

A middle-aged man with grey hair, wearing a light blue button-down shirt, is leaning on a dark wooden railing. He has a thoughtful and slightly concerned expression. In the foreground, there is a stack of several colorful books (yellow, pink, blue, orange) that are out of focus. The background consists of lush green foliage.

**'Am I meant to  
be okay now?'**

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

**'The realisation that life will never be the same and you will never be the same again – it's devastating.'**

Ciara, finished treatment for Hodgkin lymphoma 14 months ago

# How we wrote this report

Between March and April 2017, we invited members of Macmillan's Online Community to share their experiences of life after their cancer treatment had ended. The Online Community is a place for people affected by cancer to share their experiences with people who understand what they are going through.

We asked members to complete an online survey about how they felt after treatment, and to let us know if they were happy for us to contact them for a telephone interview. We then carried out interviews and spoke to some people who had already shared their stories with Macmillan. This report is a collection of these stories.

You can find out more about Macmillan's Online Community at [community.macmillan.org.uk](https://community.macmillan.org.uk)

All figures, unless otherwise stated, are from Macmillan Cancer Support/YouGov Plc online survey of 2,067 people with a previous cancer diagnosis in the UK. Fieldwork conducted 23 June – 6 July 2017. Survey results have been weighted and are representative of the cancer prevalence population. Results in this report are based on the 489 people who completed treatment within the last two years.

# Introduction

You are now twice as likely to survive for at least 10 years after a cancer diagnosis than you were 40 years ago.<sup>1</sup> This is only possible because of the progress made in diagnosing people earlier, and vast improvements in treatment and care.

But sadly, many who survive cancer then find themselves living in poor health. They may struggle with physical and mental health issues that affect their ability to live the life they want. Many people are not prepared for this, and can feel confused or guilty for not feeling as well as they, or those around them, expected they would.

'What they didn't have was anyone saying, "Now you've finished your journey, this is the general situation. This is the sort of check-up you can expect to have. These are the feelings you could experience. These are some of the actions you could take. Here are some of the contacts that you can use.'"

**Alan, Poole, finished treatment for bowel cancer five months ago**

The stories in this report show us just some of the ways that cancer can affect people's lives once they have finished their treatment. But they also tell us that there is more that can be done to make sure that everyone with cancer gets the best possible support in the future.

'What I've found immensely helpful is this post-cancer group – that's made a massive difference. That's something I'd like to see more of. Just sharing with other people who have had the same experiences. The supporting each other aspect of it has been very helpful and finding out that most of the problems you come up with, everybody else is in the same boat.'

**Kathy, East Midlands, finished treatment for bowel cancer two years ago**

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<sup>1</sup> 40 year trends in an index of survival for all cancers combined and survival adjusted for age and sex for each cancer in England and Wales, 1971–2011: a population-based study. M Quaresma et al. The Lancet 2014; 385: 1206–1218.

## Surviving doesn't always mean living well

Just because the hospital appointments and treatments are over doesn't mean that life goes back to the way it was before a cancer diagnosis.

Some people can find adjusting to life after cancer treatment relatively straightforward, but one in three people (34%) are still struggling with their physical wellbeing up to two years after treatment ends.<sup>2</sup> Problems such as incontinence, difficulty eating, or breathlessness can make people feel as unwell as they did during treatment.

The emotional impact of cancer should not be understated either. Almost a third of people (30%) who have completed treatment in the last two years say their emotional wellbeing is still affected.<sup>3</sup> People frequently experience feelings of depression and anxiety, particularly around not being able to 'get back to normal'. Instead of elation or relief when treatment is over, people can feel lost and find it hard not to worry constantly that their cancer might come back.

Living in physical and emotional ill health for months – or even years – after treatment has ended is not uncommon. Chronic fatigue alone affects 350,000 people who have finished cancer treatment in England.<sup>4</sup> Two in five people (40%) who have finished treatment in the last two years are living with moderate or extreme pain or discomfort.<sup>5</sup> Sadly, the prevalence of these issues doesn't stop many from feeling isolated. They often feel like they are the only ones still struggling to move on, to go back to work, or to just feel better.

