

**IT'S NO
LIFE**

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CANCER SUPPORT**

Living with the long term effects of cancer

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Thank you to everyone who agreed to share their stories for this research.
All quotes and stories are real but photographs may be posed for by models.

Bringing the needs of people living with or beyond cancer into the spotlight

We want to make sure that people are not experiencing unnecessary long-term medical, emotional or financial consequences of cancer.



Last year we revealed there are now two million people living with or beyond cancer in the UK¹ – people sometimes called ‘cancer survivors’. This figure was much higher than expected

and made us want to know more about the needs of those people who may have been diagnosed a year, five years or even 10 years ago and more.

It’s testament to the huge strides in treatment for some cancers, and for increasing life expectancy in general, that more people are living with cancer. But while death rates are falling, the number of people being diagnosed is rising and the number of people living with the consequences of cancer and its treatment grows by 3.2% every year in the UK¹.

Our report shows that many ‘survivors’ are unaware of the long-term physical and emotional side effects of the illness and its treatment. Worse, it appears that many healthcare professionals are not considering them either.

At Macmillan Cancer Support we passionately want to make sure that people are not experiencing unnecessary long-term medical, emotional or financial consequences of cancer so that their day does not have to be about cancer, it can just be about ... life.

Ciarán Devane

Ciarán Devane, Chief Executive
of Macmillan Cancer Support

Executive summary

- Many of the two million people living with or beyond cancer in the UK will experience long-term consequences of the disease or its treatment. These can occur months or years later, when specialist check-ups may have ceased.
- Physical effects include fatigue, weight gain, nerve damage, swelling around the arms, blood clots, hot flushes, night sweats, urinary and bowel problems and bone and heart disease. Emotional effects include depression, anxiety, memory loss and difficulty concentrating.
- In our survey, 40% of cancer survivors are unaware of these long-term side effects. This may be because information is not being communicated effectively by doctors and nurses at the end of treatment.
- As many as 78% of people living after cancer said that they had experienced at least one of the physical conditions that can occur as a result of cancer or its treatment in the past twelve months, and 62% at least one of the psychological conditions.
- But almost a fifth of those who had physical ailments and 40% with emotional difficulties had not sought medical help or other support. Of those who had visited GPs, only about half of these doctors mentioned cancer and treatment as a possible cause.
- As a result, many people living beyond cancer are not receiving the help they need. Health and social care services need to recognise these long-term effects and offer appropriate information and support services, as they do for other chronic conditions.
- Macmillan Cancer Support believes that, at the end of treatment, everyone should be offered an assessment by an appropriately trained professional, such as a specialist doctor or nurse, which would help to create a personalised care plan.
- Health professionals in secondary care must make sure that people with cancer understand the risks of possible long-term side effects, must advise on lifestyle changes, give guidance on self-management and tell people what to do if they notice symptoms.
- This must be reinforced by GPs, who need to be given more information about the ongoing needs of their patients who are living with or beyond cancer.
- There should be clear and swift access back into the specialist system if people's health needs change.
- At the same time, Governments across the UK must urgently prioritise the development of innovative new ways for health and social care services to support survivors. Otherwise, these people will continue to fall through service gaps and be left to cope alone.

Two million people in the UK are living with or beyond cancer¹

40% say they are unaware of long-term side effects².

78% have experienced physical health problems in the last 12 months².

40% with emotional problems have not sought help².

71% of those who finished treatment 10 years ago have experienced physical health problems in the last 12 months².

Background

Macmillan Cancer Support is committed to improving the lives of all cancer patients and those who have finished treatment. To do so, we actively canvass their experiences to inform our work.

In 2008, we published the results of a Health and Well-being survey of more than 4,500 people from across the UK, comparing people with cancer, individuals with other chronic conditions, carers, and people without cancer or other chronic illnesses.

The results showed that people who had been diagnosed with cancer were more likely to find it difficult to carry out simple daily activities, like housework or meeting friends, than those with no chronic conditions. Just under one third of those who had had a cancer diagnosis agreed that their health had prevented them from continuing their preferred career, compared to less than a tenth of the group with no chronic conditions³.

