

**The future of
cancer care –
the views of people
affected by cancer**



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This research project was supported by Macmillan Cancer Support, and was carried out by Opinion Leader in partnership with people affected by cancer.

Macmillan Cancer Support is a UK-wide charity that works to improve the lives of people affected by cancer. We provide practical, medical, emotional and financial support and campaign for better cancer care.

Opinion Leader is a market research company based in the United Kingdom that uses a range of qualitative, deliberative and quantitative methods.

The views expressed in this report are those of people affected by cancer and it is their voice that we set out to present through this report. These views are not necessarily shared in their entirety by Macmillan Cancer Support nor will Macmillan promise to act upon all the recommendations set out within this report.

Foreword by Margaret Johnson, Cancer Voice¹

The future – rather a difficult concept for most of us. Even more so when you are asked to think about the ideal future for people affected by cancer. Macmillan Cancer Support wanted to explore people’s hopes for what cancer care could be like in 2017 to make sure they are heading in the right direction. This was an ambitious project but one that was worth the challenge.

Cancer care has made great strides in the last 10 years. Equipped with the knowledge that we acquired through this research, it seems there is still room for vast and even spectacular improvements over the next decade. Much of this vision of the future depends on new technology. We all hope science and technology will revolutionise not only the way cancer is detected and diagnosed, but also how people affected by cancer are supported to manage their condition as they continue to live with a diagnosis.

But looking forward doesn’t always mean thinking radically. In reality the basic needs of people affected by cancer aren’t likely to change much over time. The things we want from services now – respect for who we are as people, support throughout our journey, information and choice – are going to be exactly what we want from services in the future. It should be simple to achieve.

Many people affected by cancer gave a lot of their time and energy to this project. We wanted to make sure that their experiences, both good and those that could have been better, could help to influence services for the people who come after us. As patients and carers we really do know what would make a huge difference

both now and in the future. Usually the reason we get involved is because we want to make things better. We are actually already working towards that goal.

In my role as a Cancer Voice, I have enjoyed being the ‘user’ representative on the steering group, engaging with other Cancer Voices to facilitate and emotionally support my peers throughout this research. I have experienced tremendous camaraderie from my co-researchers and have been privileged to meet so many interesting, vibrant and totally unique individuals. It has been a pleasure working with them all through both tears and laughter.

I know that other people affected by cancer found the experience rewarding. This can be summed up by a comment from one of the participants in a workshop. Thanking us at the end of the day, they said ‘for the first time, we feel that we have really been listened to’. After an exhausting but thoroughly enjoyable day with the most amazing people, this comment was so sincere that I found myself blinking away the tears, but they were tears of pride that as cancer patients and carers we had achieved this.

I hope this report goes a long way towards capturing all the ideas and aspirations of everyone who took part. There is plenty for us to get on with, if we are going to achieve our vision for cancer care in 2017. We look forward to seeing how Macmillan, other charities, government and the NHS across the UK will respond. We will all need to work together if we are really committed to improving cancer services beyond recognition in the next 10 years.

¹Macmillan Cancer Voices is a UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.



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Fast forward – cancer care in 2017

This scenario describes a vision for cancer care in the future based on the views of the people affected by cancer who took part in this project.

'A few months ago I started feeling really unwell and I was losing weight. As I hadn't found a lump, I wasn't sure whether or not to worry, but my children told me to get myself checked out – the younger generation are so much more aware of the signs and symptoms of serious illness.

It was great having the opportunity to choose whether to go to that clinic in the High Street where things are anonymous (just like my aunt prefers), or to go and have a chat with my GP who knows me as he has looked after my family for years. I have to admit I was a bit scared, but it was so reassuring being able to tell my GP my fears without being embarrassed. He understood why I suspected I might have cancer and agreed my problem needed a closer look.

One phone call got me an appointment in the next few days. My GP had already given me an idea of what to expect. The clinic was bright and airy, like a good hotel. I'd been advised to take someone along with me, so my husband and the children came too. The children were well taken care of in the play area. We didn't have long to wait, but did have time to enjoy the cuppa we were offered when we arrived.

