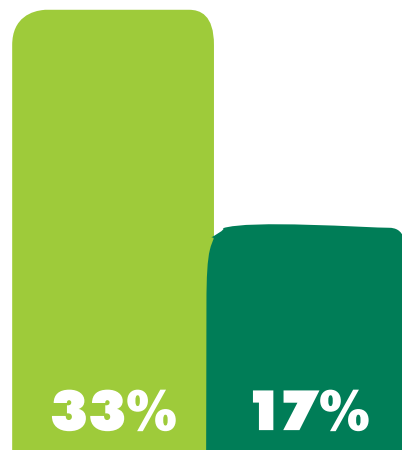
= 100,000 people

Comparison of people living with cancer and healthy people

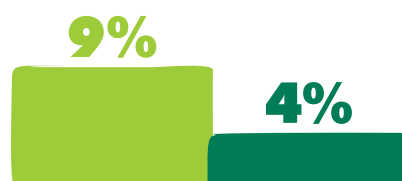
Research suggests people who have had cancer and do not have any other chronic conditions are more likely to experience health problems than those without cancer.





Find vigorous activities very difficult or impossible



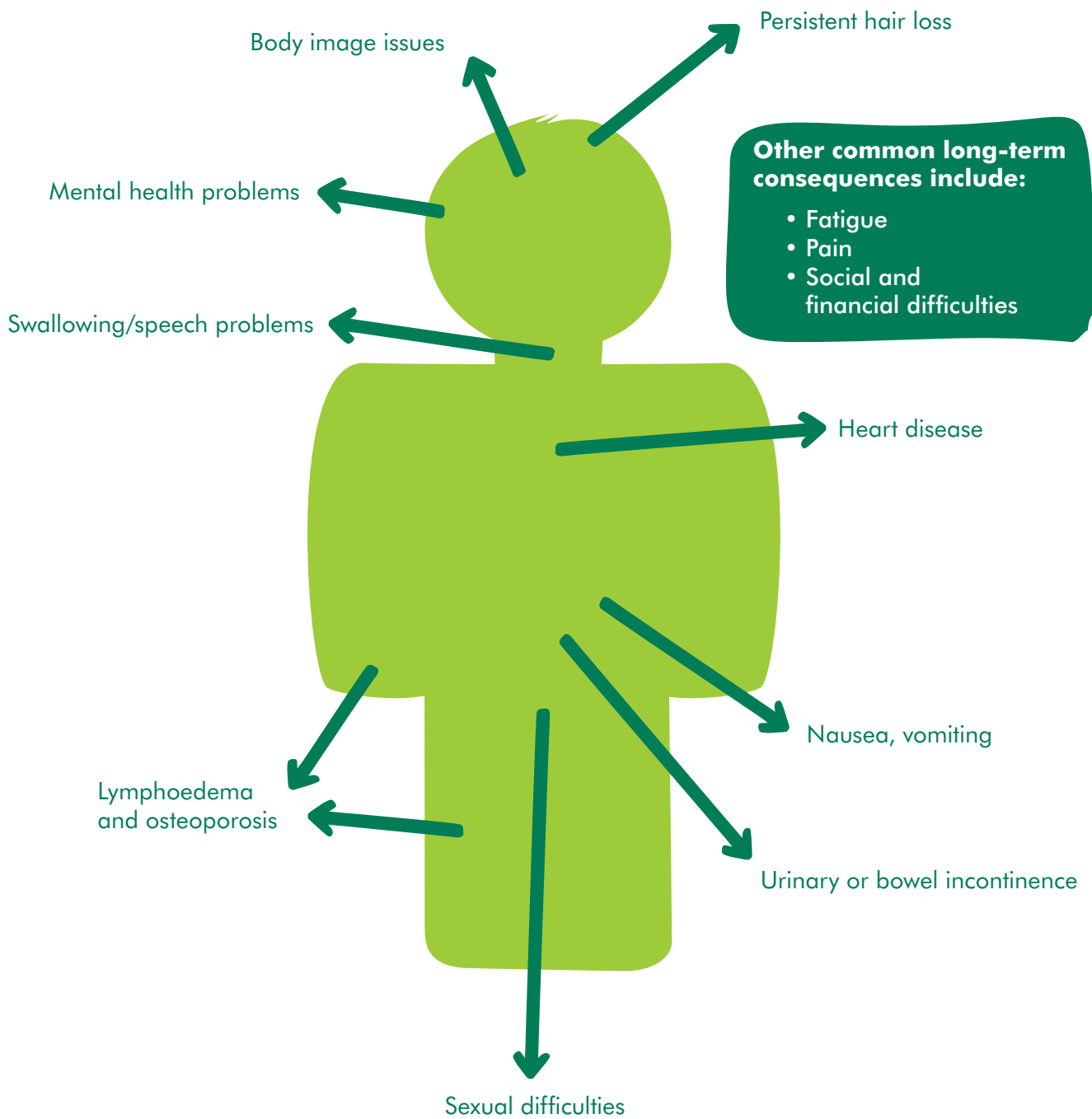
Have only average or poor health



Visited a healthcare professional 10 times or more in the last year²¹

-  = People who have had cancer
-  = People who have not had cancer

Examples of long-term consequences of cancer and its treatment



Fatigue

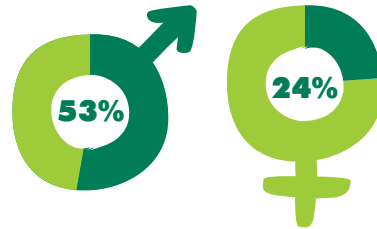
Fatigue related to cancer and its treatment can make even simple tasks feel exhausting, and it isn't usually improved by a good night's sleep. Everyday activities such as brushing hair, showering or cooking can seem impossible. At its worst, fatigue can leave people bedridden. As many as three in four (75%) people living with cancer feel fatigued at some point²². In a national survey of people living with breast, colorectal or prostate cancer or non-Hodgkin's lymphoma, more than four in 10 (43%) of those diagnosed up to five years previously reported always feeling tired²³. Fatigue is particularly common in the year following cancer treatment.

'I [don't] have the energy for [my] day-to-day lifestyle. Pre-cancer people seem to live life in the fast lane, whilst you feel as if you are on the outside looking in.'
Woman living with breast cancer, five years after diagnosis²⁴

Although fatigue affects a large number of people after cancer treatment, there are simple interventions that can reduce its impact. For example, a recent in-depth review of 22 studies shows aerobic exercise, such as walking or cycling, can significantly reduce fatigue²⁵. Other research has shown that cognitive behavioural therapy that involves increasing activity in a planned, incremental way can help fatigue²⁶. The next section of this report discusses more ways to improve the lives of those affected by this issue.

Sexual difficulties

Cancer treatment can make it physically and psychologically difficult to have sex, or leave people with reduced confidence or a poor body image.



In one study, half of men (53%) and a quarter of women (24%) who received radiotherapy to their pelvic area report issues with maintaining a sexual relationship, with the effects persisting up to at least 11 years after treatment²⁷.

Around six in 10 men (58%) diagnosed with prostate cancer up to five years previously are unable to have a full sex life as they are completely unable to get an erection, with a further 11% reporting difficulties with having or maintaining an erection²⁸.

'After I was diagnosed with womb cancer in 2011, I found it exceptionally difficult to get information on how the treatment might affect my future sexual relationships. I experienced a range of side effects from pelvic radiotherapy, including hot flushes and premature menopause, and for several months afterwards I wasn't able to have an orgasm. Before I was diagnosed I felt comfortable talking about sex, but having cancer changed that. I found it a very isolating experience.'