'There was just no plan, there was no comprehensive plan about what I should be experiencing, what I should be looking out for and I think that would have been really useful. What I really needed was someone in my community, someone close to me who wasn't just treating migraines or gynaecological problems or anxiety, but who had an overall treatment plan for me.'

**Frances, Leeds, finished treatment for Hodgkin lymphoma four years ago**

2 Macmillan/YouGov online survey of 2,067 people living with cancer in the UK. Fieldwork conducted 23 June – 6th July 2017.

3 Ibid.

4 Throwing light on the consequences of cancer and its treatment. Macmillan Cancer Support. 2013.

5 Macmillan/YouGov online survey of 2,067 people living with cancer in the UK. Fieldwork conducted 23 June – 6th July 2017.

## Things can change

The current aftercare system does not consistently provide people with the care and support they need after cancer treatment. People often report that they feel like they have ‘fallen off a cliff’ and don’t know what to expect or where to turn for help.

Over 80% of people facing physical difficulties in the two years after treatment say they have not been fully supported to get their life back on track. Similarly, nine in ten people whose emotional wellbeing has been impacted in the two years after treatment feel they have not had enough support to deal with this.<sup>6</sup>

Many of the common issues people face after treatment can be managed by the person themselves, if they have the right information, tools and encouragement. For many people, it may only take a little extra support to feel confident about managing their new reality after cancer treatment and to overcome the issues they face. But the stories we’ve heard show that many people are not getting this support from the system – this doesn’t have to be the case.

**1** The different ways cancer has affected someone’s life should be talked about from diagnosis, through treatment and beyond. This means that any needs they have can be identified and addressed, and a plan made for what action they and the health system will take. Currently, 53% of people leave hospital without a plan for their ongoing care.<sup>7</sup>

**2** Communication between the hospital and GP practice, such as a summary of the treatments received, and between the GP practice and the person with cancer should be improved. This helps people feel that they still have a support network, and they and their GP know what problems to look out for as a result of their cancer or its treatment.

**3** People should be able to access the support available in their local community – from volunteers and charities to local council-run services – to help them adjust to life after treatment and feel less isolated.

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<sup>6</sup> Macmillan/YouGov online survey of 2,067 people living with cancer in the UK. Fieldwork conducted 23 June – 6th July 2017.

<sup>7</sup> 2016 National Cancer Patient Experience Survey, Quality Health Limited, 2017. Available from: <http://www.ncpes.co.uk/index.php/reports/2016-reports/national-reports-1/3572-cpes-2016-national-report/file>.

# 'You're on your own again. You question it – am I really better now?'

Ravinder, finished treatment for breast cancer three years ago



## A growing challenge

If aftercare for people with cancer is done well, it not only prevents stress and further health complications for the individual but could help to alleviate pressure on the NHS as a whole. Recent research has shown that 15 months after their diagnosis people with cancer have 60% more A&E attendances than expected.<sup>8</sup> They also have 50% more GP visits.<sup>9</sup> Supporting people to self-manage in their communities could enable resource to be focused on those with complex health needs.

With the number of people in the UK who have had cancer at some point in their lives expected to rise to four million by 2030, and more people set to live longer after their diagnosis, cancer poses a growing challenge to the health system that is not going to go away.<sup>10</sup>

Coming to terms with life after the significant physical and emotional trauma of cancer is not easy. But the system can – and must – work better to support people at this stage of their cancer journey.

The end of treatment isn't always the end of the story.

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<sup>8</sup> Chitnis X, Steventon A, Glaser A and Bardsley M (2014) Use of health and social care by people with cancer. Research report. Nuffield Trust.

<sup>9</sup> Ibid.