We went along to the consulting room where we sat in comfortable chairs whilst the doctor, who seemed to understand how nervous I was, explained the programme for the day. I was then asked about my symptoms and some tests were recommended. I had several tests there and then. There were all sorts of scanners, one a bit like the ones you see in airports, and a hand-held one which looked for any cancer cells in my body and then made a 3D picture of them. I was told before each test exactly what would happen

and they kept checking to see if I was OK and whether I was happy to carry on. Whilst we sat in the relaxation area, my test results and scans were emailed to specialists around the world so the health professionals involved in my care could have a video chat about my diagnosis and treatment options.

They reached a diagnosis fairly quickly and my husband and I went into a really pleasant room where we were told exactly what was wrong. It was sensitively explained that I did have cancer and the 3D scan was used to explain what it was and where. Then they took us through all the treatment options and gave us plenty of time to ask questions which they answered as clearly as they could. We were told who would be my main contacts and how to get in touch any time we wanted to. They gave us an information pack to take home which included a DVD, plus my chosen option of a copy of our conversations which I could access via my own computer at home if and when I wanted. They checked that we would be safe travelling home, as I was still taking in that fact that I had been diagnosed with cancer. Still a really serious matter even though it is so much more manageable these days. The staff gave us some great advice about our worries over telling the children as well as the rest of our family and friends.

I didn't know what to expect when I was offered the chance to talk to someone else who had been through a similar experience as me, but I found it so useful. My cancer buddy was such a help – a real source of support and has become a good friend into the bargain and we still meet up. I'm now thinking that's how I can help in the future as it does make such a difference when you are going through all these strange procedures. It gives you that extra bit of confidence during a traumatic time.

At my second meeting at the clinic, my healthcare team and my husband and I decided on a personalised treatment and care plan, which was then written up with all the other relevant information from the start of my suspicions. I take it with me on a smart card to all my appointments, so everyone knows exactly what is happening without my having to go through it all over again. Today's technology makes everything so much easier now.

There were a number of different treatment options including this new surgery which doesn't leave you with a big scar, drugs which matched my genetic profile, other chemotherapy drugs which included a clinical trial and fitted my particular diagnosis, and guided radiotherapy. All these treatment options have life-long follow-up because of any possible side effects, but they can be picked up early these days and treated immediately to minimise any problems. After our decision was made, I was told how quickly my treatment would start. The side effects weren't too bad and we were both able to take advantage of some complementary therapies which were available in the same place.

The benefits I received as soon as I was diagnosed have not only helped with my travel costs and all the extra things my illness has meant I need, but have also allowed me to have time off work to concentrate on getting better. My husband has been able to take some time off too, so he could be with me when I needed help and look after our children. We had some free counselling and lifestyle and food advice too. I actually feel healthier and have quite a bit of energy which has helped me manage. All this meant that my family and friends actually managed the whole thing too. I think they felt part of the whole process.

I am now back at work. My employer has been fantastic letting me go back gradually and flexibly, working from home when I need to and they've had a temp in to cover my job, as they benefited from the cancer cover scheme. I didn't realise it at the time, but my boss told me that he wouldn't have known what to do in my situation, but he remembered seeing a campaign about working through cancer years ago and that really helped. He had even offered to run an information lunch session on work and illness.

I still have concerns about the future, but I know what to do and who to contact if I am at all worried. Apart from the support groups we attend and find really useful, I am also going to attend a class run by a cancer patient, to help me to live with my cancer. My husband, as my carer, is really pleased that he has not been forgotten as there is a similar carers class and the children are involved with online sessions for their own age groups which is just right for them. I've just joined a panel where I feed back on my experience of cancer care, which I know has improved dramatically in the last 10 years. I'd like to help with changes for the next 10 years. I'm even thinking of assisting with the health education programme at our local school as cancer is no longer a word that everyone's frightened of.'

1. Introduction

Macmillan Cancer Support works to ensure that cancer services are based on the stated needs and wants of the people they are designed to benefit – people whose lives are affected by cancer. However, we realised that although we had extensive knowledge about current problems and what changes people affected by cancer would like to see now, we did not know what they wanted services to be like in the long term. This is a gap in the knowledge of many stakeholders, including UK governments.