Vanessa, 42, south-west England

Depending on the issues involved, there are several ways people living with cancer and their partners can help themselves cope with sexual difficulties. GPs and other health professionals can also help, and Macmillan offers support and advice to people living with cancer and their partners on these issues. For example, we provide practical advice on the *Coping with sexual difficulties* section of our website, and in Manchester and Wales we work in partnership with the charity Relate to offer relationship counselling services. The next section of this report covers other general ways to improve the lives of those affected.

Mental health problems

Difficult events such as receiving a cancer diagnosis or treatment for cancer will affect most people's emotional state. Some will develop mental health problems such as anxiety or depression. Around a third of people diagnosed with breast, colorectal or prostate cancer or non-Hodgkin's lymphoma five years previously say they experience anxiety or depression. More than one in eight of those diagnosed up to five years previously say they experience moderate to extreme anxiety or depression. Other research shows people diagnosed with cancer at least two years previously are more likely to experience anxiety than people who have not had cancer²⁹.

Some psychological consequences may be particularly severe, resulting in persistent mental health difficulties. For example, people living with and beyond cancer are considered to be at risk for post-traumatic stress disorder (PTSD) due to the shock

'People need to realise that after all your cancer treatment your mind plays tricks on you. I have honestly been to hell and back. It is after your treatment that you need care. I feel totally alone.'

Woman living with depression, two years after being diagnosed with non-Hodgkin's lymphoma³¹

and trauma of being diagnosed with a life-threatening disease and receiving treatment that can be both physically and mentally gruelling³⁰.

Some mental health problems associated with cancer and its treatment can be managed by the patient, for example by joining a self-help and support group or trying relaxation techniques, but more severe problems may require professional help.

Pain

Pain can persist after the end of cancer treatment for many reasons. For example, radiotherapy and chemotherapy can cause nerve damage that leads to neuropathic pain³², while surgery or radiotherapy in the pelvic area can lead to parts of the bowel sticking together³³.

'I'm thankful the surgery allowed me to live. I try to remember that when debilitating pain makes me want to die.'

Man living with prostate cancer, five years after diagnosis³⁴

One in three (33%) people who have completed treatment intended to cure their cancer report some degree of pain³⁵. Around one in five of those diagnosed with breast, colorectal or prostate cancer or non-Hodgkin's lymphoma up to five years previously report moderate to extreme pain or discomfort after completing treatment³⁶.