A follow-up survey, which forms the basis of this report, involved a more detailed survey of 442 of the original participants who had had cancer, who again came from across the UK. Many different cancer types were represented; breast cancer was the most common. More women (69%) took part than men. More than half of the men (54%) were over the age of 65, compared to just under a fifth of the women (19%).

Most were having some sort of health check, though a minority (14%) were having no check-up at all. Almost half had had active cancer at least six years ago, and almost a quarter more than 10 years ago.

‘The cancer story has changed. It used to seem very simple – either you had successful treatment, were cured and able to take up your life where you left off, or you had incurable cancer and died very quickly.

Now we know that people need more support after treatment to live with cancer as a chronic illness. We also know that those who no longer need treatment may be at particular risk of other conditions and illnesses. This must be recognised.’

Professor Jane Maher, Macmillan Cancer Support Chief Medical Officer

The physical toll

'I just assumed that the problems were related to age, stress at work and other everyday occurrences.' Woman, early 50s⁴.

The first year after the end of treatment for cancer is a difficult one. Treatment for cancer refers to initial treatment after a diagnosis for cancer. Some respondents may be receiving follow-up treatment for their cancer. Once the relief of finishing treatment has worn off, the former patient will be thinking – what does the rest of life hold? Can I return to work, have a sex life, go on holiday? When will I be 'back to normal' again? But it is unlikely they will ever feel the same as before. The consequences of cancer and its treatment will vary depending on tumour and therapy type.

The first year is the time when it is most likely the person will experience physical side effects, but they can occur at any time. They can include fatigue, weight gain and obesity, nerve damage, swelling around the arms, lymphoedema, blood clots, hot flushes, night sweats, impotence, and urinary and bowel problems.

Over the next few years, longer-term consequences of treatment may emerge, such as heart problems and osteoporosis. After the fifth year, regular check-ups to the cancer specialist usually cease and the former patient may feel more vulnerable. Even at 10 years after cancer treatment, long-term side effects can continue, and may even heighten.

But our survey² showed that 44% of people living beyond cancer were not aware of physical long-term side effects. Of those who did know about them, only 56% knew exactly which ones might affect them personally; a further 29% knew about some, but not all, of these effects.

However, when shown a list of physical conditions – each of which can sometimes occur as a result of cancer and its treatment – 78% of respondents said that they had experienced at least one of them in the last 12 months.

More people experienced problems in their first year after treatment ended (94%) but even at more than 10 years after, 71% said they had experienced a physical condition in the last 12 months which might be linked.

Almost a fifth – 19% – had not sought medical help for these problems. 60% had been to their GP, 22% to their cancer specialist doctor and 13% to their specialist cancer nurse.

Comments made by respondents show some want a more holistic approach at check-ups, with all their physical concerns discussed, not just the actual cancer. Many people felt that they were not listened to, and that their worries were brushed aside.

The picture is complicated because people living after cancer may also experience other long-term conditions, which may or may not be related to cancer and its treatment, so will be seeing other non-oncology specialists. Just under half (49%) have at least one other chronic condition. This includes 15% who have two and 6% who have three other chronic conditions³.

'It would have been nice if the GP or Consultant had mentioned these late effects, I have experienced quite a few of the things you mention, but not once has anyone told me this could be down to the cancer and its treatment.'

Woman, early 50s.

Case study – a survivor’s story

Jim’s Story

Jim, 62, from Richmond, Surrey; diagnosed with prostate cancer in 2005 aged 59, treated with hormone therapy, then external beam radiotherapy, then brachytherapy and more hormones.

I thought I knew a lot about the possible side effects of my treatment, but now I realise I didn’t understand at all. I discussed the issue with my consultant before my treatment, but it was pretty one dimensional – let’s cure this cancer.