Macmillan commissioned Opinion Leader to help us work with people affected by cancer to develop a vision for cancer services in 10 years time. We wanted such a vision to allow us to be more proactive in influencing government and to undertake longer-term planning in designing and delivering services. The objectives for the project were to:

- Draw together the evidence already available on the views of people affected by cancer on current and future cancer care.
- Involve people affected by cancer in developing novel ideas for cancer care in the future – ideas based on people's aspirations that would challenge current thinking.

We also wanted to learn about how to develop and deliver projects that encourage people to think about the future.

This report summarises the views of the many people affected by cancer who took part. Participants were invited to discuss their recent experiences and explore how these could be different in 2017. People were encouraged not to be constrained by how things are, but instead to think about how things could be.

Participants' own words have been used to illustrate their views wherever possible.

Structure of this report

Section 2 describes the methods used to find out about people's views on cancer care in the future.

Sections 3, 4, 5 and 6 summarise what the participants said. The findings are grouped into four themes: section 3 summarises people's views on emotional support, section 4 summarises people's views on practical support, section 5 summarises people's views on physical support and section 6 summarises people's views on cancer prevention and awareness. Each section first describes participants' recent experiences of cancer care and then summarises their vision of how cancer care could look different in the future.

The overall conclusions are summarised in sections 7 and 8, and in section 9 Macmillan Cancer Support describes how it is responding to the findings.

2. Methods

The project used a range of collaborative and creative methods to engage people affected by cancer, to stimulate ideas and capture their visions of cancer care in the future.

Our approach

We worked in collaboration with people affected by cancer throughout the project by:

- Creating an advisory board of people affected by cancer. The board helped to develop the methods and materials, ensured the overall approach was appropriate for the participants and commented on the findings.
- Working with people affected by cancer as ‘co-researchers’ who helped to facilitate the workshops.

We also went to considerable effort to ensure that people who would not normally take part in research could participate in the project. We invited people to take part via:

- Adverts online and in Macmillan publications.
- Macmillan representatives and partnership groups.
- Direct contact with support groups.
- Panel members from previous Macmillan research.
- Macmillan council members (chairs and members of community fundraising committees).

Collaborative workshops

We brought diverse groups of people affected by cancer together in collaborative workshops to develop and scope future scenarios. Twenty-nine people attended an initial ‘ideas generation workshop’, which was held over one day and evening. This was followed by eight further one-day workshops at locations around the UK (a total of 146 attendees) and two half-day workshops in hospices (16 attendees). These workshops developed the ideas from the first workshop as well as generating new ones.

At the start of the workshops, participants were asked for their views on current services across the entire patient journey. This provided time and space for participants to get to know each other and to share their personal experiences. They were then asked to take part in a ‘timeline exercise’ to identify their aspirations, hopes and fears, and priorities for services in the future.

To help people think about the future, a range of ‘blue-sky’ exercises and creative tasks were used, including:

- A collage exercise to capture what future cancer care should be, and what future cancer care should not be. Participants worked in small groups to create a collage of words, magazine images and drawings.
- ‘The future according to...’ exercise where people were asked to think of a forward-looking company that embodied one of the core principles of cancer care in the future. They envisaged what future cancer care would be like if it was formed by that company.

- A guided visualisation of cancer care in 2017 in which a facilitator helped participants to relax and then described a 'journey' into the future to set the scene to imagine how the future could be. The participants then wrote down what they imagined in the exercise and discussed their ideas as a group.

The workshops ended with participants rating the ideas they had generated, then reviewing the outputs against their own priorities, hopes and concerns to make sure these had been adequately addressed.

Online ideas tree

The ideas tree was an online tool on Macmillan's website which enabled people to share and rate ideas on future cancer care. Once an idea was submitted it was displayed as an item on the 'tree', which others could browse through, read and rate on a one to five scale. Other people were then able to respond to this input. In total 177 people put ideas onto the tree and thousands more visited the site.



3. The views of people affected by cancer: emotional support

3.1 Overview

Participants described their need for emotional support at all stages of their cancer journey as summarised below. Many people said that whenever they did get emotional support, it proved to be invaluable. This support came from Macmillan nurses, support groups, drop-in groups, or friends made in hospital. People appreciated being listened to and the feeling that someone was going through the journey with them.