Pain can usually be controlled to some extent. Healthcare professionals can prescribe drug treatment, while patients can also try complementary therapies such as relaxation techniques or acupuncture³⁷.

Urinary and gastrointestinal problems

Having surgery or radiotherapy in the pelvic area often leads to changes in the way the bowel and bladder function. These can include loose stools, needing the toilet more frequently, feeling the need to rush to the toilet (urgency) and sometimes incontinence.

More than one in three men (39%) diagnosed with prostate cancer up to five years previously report some degree of urinary leakage³⁸. More than a third of women (38%) who received radiotherapy to their pelvic area report urinary incontinence up to 11 years after treatment, and more than one in 10 people (12%) who received radiotherapy to their pelvic area report bowel incontinence³⁹. More than one in eight (13%) of those who had surgery for colorectal cancer at least two years previously need to wear a protective tissue or pad all or most of the time during the day in case of bowel incontinence⁴⁰.

'I was diagnosed with anal cancer in 2007, and had chemotherapy and radiotherapy. I felt like I had been burnt to a crisp inside and out and was in agony for months afterwards. Using the lavatory became a nightmare. Then I was hit with bowel incontinence – although it's more controlled now, I still suffer from periodic bowel incontinence six years later. Having changed my own children's nappies, it's ironic that at 68 I'm now the one who needs nappies.'

Richard, 68, London

People experiencing these issues may be able to manage many of the symptoms themselves with the right support. For example, guided changes to diet and strengthening the muscles used for bowel control can reduce the severity of many gastrointestinal problems.

Lymphoedema

Lymphoedema develops when lymph nodes or vessels are damaged or blocked. Cancer cells can spread into lymph nodes from other parts of the body, and removing lymph nodes as part of diagnosis or treatment can interrupt the normal flow of the lymphatic system. This leads to a build-up of fluid in the affected area. Radiotherapy to the lymph nodes can cause scar tissue that also blocks the flow⁴¹. The condition is chronic, which means it cannot be cured but can be managed. As well as causing physical difficulties, lymphoedema can also increase the risk of infections in the affected area.

'Being diagnosed with breast cancer in 2001 completely changed my life. After the surgery, I had chemotherapy and then radiotherapy. I had a lot of unpleasant side-effects at the time, such as anaemia, hair loss, severe fatigue, depression and lymphoedema. The lymphoedema has led to restricted movement in one of my arms, which causes me physical difficulties. It's hard to find clothes that fit and it's difficult to exercise. I also have problems raising the arm, which then hinders many day-to-day activities. The doctors say it may never go away and I will just have to learn to live with it for the rest of my life.'

Asma, 50, Middlesex

There are several ways patients can help treat lymphoedema themselves, including using compression garments and techniques to relieve the swelling, such as simple lymphatic drainage. They will need to make time for lymphoedema care in their regular routine.

Other long-term effects

The above examples are just a sample of the troublesome long-term effects of cancer and its treatment. Others that may arise include hot flushes, loss of fertility, swallowing and speech problems, body image problems, second cancers^{42,43} and many more.

Increased risk of other serious conditions

Certain treatments for cancer increase the risk of other serious long-term conditions, and symptoms may only emerge decades later. For example, Herceptin or chemotherapy that uses anthracycline drugs can increase the risk of heart disease, and hormonal treatment can increase the risk of osteoporosis.

Women living with breast cancer are almost twice as likely to get heart failure as those who have not had breast cancer. Men who have had prostate cancer are 2.5 times as likely to get osteoporosis compared with those who have not had prostate cancer⁴⁴.

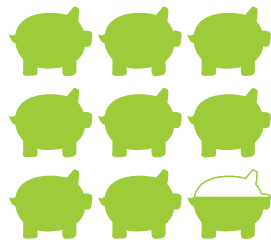
Consequences affecting survivors of childhood cancers

By 2021 there could be more than 40,000 people who have survived at least five years after developing cancer as a child⁴⁵. While the number of children affected by cancer is much smaller than the number of adults, treatment in this age group is now often highly successful and a high proportion will live into middle and old age. The NHS will need to support a growing population of older people who have several long-term consequences after their cancer treatment as a child or young person, such as heart problems, second primary cancers, bone health problems, metabolic syndrome, and fertility or cognitive issues.

Wider implications of long-term consequences

The impact of cancer and its treatment affects much more than just health and wellbeing. The physical and emotional effects of cancer and its treatment are the two most common reasons why employees diagnosed with cancer give up work or change jobs. Almost half (48%) of those who do so say it's because they were not physically able to return to the same role, while one in three (33%) say they did not feel emotionally strong enough⁴⁶.

Not being able to work as a result of cancer can have a significant financial impact.



Macmillan's *Cancer's Hidden Price Tag* report showed that almost one in three (30%) people living with cancer experience an average loss of income of **£860** a month.



In addition, more than one in three (37%) spent an average of **£70** a month on clothing, wigs and other head-coverings or other modifications as a result of their diagnosis⁴⁷.