<sup>10</sup> Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010–2040. *Br J Cancer* 2012; 107: 1195–1202. (Projections scenario 1). Macmillan analysis based on extrapolation of 2010 and 2020 projections that the number of people living with cancer will hit an estimated 2.5 million in 2015.



**'Finishing the treatment was the worst thing that ever happened.'**

Sue, Warwickshire, finished treatment for squamous cell carcinoma six months ago



# Sue's story

'I've lost a tremendous amount of weight and I have no bottom teeth now; swallowing is so difficult and I have a very dry mouth. I need a regimen where I have certain fortified drinks and I have to have soup, but there is no pleasure in it. It used to be part of our social life, cooking for other people, but I haven't got the stamina to do that anymore.

'Sometimes I just can't be bothered to eat this awful mashed up stuff, so I'll have a fortified drink instead, but the next day I pay for it because I'm light-headed and lacking nutrition. It feels as if I'm on a very fine balance. I turned up to clinic shortly after treatment and the young registrar got a shock when she saw how much weight I'd lost, and she put me straight into hospital for malnutrition. I was put on an overnight feed which I hated but without it I think I might have died.

'Being discharged from hospital when I was recovering from the malnutrition, my daughter and I didn't know what to do, so there was a period where we felt as if we just had to battle on. That was when we had our worst disagreements.

'My daughter was terrified and I was too weak to really know what was happening. She did

all she could to encourage me – she's a great cook herself – but I would actually say to her, "Will you stop bullying me? I've been through enough." But all she was trying to do was keep me alive, so it was dreadful for her.

'I was terrified of eating, terrified that things were going to get stuck in my throat. I couldn't even take medication, I had to have it by tube.

'Finishing the treatment was the worst thing that ever happened. It's almost as if you're struggling

to the top of a hill and then all you have is a plateau which gradually eases down for six months. Your 'recovery' doesn't feel like it starts until three months after treatment

ends. I found that hard, and now six months on I am not even 80% recovered. I'm on a plateau that's probably getting slowly better. One consultant told me that cancer and the current treatments are like a car crash to the human body. That's how it feels really.

'Fear of re-occurrence, loneliness and general fatigue sometimes made me despair and it was a battle to keep going. There have been times when it's been so bleak, you think, "It's just not bloody worth it". I can't accept what they call the new norm. They say, "You just have to get used to the new normal." I don't want to.'

**'They say, "You just have to get used to the new normal." I don't want to.'**

**'I think I was  
shell-shocked.'**

Frances, Leeds, finished treatment  
for Hodgkin lymphoma four years ago



# Frances' story

'It was actually a couple of months until I realised that my body was really struggling. When I first finished chemotherapy, I think I was still almost running on the adrenalin and managing to cope quite well.

'It was really important [for me] to go back to work because it was normality and it was a goal in my mind – once I'd finished treatment I would just go back to work. It was when I tried to go back into the same routine that it suddenly occurred to me that I wasn't just waking up the next day and feeling better – that I was continually feeling ill.

'I started to have quite acute problems with my mental health, including strong panic attacks that would leave me completely bedbound for a couple of days. On one occasion, I actually collapsed with a panic attack.

'I did my own research about my drugs and it did say that some of them trigger the physical symptoms of anxiety – like the adrenalin and the beating heart – that also stimulate panic attacks, and I hadn't been made aware of that. I'd been made aware of things like nausea and hair loss and fatigue, but I didn't know that it would potentially induce these symptoms. That was new for me.

'I had anxiety about what my body was doing, why was it in pain. I remember going back to my haematologist and my nurse saying, "I think something's wrong, I've got this." That started this slightly paranoid cycle with your health and your body because it feels like you've no idea what's really going on.

'I don't think it was the depression that was overriding at that time – it was panic. I was on

my own with my own health, really kind of shocked by what was happening, thinking I was the only person it was happening to.

'I had to find all the help myself, whether

that was trying to get referrals for cognitive therapy or meditation, it was just me that was doing it. When I look back on that initial year, the support definitely dropped off a cliff, and the effects are lasting.