'My Macmillan nurse gave me an opportunity to talk about how I felt. Without her I'm not sure how I would have managed.'

'One of the life enhancing things that I've had over the last couple of years is being involved with a prostate cancer support group and meeting so many people in the same boat with all the men there and their partners and so on, you know, you're all involved with prostate cancer and it's very positive.'

Vision for 2017

- **Emotional support is a formal and integral part of every treatment and care plan.**
- **People are provided with personalised information on support groups at the start of their journey.**
- **People affected by cancer can visit a community drop-in centre, located in the town centre, which provides information, advice and guidance as well as in-house counsellors offering support.**
- **Support is available from 'cancer buddies'.**
A buddy is a local person who has had cancer or has been a carer themselves. Cancer buddies support the person with cancer and their families, offering opportunities to talk and listen, and also offer guidance and advice. Anybody willing to become a buddy registers their interest and people with similar cancer types and demographics are matched up.

'Someone working with you where you can then contact them, or they can be readily available to you, no matter what.'

3.2 At each stage of the cancer journey

In this section, people's views on the provision of emotional support at each stage of the cancer journey will be discussed in turn. This discussion also includes people's views on what cancer services should be like in 10 years time, so that they cause as little stress and anxiety as possible.

Waiting for a diagnosis

Getting referred for tests and waiting for the results of those tests is a particularly anxious time. Some people felt their GPs did not take them seriously. Many were angry about having to 'fight' to be heard at the start of their journey. Younger people and those with rarer forms of cancer often battled most.

'Sometimes the doctor doesn't look into it... saying you can't have cancer you're too young.'

Vision for 2017

- **People get into the system quickly, get their results back quickly, and have their concerns addressed and treated with respect.**
- **GPs are well informed about cancer symptoms. They are understanding and quick to act—telling their patients 'you know your body better than me'.**
- **GPs receive regular updates and training in cancer diagnosis from cancer specialists and have access to a specialist cancer website specifically aimed at GPs.**

- **High-tech specialist cancer centres are accessible to anyone who is worried about their symptoms. Tests and results are provided on the same day. The centres attract the world's best cancer specialists. Any specialist can be contacted remotely by consultants at the centre to get a second opinion on problematic diagnoses. People affected by cancer are able to access up-to-date information via digital libraries.**
- **Systems help individuals to take more control for example self-testing kits sold in chemists or 'analytical toilets' (toilets that analyse samples) that send results directly to health professionals.**
- **Scanning machines confirm where the cancer is and how advanced it is. It is pain free and non-invasive.**

'Quicker referrals to hospitals from GPs.'

'If we could get quicker diagnosis, if the diagnosis can be done, even in a GP clinic or as you say self-diagnosis, that would be pretty good.'

Receiving a diagnosis

Receiving a cancer diagnosis is often the most distressing part of the cancer journey, and requires sensitive and careful handling.

'When he told me, I collapsed and I couldn't walk.'

'I was in such a shock at the diagnosis I don't think I took in a third of what she was saying.'

Some people had found that medical staff had been very blunt:

'I was working nights, it was like 10 o'clock in the morning, so I had been to bed for about three hours – phone rings by the side of the bed – the first thing I hear is the doctor, "You've got cancer".'

Vision for 2017

- **Everyone is asked to bring someone with them when they receive a diagnosis.**
- **People are treated with compassion when they are diagnosed. They feel supported and are able to ask all the questions they need.**
- **People are given a choice about how and when they receive their diagnosis, for example, by interactive TV so they can be in their own home, at a time that suits them with support from their family.**

'A friend or family member to be with you at consultations so that you don't come out saying "what did he say?".'

'No time pressures, so we can either go away and have a coffee and come back, or if you want to go home and speak to your family then somebody can [come] out to the house later on that night, [or] the next day.'

Making a decision about treatment

Having enough information to make a decision about what's the 'right' treatment for them is an important way that people with cancer can feel in control and manage their experience.

However, many people said that even if they were offered choices, they often did not have enough information to make an informed decision. In particular, they felt they didn't get enough information about the side-effects of treatments.

'Side effects were played down, minimised by medical staff. Chemo floored me – I couldn't get out of bed, I lost so much weight, I was very weak. I wasn't told about loss of appetite.'