The big issue afterwards was the damage to my colon and bladder, which I hadn’t expected at all and had not been warned about. I am a busy consultant in the media world and have to attend a lot of high level meetings. But I have had very bad urinary infections, with urgent, uncontrollable needs to pee which has been excruciatingly embarrassing.

When I talked to my consultant about my problems, I felt I was becoming an irritation. He couldn’t resolve the problem, and eventually I was referred to someone else. Some of these people are highly specialised and celebrated in their field, but when it comes to being able to treat someone for the side effects of their treatments they simply do not have the same level of expertise or drive.

I wonder now is there such a thing as ‘after’ cancer? The treatment is over but the after-effects aren’t.

Case study – a survivor’s story

Tom’s Story

Tom, 53, from Hertfordshire; diagnosed with neck and tonsil cancer in 2004 aged 48, treated with surgery, chemotherapy, radiotherapy.

I had anticipated the physical effects of my cancer but not the emotional ones, which started early on. I was waiting for some radiotherapy one day when I just burst into tears. One of the nurses arranged for me to see a counsellor. That was really useful at that stage.

My treatment finished in July but by October I was getting very tearful and the slightest thing would start me off. My GP put me on mild anti-depressants. But I became depressed again a year later and in April 2006 – the second anniversary of my diagnosis – I reached a very low ebb.

My employer arranged for me to see an occupational health specialist and a counsellor. Both said, ‘It’s like you are mourning the anniversary of a death.’ It always came back to the cancer diagnosis and the anniversary. Looking back, something that perhaps could have helped minimise the depression was someone at work formally continuing to check up on me regularly. When you buy a new car, you take it back to the garage for regular check-ups. I needed an aftercare service, too.

Case study – a survivor’s story

Jen’s Story

Jen, 45, from Maidenhead; diagnosed with breast cancer 2004, aged 40, treated with surgery, chemotherapy and radiotherapy.

After my treatment finished, I felt like a wet rag. Emotionally I was scared and truly lost. People think it will take a month or two for you to recover; there is an expectation that you will be back to your old self, but the reality is several years. I felt I had to put a mask on in order to be the loveable, funny, Jen that people liked to be with.

I lost a couple of really good friends because of the after-effects. One of them said ‘Cancer changes people’. I really felt I was being punished for having this dreadful illness. That first year, I had the worst Christmas ever and seriously considered taking my own life. I was living in a constant anxiety attack. Physically I have been affected too. The chemotherapy has thinned my bones and I have got osteoporosis in my spine and my hip, the treatment for which gives me blisters in my mouth. I have developed hearing problems including tinnitus and have to wear hearing aids.



The emotional burden

'I have had little support since radiotherapy ended, and have struggled ever since. I thought that I would feel better as the years went on, but I find that depression is worse now.' Woman, late 50s.

Emotional and psychological long-term side effects of cancer and its treatment include depression, anxiety, memory problems, difficulty concentrating, sexual problems and a lack of confidence in engaging socially.

People living beyond cancer may find it difficult to gain the strength to carry out day-to-day activities, causing distress, and may worry about their ability to cope in the future. They may be concerned about whether the cancer will come back, and worry whether they have passed on the disease to their children. Difficulty carrying out mental and physical tasks may hinder a return to work and social activities.

Sexual relationships are still extremely important, but the illness might make intimacy difficult: they may think they are unattractive to their partner and have a negative body image; they may worry about sexual function. The fact that their partner may have changed from lover to carer may impact on their physical relationship. Infertility, and subsequent grief about not becoming a parent, may be considerable.

Many people may see their unhappiness as an inevitable side effect of cancer, and not recognise it as depression. It may come at a time when they may be experiencing other, unrelated, health problems. Older people may be isolated, living alone without a good support network of friends or family.

Our survey revealed that when people living after cancer are shown a list of psychological conditions that can occur as a result of the disease and its treatment, 62% had experienced at least one of them in the previous 12 months. However, 40% of them had not sought help from healthcare professionals. Of those who did seek help, their GP was by far the most likely source.