= £100

'Problems such as bowel incontinence can stop people going back to work, or even just leaving the house to do something as basic as going to the shops. It can be completely immobilising, and very socially isolating. Nobody should be left to deal with these issues alone.'

**Professor Jessica Corner,
Chief Clinician, Macmillan
Cancer Support**

The effects of cancer and its treatment may also contribute to people experiencing isolation. As part of research for Macmillan's *Not Alone* campaign, we found that almost nine in 10 cancer patients (86%) who lack the support of family and friends during their treatment and recovery do not ask anyone else for support, and of these one in eight (12%) say it's because they felt too ill or tired to do so. Around half of those who lack support have skipped meals or not eaten properly because they felt too tired or unwell⁴⁸.

Having to take time off school for cancer treatment and recuperation can disrupt children and young people's education, potentially affecting their future prospects. For example, there is some evidence that adult survivors of childhood cancer are more likely to drop out of school and to not have a degree than people who have not had cancer, and more likely to be unemployed⁴⁹.

Improving the lives of those affected

The NHS must regard the consequences of cancer and its treatment as long-term conditions, many of which can be helped with some basic interventions and support for self-management, while more complex issues will require specialist services.

'Although a small number of people will need specialist care, the quality of life of most of those affected can be improved by simple, inexpensive and effective interventions delivered by informed GPs and nurses.'

**Dr Charles Champion-Smith,
Macmillan GP**

The previous section of this report gave some examples of interventions for specific long-term consequences. Here are just some of the more general ways we can improve the lives of those experiencing the long-term effects of cancer and its treatment.

Recovery Package

As part of the National Cancer Survivorship Initiative (NCSI), Macmillan has worked with the Department of Health to develop a 'recovery package' for cancer patients in England⁵⁰. This comprises four main parts:

- A Holistic Needs Assessment (HNA), to be carried out at or near diagnosis, at the end of treatment and at any other time the patient's needs change. The HNA should use a standardised assessment tool and result in a written care plan outlining the actions to be taken to address identified needs.
- A Treatment Summary, to be completed by the patient's hospital team using a structured format and shared with the patient and their GP.
- A Cancer Care Review, to be carried out by the patient's GP practice three months post-diagnosis and to include discussion of the potential long-term effects of the patient's cancer and treatment.

- A Health and Wellbeing Clinic, to help prepare the patient and their carers for supported self management. It should cover what signs and symptoms they need to look out for, what resources are available to help them and what to do if they are worried, plus advice on healthy lifestyles, including physical activity, and work and financial issues.

Implementing the Recovery Package is currently the most important step we can take to improve the lives of those affected by the consequences of cancer and its treatment.

Physical activity

A comprehensive evidence review carried out for Macmillan's Move More campaign showed that physical activity after treatment for cancer can reduce some of the effects of treatment, including lymphoedema, anxiety, depression, fatigue, impaired mobility and weight changes. It can also reduce the risk of recurrence for some cancers⁵¹.

The Walking for Health scheme, coordinated by Macmillan and the Ramblers, offers regular short guided walks suitable for people living with cancer⁵².

Specialist services

While many consequences of cancer and its treatment can be self-managed by the patient with support from their healthcare team, other more complex issues require specialist NHS services. For example, the national breast radiotherapy injury rehabilitation service, which Macmillan campaigned for in partnership with the Radiotherapy Action Group Exposure (RAGE) group, supports women who have severe, chronic and complex conditions as a result of receiving a now-obsolete form of radiotherapy for breast cancer in the 1970s and 1980s. The service is currently available at three NHS trusts in England: Royal National Hospital for Rheumatic Disease NHS Foundation Trust in Bath, The Christie NHS Foundation Trust in Manchester and Barts Health NHS Trust in London⁵³.

The Royal Marsden NHS Foundation Trust in London provides a specialist service for patients experiencing bowel, digestive or nutritional problems during or after cancer treatment. The service currently consists of a consultant gastroenterologist, a Macmillan nurse consultant and a Macmillan specialist dietician, and receives approximately 250 new referrals per year from across the UK (see clinical case study on the following page)⁵⁴.

Many NHS hospitals, hospices and community services also provide specialist lymphoedema services.

Clinical case study – treating bowel incontinence at The Royal Marsden Hospital

Fiona*, 38, was referred to the gastrointestinal and nutrition service at The Royal Marsden Hospital after experiencing serious bowel and urinary problems following treatment for cervical cancer, which included bowel surgery and pelvic radiotherapy. She had weekly episodes of bowel incontinence, severe abdominal pain and regularly soiled herself in her sleep, among other symptoms. Her incontinence had financial implications as it interfered with her ability to work and she also had to spend more on clothing, laundry and incontinence supplies.

The Royal Marsden team carried out a range of specialist tests and investigations, which revealed there were several factors contributing to Fiona's symptoms. She had too many bacteria in her small intestine – one of the potential side-effects of bowel surgery – and her body was not re-absorbing bile acids released during digestion. She also had weak muscle tone in her lower abdomen.