Some people felt they had to be very proactive to understand their options: asking doctors the 'right questions', finding out information for themselves and really having to push for preferred treatments. They did not feel supported as partners in making decisions about care.

'No information was given when I was diagnosed. I had to ask [the] doctor for a contact number for Cancerbackup and they had to look it up.'

Vision for 2017

- **Treatment options are explained clearly so that patients know what to expect and can make decisions 'with' the clinician.**
- **Every cancer patient receives the information they need to make a decision about treatment options. This could include a risk assessment sheet which provides details of the possible side effects and late effects of every treatment they are prescribed. It would indicate the likelihood of experiencing side effects and how to recognise these symptoms early. Testimonies from patients would provide a more realistic account of what the treatment is like.**
- **There is an online programme that takes your personal details and tells you the most effective treatments available for your particular circumstances.**

'More choice and the patient being involved in decisions... a type of joint decision.'

'We want more readily available risk assessment. If you want to use a chemical, you have to do a risk assessment...we don't know what the side effects are, other than they say it may be this or it may be that and we don't know the risk of getting those side effects.'

Receiving treatment

Many felt that their emotional needs were not met while they were in hospital receiving treatment. They felt staff were too busy or did not treat them particularly well.

'I had a really bad experience in hospital and I know it's not true of everyone, but for me the staff were absolutely awful.'

'There isn't the training for people in hospitals, you know, in terms of cancer....Most people don't like talking about it...a lot of them are still just geared up to dealing with the physical – the pre-op and post-op things – but not the emotional things that occur because somebody's got cancer.'

Some people had become distressed and anxious during their treatment because they had received conflicting information about their progress or treatment by different doctors. This is often due to poor communication between health professionals.

'The haematologist first of all said he was going to do radiotherapy and I thought well that's great because I won't lose my hair, so I went along to the appointment and they said, "we've changed our minds, we're going to do chemo instead to start with and we're going to start it today," at which point I broke down in tears, because I thought I'm going to lose my hair, I'm starting today, I've got no time to prepare so that was it, so here we go.'

Vision for 2017

- **People get all the information at the beginning of the journey to help them cope better emotionally at the various stages.**
- **Patients and clinicians work together to draw up a personalised, written care plan. This is a contract which outlines treatment decisions in terms of when, where and how treatment is provided.**

'Information was given in small drips rather than full information. This made me less able to come to terms with my disease and consequently every stage became a shock to me.'

'Draw up a written programme of care as and when the patient, carer or professional thinks necessary.'

After treatment

For some people it is the end of their treatment that is the most stressful. The constant medical contact, and the emotional support it provides, which their life has revolved around for the past months or years, disappears. This leaves people feeling disorientated or abandoned.

‘We fell into this black hole and you feel as if you’ve been forgotten about.’

‘All of a sudden that was taken away [being in hospital], plus all the people... you may not even know them that well, but you connect because you’ve been through similar journeys and they don’t all make it. But, you miss them anyway, and you miss the staff, strange as it might seem.’

Many people describe being confused about their status – are they cured, in remission, still in treatment?

‘I’m still technically under a doctor’s care, although there’s no active disease, so I’m not quite sure what I consider myself to be these days, you know, patient or what.’

Before treatment finishes they feel they are just getting through it and trying to stay alive. Now they are in remission, it all hits home. This is the time they really need support emotionally and financially, but are often unsure if it exists and where to find it.

‘For me, when I was physically getting better that’s when I was realising ‘my god, what have I been through, what could have happened to me?’ and that’s when the emotional thing came tumbling down. And I found that I had to take extra time in terms of healing because emotionally I was now just beginning to realise what I’ve gone through.’

Others wrestle with the fear of the cancer returning and the guilt of survival when others have not.

‘It’s funny I almost feel guilty for having survived. I had great difficulty with this at first but it’s got easier meeting other patients but it’s something I found quite significant.’

Other people’s assumptions about the person with cancer can be difficult to manage. Others tend to assume that as the person is physically better, they have also ‘got over’ the cancer emotionally as well.

‘The recovery time is much, much longer than anybody will acknowledge. It can lead to a lot of depression.’