'Emotionally in the first year [after treatment], I think I was shell-shocked because you're trying to catch up with everything that has happened to your body, and all your family and relationships. You feel like you're a failure and you've failed to bounce back in the way you think you should have done.'

**'You feel like you're a failure and you've failed to bounce back in the way you think you should have done.'**

# 'It's like falling off a cliff'

'You're on your own again. You've had a year full of doctors, nurses and support, and then when you're told that you're in remission, you question it – am I really better now?'  
**Ravinder, finished treatment for breast cancer three years ago**

'Once you've got over all your treatment and everything's finished, your safety net has gone.'  
**Fliss, finished treatment for womb cancer 18 months ago**

'There's a focus on survival at all costs but then you finish treatment and it's like you've come off this conveyor belt of hospital and treatments and then nothing. Just this barren wasteland of feeling awful.'  
**Ciara, finished treatment for Hodgkin lymphoma 14 months ago**

'You just fall off the end of a cliff when you come out of treatment.'  
**Chris, finished treatment for head and neck cancer 10 months ago**

# 'They just haven't got the time'

'When I had my last check-up, the oncologist was so rushed and so busy, it was straight in, straight out. If you've got something you want to discuss, you didn't have time. It was a case of, "Everything's alright, we'll see you in six months." I have thought about going to my GP and saying, "I don't think I'm dealing with things properly." But you know, they're just in and out, the GPs. In for whatever, out. It's not their fault, they just haven't got the time to sit down and talk to you.'

**Fliss, finished treatment for womb cancer 18 months ago**

Nobody warned me about the emotional fragility and depression which could set in. [When] it's all done they can't pass you onto anybody who can take over at that point.'

**Sue, finished treatment for squamous cell carcinoma six months ago**

'Doctors are busy, you go and you can only discuss one thing. You might have half a dozen symptoms, which I did have soon after, but when I've been [seen by the doctor] it was only because of the breathlessness.'

**Helen, finished treatment for lung cancer one year ago**

'[Things changed] when I finally managed to go and make an appointment with the 'good' doctor in the practice. It takes a lot of mental energy and determination to get an appointment with her, as you can imagine. The stress most GP practices are under anyway, getting a GP appointment is difficult, but getting an appointment with her is nigh on impossible.'

**Kathy, finished treatment for bowel cancer two years ago**

**'I didn't really admit  
how bad I was feeling.'**

Kathy, East Midlands, finished treatment  
for bowel cancer two years ago



# Kathy's story

'I think when the treatment finished, it was a great feeling of flatness. Everybody thinks that the difficult bit is going to be the treatment and the surgery, but I found that reasonably easy to cope with because it was structured. Suddenly, that's all gone and I just kind of let everything slide a bit, I felt a bit rudderless. That's how it started.

'I've also struggled lately with depression. I felt oddly guilty. It sounds bizarre, but I finally put on all the weight that I'd lost when I was ill after surgery and everybody's saying, "You look well, it must be so nice to be back to normal," and it's very hard to actually say, "No, I feel awful."

'I think one of my big issues with the aftercare I received was that nobody really said anything. I felt that's where the care was really lacking. I came out [of hospital] immediately after my operation. I hadn't managed to regain control of my bowels, but they let me just sort of wander off into the night with no incontinence care, no nothing. I was fine for a bit, until I started experiencing the diarrhoea problems again. I went to see the GP, who said, "I don't know what's going on and I can't really treat you with

anything because I don't know what the hospital are doing."

'It made a big hit on my quality of life because I was always scared about going out. Some days were absolutely fine, [but] I never knew when I was going to have diarrhoea and struggle to keep control. I was just so tired and so drained,

I didn't have the energy to think about anything. The more recent depression, I think it got caught in a vicious spiral where the less I was doing, the worse I felt.

'There needed to be somebody who offered the support as a routine because you're not in a very good place to go and think, "I need some help here and I'm going to go and find out how to access it and get it myself." Just by the nature of cancer and cancer treatment and depression, that's quite hard to do.