These issues were more common in the first year after treatment, experienced by three-quarters of respondents. But our survey suggests that even after 10 years, just over half (54%) said they had at least one emotional issue.

These problems can be underestimated, particularly as there is a focus by healthcare professionals to deal with the disease itself. Failure to help people with cancer recognise and deal with such issues can make them worse.

Comments show some people feel 'abandoned' at the end of treatment and a few wish that healthcare professionals would phone or visit to offer help rather than they themselves having to make contact. A number of respondents said having no one to talk to was distressing, while others said they found it difficult to admit depression.

'I've certainly had post traumatic stress disorder in some degree but this has never been dealt with.'
Woman, late 40s.

Invaluable information and support

‘I felt I should have been told the implications the treatment would have on the rest of my life, and had the opportunity to refuse it.’ Man, early 60s.

People will obviously have different information requirements throughout their cancer journey, but the end of treatment is a key opportunity to provide information on the management of possible long-term consequences and healthy lifestyle messages. A post-treatment assessment and future care management plan are an important part of this process.

This information given should include self-management of conditions, how to spot signs of recurrence, and clear guidance on when and how they should contact healthcare professionals in the future.

As time passes from the end of treatment, information needs may change, and some people may want signposting to appropriate services that could help with the problems they are experiencing, such as counselling for psychological effects.

But our survey showed that a third of people who have had cancer didn't have all the information they needed, and were not aware that it could be more important for them to adopt a healthy lifestyle. Respondents said they would like more information on diet and nutrition, weight management, genetics, stress and exercise.

‘I was told about some late affects, ie more prone to skin cancer ‘so take care in the sun’. However, I wasn't told that until 10 years after my last treatment.’

Man, early 40s.

Those having specialist nurse check-ups are the most likely to be aware of late consequences, and the importance of adopting a healthy lifestyle. But only 28% of our respondents have check-ups with a specialist cancer nurse.

People who are ‘out of the system’ and no longer having check-ups are more likely to be unaware of long-term effects of cancer and the importance of a healthy lifestyle, and are least likely to access support than those under some sort of care.

‘When my chemo, then radiotherapy stopped, I felt pushed out into the cold, or as if I was walking the plank...isolated from qualified/informed support.’

Woman, early 50s.

GPs – the key link

‘My GP was very good, he referred me to a hospice where I see a Macmillan nurse... but I wasn’t aware of this, I waited until I was at the end of my tether.’ Woman, early 40s.

Our survey shows that survivors who develop physical and emotional health problems which may be linked to cancer are more likely to contact their GP for help than anyone else. This is true even if the person is still seeing a specialist nurse or doctor for check-ups.

It is therefore vital that the information given in secondary care at the end of treatment is reinforced in primary care by the person’s family doctor.

‘I am supposed to have annual scans organised by my GP ... it is usually up to me to remember. In the past there has been too great a delay.’

Woman, late 40s.

GPs need to have the right information to enable them to recognise and treat the consequences of cancer and its treatment. To this end, it may be helpful for health professionals in secondary care to highlight the specific ongoing needs or potential needs of the patient to family doctors as quickly as possible.

In the current system, information will be passed by letter from the acute trust to the GP, which can be very slow, and may not include all the information which would be useful for the GP during a consultation with their patient.

So, although the GP will be aware of the cancer, he or she may not know details of treatment and so may not associate health problems the patient is experiencing with that treatment.

The lack of this information has a knock-on effect. Our data suggests that about half of GPs mention cancer or its treatment as a possible cause of these conditions that may be side effects.

General practitioners may need to ask if the patient is having certain side effects proactively, as the patient may not know the symptom could perhaps be treated or managed.

Family doctors also need to be able to offer key support and information, and be aware of other sources of support, such as counsellors, to whom their patients can be referred.

‘I have had lots of side effects, nerve damage and hot flushes but when I have sought advice from the NHS, I have been made to feel I should be thankful to have survived so far!’

Woman, late 50s.

Best practice

Here are some examples from across the UK of innovative services helping to meet the needs of cancer survivors.