Her treatment included a course of antibiotics for the bacterial overgrowth and other drugs for the bile acid malabsorption, as well as personalised dietary advice and being shown how to do pelvic floor exercises. As her symptoms improved, she was advised to start doing gentle exercise to combat the fatigue.

After five visits to The Royal Marsden, Fiona's symptoms had significantly improved. She no longer had any bowel incontinence or pain, and the gentle exercise had reduced her fatigue. Her isolation and financial worries had reduced as she was able to participate in work and social activities, and her mood was much improved.

*Not her real name

Patient information

More than one in four people living with cancer say they would have found it helpful to have had more advice or information on the physical long-term effects of cancer, while around one in four said the same for the emotional effects⁵⁵. Patients who have had pelvic radiotherapy frequently report being unaware of possible long-term effects to the bowel, bladder and sexual function – in one study, less than half of patients reported receiving both verbal and written information on potential long-term effects of treatment⁵⁶.

'Having endured anal cancer treatment, I am still coming to terms with after-effects a year later. I wish I had read [the Macmillan booklet] earlier so that I could identify all my symptoms as being a direct result of radio/chemo. Most doctors, employers and public are unaware of the effects on one's life. This book made me feel less isolated.'

Feedback from a cancer patient on a Macmillan patient information booklet

Many patients may also be unaware that they can get products such as incontinence pads and other supplies on prescription from their GP, potentially reducing or removing the financial burden they represent. Thanks in part to Macmillan, people diagnosed with cancer in England can get all their prescriptions for free for at least five years after diagnosis.

'Most patients are well informed about the immediate side-effects of treatment, but far fewer know what could happen once their treatment ends. Some of those who do experience problems will be afraid that if they ask for help, they'll face more harsh treatment. The good news is many of the consequences of cancer and its treatment can be reduced with simple, safe and non-invasive interventions.'

Dr Adam Harris, Chair of clinical services and standards committee, British Society of Gastroenterology

Public toilet access schemes

People living with bowel or urinary urgency and incontinence often need urgent access to toilets while out in public. The National Key Scheme (NKS), coordinated by Disability Rights UK, offers people with a disability independent access to selected public toilets across the UK. Toilets fitted with NKS locks can be found in shopping centres, pubs, cafés, department stores, bus and train stations and many other locations.

The Bladder and Bowel Foundation (B&BF) produces a 'Just Can't Wait' toilet card that people can show to a member of the public or staff in places they visit, providing a discreet way of asking for access to a toilet.

Better data collection, coding and research

Exactly which treatments patients have received, whether they have any consequences of treatment and what their needs are – none of this important information is consistently recorded in patients' medical records. Without it, our estimates of the number of people affected by the consequences of cancer and its treatment cannot be confirmed, and healthcare professionals and managers cannot plan effectively for patients' needs either now or in the future. In addition, there is a lack of long-term data on the consequences of treatment, as most drug or radiotherapy machine manufacturers will only study what happens to patients for a few years after treatment ends. We also do not know the extent of problems for people experiencing multiple consequences of cancer and its treatment.

We must improve what data is collected, how it is recorded and what research is done on the long-term effects of treatment.

Conclusion and recommendations

The long-term consequences of cancer and its treatment affect many more people than we first realised. The NHS and service commissioners have underestimated this issue for too long. We must take action now to improve the lives of those affected and to prepare for the needs of the growing number of people surviving cancer.

'The better we get at treating and curing cancer patients, the more people we will have living with the long-term effects of cancer and its treatment. If we do not tackle this issue head on, more and more people will continue to suffer in silence or, if they do speak up, have unhelpful consultations with doctors and nurses that may add to their distress. This is a poor use of precious NHS resources.'

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

As a first step, Macmillan calls for the following:

- Healthcare professionals should ensure patients at risk of or experiencing long-term effects are identified earlier and given the right information and support. This should include regularly asking tailored questions about the patient's general health and quality of life during and after treatment, and GPs ensuring they are familiar with possible long-term consequences of cancer and its treatment. Healthcare professionals must also improve how types of treatment and long-term consequences are coded in patients' medical records, so that we have better data on the number of people affected by treatment, and which specific types of treatment cause more long-term effects than others.

- Service commissioners (both national and local) should ensure that the NCSI Recovery Package and any required specialist services are available to healthcare professionals and patients. NHS England should ensure that the pilot *Quality of Life of Cancer Survivors in England* survey is rolled out at a national level, and it should work with Macmillan to develop a process for using the results as a driver for service improvement.
- Patients should recognise that they are not alone if they are experiencing long-term effects following cancer treatment. We urge anyone affected by or worried about these issues to speak to their healthcare team – in many cases there will be simple but effective steps they can take to make a real improvement to their quality of life. They can also call the Macmillan Support Line. No-one should feel that they simply have to put up with distressing consequences of cancer and its treatment.

We also need the wider research community, including drug and radiotherapy machine manufacturers, to increase their efforts to study the long-term effects of cancer and its treatment. Those who work with healthcare data should also investigate using routinely collected data to better identify the patients who could be at risk of these problems. Macmillan will be leading by example in this regard, as improving our understanding of the issues facing the population of people affected by cancer is one of our ongoing research priorities.