Vision for 2017

- **All cancer patients continue to receive aftercare when their treatment finishes. They can easily access any further information or emotional support they need.**

'A team on 24-hour call, 365 days a year. The team would deal with everything to do with your query or your problem.'

'One of the things I thought they could do was an exit interview.'

Receiving a diagnosis of secondary cancer

If their cancer does return, for some people the process is easier as they know more about what to expect. However, others find it more traumatic as the implications are potentially more serious. People may need extra support at this time.

'What I'm worried about – and it really worries me terribly – when they get a secondary, do they get the support that they should do about the secondary cancer? And my own personal findings have been no.'

3.3 Emotional support for the friends and family of people with cancer

Providing information on cancer to families and friends and the wider community

Often people say their friends and colleagues treated them differently after their diagnosis. Many think this is because there is a stigma around cancer; people do not understand that you can 'live with' cancer and think that cancer is a death sentence.

'This kind of disease is very misunderstood generally by the public.'

Black and minority ethnic participants can find the stigma of cancer even more pronounced in their communities. A few participants had only discussed their cancer with their immediate family, not their friends or more distant relations. A Muslim woman set up a help group in her mosque, but could not attract new members because cancer was such a taboo in her community. Some had the added problem of being a long way from their family support networks.

A lack of understanding about cancer can lead to family and friends making the wrong assumptions about people with cancer and not being sensitive to their needs.

'I kept meeting people in the street and they would say, "How are you, Annette? You look so well. You've done so well. The rosy cheeks". And, I would say, "Oh yes, I'm fine." [And I'd] cry inside and say that I'm not fine and I'm not well. I'm feeling awful. Can you not see?'

The impact on relationships

Cancer has a big impact on the friends and families of people with cancer. Many people's relationships are put under enormous strain. Although it can sometimes bring families together, it can also lead to relationships failing. People feel that the wider impact of a cancer diagnosis is often forgotten.

'I know I'm not the only one but my marriage broke up as a result of having had cancer and the effect it had on our relationship.'

Support for carers

Because being a carer for a person with cancer is emotionally draining, carers also need appropriate emotional and psychological support.

'Trying to help my wife through 24 hours a day was exhausting, stressful and sometimes the feeling of being useless when you're needed the most.'

This is particularly important in supporting carers through bereavement. There were concerns about communication between health professionals and the friends and family of a person with cancer. Some carers felt they were not told honestly and openly that their loved one was going to die, and so did not have enough time to prepare. They did not always feel they were told in a compassionate way and did not feel they got enough support at this time.

Involving carers in decisions about treatment

Family members can often feel left out of the process. But they want to be involved, they want to understand, they want information about what is happening and they want to feel part of the decision making. Without this involvement, they do not know how best to support the person with cancer.

'The family and carers are given no information at all. My mother [the carer] was distraught and did not know who to talk to.'

Involving carers becomes particularly important in decisions about end-of-life care. People close to the person with terminal cancer often find it hard to discuss it with the patient directly. They said there was no way of finding out information easily without discussing it directly with their loved one and that they hadn't been given enough guidance on how to approach the topic with them.

Vision for 2017

- **Cancer is 'destigmatised'. People understand cancer and its effects.**
- **Families and friends of people with cancer receive better information in a more systemised way.**
- **Families and friends of people with cancer receive counselling if they want it.**
- **Families and friends of people with cancer are more involved in treatment decisions and developing the care plan.**

'The families should be more involved, I think, as to what the various options are.'

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4. The views of people affected by cancer: practical support

Financial advice and support

The financial impact of having cancer is often far from people's minds when they are first diagnosed. However, it can become a big problem for people with cancer and their families.

'Sometimes you lose your home, because you are not at work, you cannot make the payment... and I think that is something very, very draining because I think if you lose that you lose everything.'

Travelling to and from hospital and paying for car parking exacerbates the problem, especially in rural areas. Often carers have to take the day off work to help people access their treatment.

'I did bring it up in the hospital when I was in the chemo suite and I said to him, you know it's too expensive. Cancer patients are out of work, and it's too much money for the car park, and they said they were going to sort something out for cancer patients at the hospital, but it hasn't been done.'