'I didn't really admit how badly I was feeling. I didn't want to be a burden on my friends and family – they have busy lives themselves – they'd been terrifically supportive while I was in hospital and having treatment. It was this feeling that, "I ought to be better by now."

**'I think the expectation almost is, "You've had cancer, you're over it, there's no more left so therefore you're better." I felt that was the expectation and I tried to live up to it.'**

# 'Am I meant to be okay now?'

Alan, Poole, finished treatment for bowel cancer five months ago





# Alan's story

'Cancer's an emotional journey that no one wants a ticket for. When the journey comes to an end, you start planning for the future.

'It's a totally new chapter which no one really prepares you for, because the focus is on cutting this thing out and treating you. And then it's like falling off a cliff because you're having to start a recovery process.

'I think it's because you've been hand-held during the cancer treatment, it's all flowed like clockwork, you come out the other end and it's a sort of vacuum. [You think] "Is that it?" and, "Am I meant to be okay now?"

'I felt really physically drained at the end and it feels as if you have an emptiness. It sort of drains all your energy. You think, "Now everything's got to be turned around somehow." But it's not like a switch. You don't turn it on.

'How do I get things back into order? How do I get back to how I felt before my surgery?

'And emotionally you've had all this focus, all this attention. You've gone on this rollercoaster ride and gone along with everything, and you get to the end and then you think, "What's going to happen now?"

'When I see my GP, he's only looking at treating reactions to the side effects. I don't see any evidence that they are picking me up or

communicating to me, saying, "Yes, we know that you've come out from the hospital system after being treated for cancer, and just to make you aware, if you've got any issues, concerns, reactions, then come to us."

'The hospital has got its process in place, but I think it would be nice if you had more of a proactive closed loop from the hospital handing you back to the GP surgery.

'I know that there is going to be regular reviews and check-ups, but obviously the fear you have is, "Is it going to come back? Is it going to spread? Am I going to have to go through this awful journey again?"'

**'I think it's because you've been hand-held during the cancer treatment, it's all flowed like clockwork, you come out the end and it's a sort of vacuum.'**

# 'They don't really understand'

'I think the expectation that I had – and that many have – is that there will be a sense of elation once the treatment is done. That never happened. After treatment, I became very anxious and had panic attacks. Family and friends had very much the attitude, "Great, it's over. Now you'll go back to normal and it's all okay." But that's not so.'

**Ciara, finished treatment for Hodgkin lymphoma 14 months ago**

'They think that once you've finished treatment, you're okay. But it's exactly the opposite. You're at the lowest point because you don't have the cancer anymore. That was what was motivating you in the first place, and not having it after having it is almost more unsettling.'

**Florencia, finished treatment for bone cancer 21 months ago**

'Some members of my family really thought that the treatment had finished and it was like, Bam! [You] get over it, you go back to life, and everything is absolutely fine. [They] couldn't understand what I meant when I said that I was still ill and that I couldn't work.'

**Frances, finished treatment for Hodgkin lymphoma four years ago**

# 'Is it going to come back?'

'I can remember driving in the car and 100% of the time I was thinking about cancer and the big worry about whether it was coming back. That's all I thought about all day.'

**Chris, finished treatment for head and neck cancer 10 months ago**

'I pick up colds and other illnesses quite easily. But now I get very paranoid if I get ill. Any aches or pains make me convinced that I'm sick again.'

**Ciara, finished treatment for Hodgkin lymphoma 14 months ago**

'If I wake up in the night and something hurts, or sometimes I'll wake up and my heart's thumping, I automatically think, "Oh my god, something's happening."'

**Fliss, finished treatment for womb cancer 18 months ago**

'I'm just on this check-up process now, but there's nothing addressing emotionally or physically how you might feel, or your family. I've got to go and get my CT scan. I don't know how that's going to come out or what the outcome's going to be, which is extremely stressful and worrying.'