Too many people pay a heavy price for surviving cancer. We must work together to reduce the cost of being cured.

For more information on how we can improve the lives of those affected by the consequences of cancer and its treatment, please see the full Macmillan report, *Throwing light on the consequences of cancer and its treatment*, and the NCSI report *Living with and beyond cancer: taking action to improve outcomes*.

References

- ¹ Figures quoted from expert consensus collated as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*. Consensus was reached by consulting with a range of UK experts in the field, including members of the National Cancer Survivorship Initiative (NCSI) Board, the NCSI Pelvic Cancers Project Steering Group, the Consequences of Cancer and its Treatment Collaborative (CCaT) and other leading researchers and professional societies.
- ² Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Watson E, Adams E, Boulton M, Rose P, Horne A, Durrant L, Collingwood M, Wilkinson C, Ozkrochi R and Davidson S. 2012. The late effects of pelvic radiotherapy in long-term cancer survivors: a feasibility study. Oxford Brookes University report for Macmillan Cancer Support/National Cancer Survivorship Initiative. *Clinical Oncology* (in press)
- ³ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Khan NF, Mant D, Carpenter L, Forman D and Rose PW. 2011. Long-term health outcomes in a British cohort of breast, colorectal and prostate cancer survivors: a database study. *British Journal of Cancer* 105, S29–S37.
- ⁴ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Ng AK, Travis LB. 2008. Subsequent malignant neoplasms in cancer survivors. *Cancer J*, 14, 429–434.
- ⁵ Zhang W, Becciolini A, Biggeri A, Pacini P, Muirhead CR. 2011. Second malignancies in breast cancer patients following radiotherapy: a study in Florence, Italy. *Breast Cancer Res*, 13, R38.
- ⁶ Latest UK cancer incidence figures (2010) are sourced from: Office for National Statistics; Information Services Division (ISD) Scotland; Welsh Cancer Intelligence & Surveillance Unit; Northern Ireland Cancer Registry
- ⁷ Cancer Research UK. Survival statistics for the most common cancers. <http://www.cancerresearchuk.org/cancer-info/cancerstats/survival/Latestrates/survival-statistics-for-the-most-common-cancers> Accessed May 2013
- ⁸ Macmillan Cancer Support (2013). *Cancer mortality trends: 1992–2020*. <http://www.macmillan.org.uk/Documents/AboutUs/Newsroom/Mortality-trends-2013-executive-summary-FINAL.pdf> Accessed May 2013
- ⁹ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Vale CL, Tierney JF, Davidson SE, Drinkwater KJ and Symonds P. 2010. Substantial improvement in UK cervical cancer survival with chemoradiotherapy: Results of a Royal College of Radiologists' Audit. *Clinical Oncology* 22, 590–601.

- ¹⁰ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Stephens RJ, Thompson LC, Quirke P, Steele R, Grieve R, Couture J, Griffiths GO, and Sebag-Montefiore D. 2010. Impact of short-course preoperative radiotherapy for rectal cancer on patients' quality of life: data From the Medical Research Council CR07/National Cancer Institute of Canada Clinical Trials Group C016 Randomized Clinical Trial. *JCO* 28, 4233–4239.
- ¹¹ Figures quoted from expert consensus collated as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*. Consensus was reached by consulting with a range of UK experts in the field, including members of the National Cancer Survivorship Initiative (NCSI) Board, the NCSI Pelvic Cancers Project Steering Group, the Consequences of Cancer and its Treatment Collaborative (CCaT) and other leading researchers and professional societies.
- ¹² Identifying the precise numbers of people affected by particular consequences (and how severely), or how many are currently at risk of consequences, is very difficult as this information is not consistently recorded in patients' health records. We also do not currently know how many people receive what combinations of treatment or how many may have multiple consequences. Here we present estimates relying largely on published studies of cancer survivors in general, or consequence-specific studies, along with known cancer prevalence figures. We acknowledge that the experiences of individual patients will vary greatly and our estimates are indicative only. As more information becomes available we will refine our estimates. Full details are outlined in Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*.
- ¹³ Estimate based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Prue G, Rankin J, Allen J, Gracey J, Cramp F. 2006. Cancer-related fatigue: A critical appraisal. *European Journal of Cancer* 42, 846–863 and UK cancer prevalence data.
- ¹⁴ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Department of Health. 2012. *Quality of Life of Cancer Survivors in England. Report on a pilot survey using Patient Reported Outcome Measures (PROMS)* and UK cancer prevalence data
- ¹⁵ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Department of Health. 2012. *Quality of Life of Cancer Survivors in England. Report on a pilot survey using Patient Reported Outcome Measures (PROMS)* and UK cancer prevalence data
- ¹⁶ Estimate based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: van den Beuken-van Everdingen MHJ, de Rijke JM, Kessels AG, Schouten HC, van Kleef M & Patijn J. 2007. Prevalence of pain in patients with cancer: a systematic review of the past 40 years. *Ann Oncol* 18, 1437–1449 and UK cancer prevalence data.
- ¹⁷ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Department of Health. 2012. *Quality of Life of Cancer Survivors in England. Report on a pilot survey using Patient Reported Outcome Measures (PROMS)* and UK cancer prevalence data.