- Specialist cancer nurses from the Mount Vernon Cancer Centre in north London hold dinner parties for head and neck cancer patients who may have difficulties eating. This gives them the confidence to eat out in restaurants with their families – a social activity that is very important.
- At the Living Well Service in the Peak District, people living with cancer receive post-treatment assessments and clinical care, as well as emotional and practical support services in a primary care environment. This holistic approach is particularly appropriate for the rural community, who may find it difficult to access hospital services.
- In South Devon, the charity-funded Moving On Programme helps women who have finished treatment for breast cancer and are 'moving on' to the post-treatment phase. It aims to teach them skills and strategies to help manage the situations they may face more effectively, using mutual support from all the women attendees.
- People who have been treated for colorectal cancer in the Grampian area of Scotland now have the option of GP-led follow-up rather than having to go back to hospital. This is important in an area that has significant remote and rural areas. The GP maintains close links to the hospital to ensure issues raised at clinics are dealt with rapidly and, if necessary, patients are referred for further investigations.
- In north east Wales Macmillan has funded a holistic service to support people with cancer affected by lymphoedema, (a late effect of cancer which results in swollen parts of the body such as an arm or leg). Nurses help patients cope with the painful physical symptoms of lymphoedema through massage and draining techniques, and a specialist social worker within the team is available to support patients to cope with the emotional effects of their condition.



Conclusion and key recommendations

Our survey shows that people living with, or beyond, cancer have many unmet needs because they are not receiving help for significant physical and emotional long-term side effects of cancer.

This is because many are not aware their symptoms may be linked to their cancer diagnosis or its treatment, often due to a lack of effective communication in the healthcare setting; if they do know, they are not aware there may be services for them.

However, in many areas there are no services; so for all these reasons a growing number of people are falling through service gaps and left to cope alone.

We are calling for the Government to urgently prioritise the development of new ways for health and social care services to support people to recover from cancer and help them cope with any ongoing needs they may have, or subsequently experience.

In particular, we believe there are some simple measures which must be implemented to support cancer survivors, including:

- 1** Everyone who finishes treatment should be offered a post-treatment assessment that informs the development of a personalised care plan, which allows more support for complex cases.
- 2** As part of that plan, people should be provided with information about possible consequences of cancer and its treatment, any changes that they can make to their lifestyle to minimise the impact of their cancer and its treatment, self-management and support services, and what to do if they suspect recurrence.
- 3** There should be clear and swift access back into the specialist system if people's health needs change. Anyone who has ever had a cancer diagnosis, however long ago, should be able to access help and support.
- 4** GPs need to be enabled to support people living beyond cancer, by ensuring they are informed about their patients' treatment and ongoing needs, and how they might be met. This could be done in the form of a standardised electronic treatment record, which is easily accessed online during a consultation.

Appendix

¹ King's College London, Macmillan Cancer Support, National Cancer Intelligence Network Cancer Prevalence in the UK 2008. According to our research, by the end of 2008 there were 2 million people living with or beyond cancer in the UK, almost double the previous estimate of 1.2 million. This is based on the most up-to-date cancer registry data available.

² Macmillan Study of the Health and Well-being of Cancer Survivors – Follow-Up Survey of Awareness of Late Effects and use of Health Services for ongoing health problems, Macmillan Cancer Support, 2008 – see the background to this report.

³ Macmillan Study of the Health and Well-being of Cancer Survivors, Macmillan Cancer Support, 2008.

⁴ All anonymous quotes are comments from the Macmillan Study of the Health and Well-being of Cancer Survivors – Follow-up Survey of Awareness of Late Effects and use of Health Services for ongoing health problems, Macmillan Cancer Support, 2008.

Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial support, and push for better cancer care. One in three of us will get cancer. Two million of us are living with it. We are all affected by cancer. We can all help. We are Macmillan.

For further information, please call
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Case studies are available for interview

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Scotland (SC039907) and the Isle of Man (604). April 2009. MAC12447

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