**Alan, finished treatment for bowel cancer five months ago**

Every niggle or pain or anything that happens, you immediately think, "The cancer's come back." That's never going to go away completely.'

**Michelle, finished treatment for breast cancer two years ago**

# Chris' story

'After you come out of the hospital where you had all that attention, you're left to your own devices.

'I probably spent a good month – if not six weeks – suffering with depression, and I have to say when I got the counselling, it was a real help. Because the recovery was far worse than the treatment – far worse – and I definitely wasn't prepared.

'I was lucky enough, I've got a great doctor. But when you're depressed and you've got fatigue and all those things, the last thing that's on your mind is to go and try to get yourself some counselling.

'It's such a struggle. You can't eat, you're suffering from fatigue, you can't interact, you can't play with your children, you can't do all these things. If I had known beforehand maybe I would have been better prepared, but I wasn't.

'I've heard people say to other people with cancer, "Aren't you lucky to be alive?", which I think is an absolutely terrible thing to say to people, as if I brought this on myself.

'The other thing is, "You have your family to live for." You're thinking that you could die and leave them with nothing, so that just puts a lot of pressure on you.

'When you come out of cancer and you're worried about a recurrence and you're worried about dying or whatever else, that's your future. The diagnosis of cancer in the first place really scares you, it just totally takes all your confidence away. While going through the recovery, you lose all those things, you lose your self-esteem, you lose your confidence.

'It seems to drag you down and down and down. [It] just seems to get worse and worse as you come out of the treatment and you've less attention, you've less support around you.

'People say to me, "I bet you wake up every morning feeling glad to be alive." You know, it can't be further from the truth.'

**'Because the recovery was far worse than the treatment – far worse – and I definitely wasn't prepared.'**

**Chris, Northern Ireland, finished treatment for head and neck cancer 10 months ago.**

# 'They think once you've finished treatment you're okay.'

Florencia, Edinburgh, finished treatment for bone cancer 21 months ago



## What next?

The stories in this report reveal just some of the challenges facing people after their cancer treatment ends. We know that there are many more. But we also know that there are ways that the health and care system can work better to empower people to live well after cancer treatment.

That's why we want to see everyone with cancer have access to the Recovery Package. This key series of interventions aims to make sure people's needs after treatment are identified and addressed, and that they don't fall through the gaps between the hospital and their GP practice.

Transformation of care for people with cancer after treatment is beginning to make progress across the UK.

- The Scottish Government is working with Macmillan to implement the Recovery Package throughout health and social care.

- In Wales, Macmillan is calling on the Wales Cancer Network to apply the Recovery Package in a consistent way across Wales.
- The Recovery Package was first introduced into cancer services in Northern Ireland through the Transforming Cancer Follow-Up programme, the principles of which now being implemented across a wide range of tumour sites.
- In England, the Government has said that everyone should have access to the Recovery Package by 2020.

The stories in this report show how important it is that these commitments are delivered on. Aftercare for people with cancer should not be an afterthought.

Now is the time to act to make sure everyone with cancer has access to the Recovery Package and is supported to live as well as possible after treatment.

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

**We can be there for you during treatment, help with work and money worries and we'll always listen if you need to talk. We've helped millions of people through cancer and we can do the same for you. Life with cancer is still your life and we will help you live it.**

**From the moment you're diagnosed, for as long as you need us, you can lean on Macmillan.**

**Call us free on 0808 808 00 00**

**(Monday to Friday, 9am–8pm)**

**or visit [macmillan.org.uk](http://macmillan.org.uk)**

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

**'The fear of cancer never leaves you but I'm trying now to think, if it comes back, it comes back. I can't live under that shadow. But it is so difficult to mentally recover.'**

Ciara, finished treatment for Hodgkin lymphoma 14 months ago

**'People say to me 'I bet you wake up every morning feeling glad to be alive' You know, it can't be further from the truth.'**

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# **STORIES OF LIFE AFTER CANCER TREATMENT**

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