Finding out about, and applying for, financial support is often frustrating or confusing, with many forms to fill in, and considerable detail required. Patients feel they have to fight for benefits and funding.

What's more, the financial effects do not stop when treatment does. High insurance premiums, covering all areas from travel insurance to mortgage cover, continue long after people with cancer are 'cured'. These high premiums can prevent people from returning to a 'normal' lifestyle, like going on family holidays.

'When she was diagnosed, there were only two products on the market that would cover mortgages being paid if your child gets terminally ill...that's ridiculous, you know because it does happen...the same with travel insurance, the same with health insurance; cancer is a reality and...they should be catering for it.'

Vision for 2017

- **People receive financial advice and support at all stages of their cancer journey from diagnosis to after remission.**
- **Cancer patients are given a cancer pass which exempts them from certain fees, such as child care and car parking fees.**
- **People apply for benefits on a single online password-protected site which takes their details once, works out what benefits they are eligible for, what support is available and automatically fills in all the forms (insurance forms, critical illness forms etc) according to the information they have provided.**
- **Specialist travel insurance policies are available to cancer patients, providing affordable cover for overseas holidays. Premiums decrease when the patient goes into remission. These are also available for the families of people with cancer.**

'You just get sick and tired of filling in your details again and again on different forms, so if you could just put it in one place and everybody feeds off that, it's easier.'

4.2 Support in returning to work

Some people with cancer find that they can't carry on working. This affects them psychologically.

'It was awful because I have worked full time since the age of 17 and I have never claimed benefits. And as soon as I got diagnosed I couldn't work.'

People who do want to go back to work can find the transition quite difficult. Some employers replace them, unable to deal with them being on sick leave for so long. Others expect people whose treatment has stopped to come back full time immediately, and are unsympathetic if they need to go part time or take further sick leave.

'I went from being a management accountant to being a temporary filing clerk because it was the only way that I could get back into work, and it took a long time for me to effectively improve myself.'

Carers can also find it difficult to carry on working, either due to the time it takes to care for someone with cancer (for example travelling to and from hospital or looking after them physically) or due to the emotional strain.

Vision for 2017

- **Once a person who has had cancer, or their carer, wants to return to work, they can contact a DWP-trained advisor who provides support and advice on planning a return to work, as well as telling people their legal rights.**
- **Employers have access to expert advice and support on managing employees who are diagnosed with cancer. All employers can receive information about cancer and its effects.**
- **Smaller employers can take part in government aided back-to-work packages, which cover the cost of allowing flexible working patterns for those recovering from cancer.**
- **Like maternity cover, cancer treatment cover has become a statutory right for workers.**

'My husband couldn't cope with my cancer diagnosis at all, and he ended up having quite a serious nervous breakdown... He lost his job, because well, he gave it up, he just walked away in the end. They were not very supportive, so financially, we were really struggling and he has never actually returned to work.'



5. The views of people affected by cancer: physical support

5.1 Receiving treatment – the physical environment

Most treatment for cancer takes place in hospitals. Many people found their experience of hospitals did little to aid recovery. Many want to avoid going to hospital for regular ongoing treatment. However, they also want the most effective treatment possible. People would like to have greater control over their own treatment – ie manage it themselves. They also want to receive treatment within ‘healing environments’ to minimise stress and anxiety.

Vision for 2017

- **People are offered a choice of their place of treatment. In the NHS there are specialist cancer centres with family areas to allow people to be treated in a specialised environment with their relatives nearby. Hospitals are calm and clean ensuring a dignified experience, with single-sex, age-relevant wards and robes that fit.**
- **People can also receive treatment either close to home or at home. People can order their drugs through repeat prescriptions online and have regular check-ups from specialists who come to their homes.**
- **Mobile treatment services visit your area or home in a hi-tech vehicle and are able to reach you within 24 hours.**
- **People with cancer can opt to take part in an ‘expert patient programme’ which offers support to people so they can look after themselves. There is also the option for carers to take basic nursing courses.**
- **People who are recuperating after treatment, or who do not need complex treatment, can attend holistic healing centres. These centres provide an opportunity for people to get away from it all and really concentrate on getting better. They offer a healing environment with lots of plants, water features, a nutritious cafe, a chill out room with reading materials and music. Complementary therapies, counselling and lifestyle advice are available. People are provided with a personalised plan to help them stay healthy during treatment and to make positive changes to their lifestyles on a long-term basis.**

‘You know, hopefully, in the future, people who choose to have their treatment at home can have it, and if they choose to have treatment in a hospital, then it can also be catered for.’