- ¹⁸ Estimate based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Andreyev HJN, Davidson SE, Gillespie C, Allum WH and Swarbrick E. 2012. Practice guidance on the management of acute and chronic gastrointestinal problems arising as a result of treatment for cancer. *Gut* 61, 179–192 and UK cancer prevalence data.
- ¹⁹ Estimate based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Report to the National Cancer Action Team (NCAT). *Case for a strategy for lymphoedema services in England* (in press)
- ²⁰ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Watson E, Adams E, Boulton M, Rose P, Horne A, Durrant L, Collingwood M, Wilkinson C, Ozkrochi R and Davidson S. 2012. The late effects of pelvic radiotherapy in long-term cancer survivors: a feasibility study. Oxford Brookes University report for Macmillan Cancer Support/National Cancer Survivorship Initiative. *Clinical Oncology* (in press)
- ²¹ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Elliott J, Fallows A, Staetsky L, Smith PWF, Foster CL, Maher EJ and Corner J. 2011. The health and well-being of cancer survivors in the UK: findings from a population-based survey. *British Journal of Cancer* 105, S11–S20.
- ²² Macmillan Cancer Support. Fatigue and cancer. <http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Symptomssideeffects/Fatigue/Aboutfatigue/Fatiguecancer.aspx> Accessed May 2013
- ²³ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Department of Health. 2012. *Quality of Life of Cancer Survivors in England. Report on a pilot survey using Patient Reported Outcome Measures (PROMS)*.
- ²⁴ University of Southampton. 2013. *Quality of life of cancer survivors in England: Analysis of patients' free text comments: Final report*.
- ²⁵ Cramp F, Byron-Daniel J. 2012. Exercise for the management of cancer-related fatigue in adults. *Cochrane Database of Systematic Reviews*, 11.
- ²⁶ Armes J, Chalder T, Addington-Hall J, Richardson A, Hotopf M. 2007. A randomized controlled trial to evaluate the effectiveness of a brief, behaviorally oriented intervention for cancer-related fatigue. *Cancer* 110, 1385–1395.
- ²⁷ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Watson E, Adams E, Boulton M, Rose P, Horne A, Durrant L, Collingwood M, Wilkinson C, Ozkrochi R and Davidson S. 2012. The late effects of pelvic radiotherapy in long-term cancer survivors: a feasibility study. Oxford Brookes University report for Macmillan Cancer Support/National Cancer Survivorship Initiative. *Clinical Oncology* (in press)
- ²⁸ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Glaser AW, Fraser LK, Corner J, Feltbower R, Morris EJA, Hartwell G, Richards M. 2013. Patient-reported outcomes of cancer survivors in England 1–5 years after diagnosis: a cross-sectional survey. *BMJ Open* 2013, 3 e002317 doi:10.1136/bmjopen-2012-002317

- ²⁹ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Department of Health. 2012. *Quality of Life of Cancer Survivors in England. Report on a pilot survey using Patient Reported Outcome Measures (PROMS)*; Mitchell AJ, Ferguson DW, Gill J, Paul J, Symonds P. 2013. Depression and anxiety in long-term cancer survivors compared with spouses and healthy controls: a systematic review and meta-analysis. *Lancet Oncology*, doi:10.1016/S1470-2045(13)70244-4
- ³⁰ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*, including: Mehnert A and Koch U. 2007. Prevalence of acute and post-traumatic stress disorder and comorbid mental disorders in breast cancer patients during primary cancer care: A prospective study. *Psycho-Oncology* 16, 181–188.
- ³¹ University of Southampton. 2013. *Quality of life of cancer survivors in England: Analysis of patients' free text comments: Final report*.
- ³² Macmillan Cancer Support. Causes of pain. <http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Symptomssideeffects/Pain/Causesofpain.aspx> Accessed May 2013
- ³³ Macmillan Cancer Support. Possible changes caused by surgery to your bowel. <http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Lifeaftercancer/Lateeffectsbowel/Possiblelateeffects/Possiblechangescausedbysurgery.aspx> Accessed May 2013
- ³⁴ University of Southampton. 2013. *Quality of life of cancer survivors in England: Analysis of patients' free text comments: Final report*.
- ³⁵ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: van den Beuken-van Everdingen MHJ, de Rijke JM, Kessels AG, Schouten HC, van Kleef M & Patijn J. 2007. Prevalence of pain in patients with cancer: a systematic review of the past 40 years. *Ann Oncol* 18, 1437–1449.
- ³⁶ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Department of Health. 2012. *Quality of Life of Cancer Survivors in England. Report on a pilot survey using Patient Reported Outcome Measures (PROMS)*. Majority of respondents (96%) had completed treatment.
- ³⁷ Macmillan Cancer Support. Dealing with physical effects after cancer treatment. <http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Lifeaftercancer/Dealingwithphysicaleffects.aspx> Accessed June 2013
- ³⁸ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Glaser AW, Fraser LK, Corner J, Feltbower R, Morris EJA, Hartwell G, Richards M. 2013. Patient-reported outcomes of cancer survivors in England 1–5 years after diagnosis: a cross-sectional survey. *BMJ Open* 2013, 3 e002317 doi:10.1136/bmjopen-2012-002317
- ³⁹ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Watson E, Adams E, Boulton M, Rose P, Horne A, Durrant L, Collingwood M, Wilkinson C, Ozkrochi R and Davidson S. 2012. The late effects of pelvic radiotherapy in long-term cancer survivors: a feasibility study. Oxford Brookes University report for Macmillan Cancer Support/National Cancer Survivorship Initiative. *Clinical Oncology* (in press)

- ⁴⁰ Knowles G, Haigh R, McLean C, Phillips HA, Dunlop MG, Din FV. 2013. Long term effect of surgery and radiotherapy for colorectal cancer on defecatory function and quality of life. *Eur J Oncol Nurs*. doi: 10.1016/j.ejon.2013.01.010
- ⁴¹ Causes of lymphoedema, Macmillan Cancer Support. <http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Symptomssideeffects/Lymphoedema/Aftercancertreatment.aspx> Accessed May 2013
- ⁴² Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Ng AK, Travis LB. 2008. Subsequent malignant neoplasms in cancer survivors. *Cancer J*, 14, 429–434.
- ⁴³ Maddams J, Parkin D M and Darby S. 2011. The cancer burden in the United Kingdom in 2007 due to radiotherapy. *Int J Cancer* 129, 2885–2893.
- ⁴⁴ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Khan NF Mant D, Carpenter L, Forman D and Rose PW. 2011. Long-term health outcomes in a British cohort of breast, colorectal and prostate cancer survivors: a database study. *British Journal of Cancer* 105, S29–S37.
- ⁴⁵ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Department of Health (2013). *Living with and beyond cancer: taking action to improve outcomes*. Original source: Stiller C. Personal communication – unpublished analysis of data from National Registry of Childhood Tumours.
- ⁴⁶ Macmillan Cancer Support/YouGov online survey of 2,142 UK adults living with cancer. Fieldwork took place 26 November – 14 December 2012. Survey results are not weighted. Figures presented here are based on the 132 respondents who were employed at the time of their diagnosis, and who gave up work or changed jobs as a result of their diagnosis.
- ⁴⁷ Macmillan Cancer Support (2013) *Cancer’s hidden price tag: Revealing the costs behind the illness*. Figures based on a postal survey of 1,610 adults with a cancer diagnosis, recruited from a database of callers to the Macmillan Support Line and visitors to a sample of Macmillan Information and Support Centres located in hospitals across the UK. The majority (95%) had received cancer treatment within the last six months. Fieldwork took place between August and October 2012. Results were weighted to be representative of all people with a cancer diagnosis in the UK by age, gender, cancer type and country of residence. The research was commissioned by Macmillan Cancer Support, carried out by researchers from the University of Bristol Personal Finance Research Centre in partnership with TNS BMRB, and part-funded by our partner The RBS Group.
- ⁴⁸ Macmillan Cancer Support/YouGov online survey of 1,794 people living with cancer in the UK. Figures presented here based on the 437 respondents who were identified as isolated (i.e. received no support from friends or family during treatment or recovery, or only received support some of the time/occasionally) and completed a follow-up interview. Fieldwork conducted 10-20 July 2012, with additional interviewing conducted in Northern Ireland 26 November – 13 December 2012. Survey results are unweighted.

- ⁴⁹ Langeveld NE, Ubbink MC, Last BF, Grootenhuis MA, Voûte PA, De Haan RJ. 2003. Educational achievement, employment and living situation in long-term young adult survivors of childhood cancer in the Netherlands. *Psychooncology* 12, 213–225.
- ⁵⁰ <http://www.ncsi.org.uk/what-we-are-doing/the-recovery-package/>
- ⁵¹ Macmillan Cancer Support (2011) *The importance of physical activity for people living with and beyond cancer: A concise evidence review*
- ⁵² www.walkingforhealth.org.uk
- ⁵³ NHS Specialised Services. <http://www.specialisedservices.nhs.uk/service/breast-radiotherapy-injury-rehabilitation-service> Accessed May 2013
- ⁵⁴ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Department of Health (2013). *Living with and beyond cancer: taking action to improve outcomes*.
- ⁵⁵ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Department of Health. 2012. *Quality of Life of Cancer Survivors in England. Report on a pilot survey using Patient Reported Outcome Measures (PROMS)*. Majority of respondents (96%) had completed treatment.
- ⁵⁶ Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*: Watson E, Adams E, Boulton M, Rose P, Horne A, Durrant L, Collingwood M, Wilkinson C, Ozkrochi R and Davidson S. 2012. The late effects of pelvic radiotherapy in long-term cancer survivors: a feasibility study. Oxford Brookes University report for Macmillan Cancer Support/National Cancer Survivorship Initiative. *Clinical Oncology* (in press)

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

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