‘I was thinking... you can deliver cancer care to people’s doors – that would be a definite step forward.’

‘I would want a care centre like Center Parcs. Park-like surroundings, maybe a pool, a jacuzzi, relaxation.’

‘I’d like to see more alternative medicines really on the NHS as well, and health foods promoted, antioxidants, that sort of thing.’

5.2 Managing long-term side effects

Many people feel unprepared for the physical and psychological impact of the long-term effects of treatment and find they that they have no access to advice and support at this stage.

‘Now that you are well you can get on with life as normal. How? With a weaker arm, less reach, numbness, swelling, aching joints, fluid retention, hot sweats day and night, fatigue that suddenly overcomes you, self esteem that’s given a knock as you don’t look or feel the same, sexuality levels low, mood swings, weight gain. You do not feel “normal”.’

‘You think it is all over and then it is still going on 18 months, 2 years down the line and you are still having side effects from your treatment. And there is no one. I mean, I will access information because I am that type of person, I will go and find it, speak to somebody, but for other people, that’s really difficult who do you turn to?’

Most people want to have follow-up appointments to help them manage any long-term side effects, preferably with the doctors who have been involved in their care and know their case well.

Vision for 2017

- **Late side effects are very infrequent, because of the efforts that have been channelled into reducing side effects for cancer drugs.**
- **Patients and clinical staff jointly agree on an ‘after-care package’ which includes an exit interview with an opportunity to provide feedback on the service, details of a contact to call if problems occur and a plan for physical and emotional support.**
- **The patient passport that has guided patients through their treatment is constantly updated online with the contact numbers of medical professionals that people can contact if they feel that late effects from their treatment are emerging.**
- **Patients are automatically recalled for regular check-ups.**

‘If you have got this core of five or six people that you deal with and you then maybe come back 18 months, 2 years later and there have been changes there should be new names in there for you to contact.’

‘Automatic recalls for check-ups instead of having to wait for the appointment to come. It should all be just sent on a computer system.’

5.3 Making decisions about end-of-life care

People want more support to be able to make their own decisions about end-of-life care and would like the environment and setting of hospices to be carefully planned.

Vision for 2017

- **People with terminal cancer are told immediately and sensitively by their key worker. They are also told all of the options, including living wills, and treatment opt-out clauses, which can be used without pressure from family, friends or the medical professionals. If they choose to do so, they can have a session with the key worker and family members, so that everyone is aware of what is happening. Alternatively, the key worker is available to meet with close family and friends (with the patient's permission) to answer any questions they might have and give advice about discussing end-of-life issues.**
- **People have the option to express their wishes either directly to health professionals or indirectly through written or online methods. The person with cancer is given a final wishes package, which helps them to share things such as what song they would like played at their funeral or final messages to their loved ones, without any awkward conversations.**
- **Hospices are set in 'beautiful and tranquil surroundings' with ready access to counselling services as well as other facilities.**

'[they could] issue you [with] a software pack, it would be a very standard format you could update, and it is automatic, so that you could say, you could put down your own ideas and views, what your wishes would be, so that you did not have to go through discussing with other people and members of family.'



Italian
The
with love

How to make the best of both worlds

By [Name]

It's a common mistake to think of Italian food as just pizza and pasta. In reality, it's a cuisine that's as diverse as the country it comes from. From the hearty stews of the north to the light, fresh dishes of the south, Italian food has something for everyone. And now, with the help of a few key ingredients, you can bring a taste of Italy into your own kitchen.

Ingredients: 1 lb. ground beef, 1/2 cup onion, 1/2 cup garlic, 1/2 cup tomato sauce, 1/2 cup Italian sausage, 1/2 cup mushrooms, 1/2 cup spinach, 1/2 cup cheese, 1/2 cup herbs.

Instructions: 1. Brown the beef in a large skillet over medium heat. 2. Add the onion and garlic and cook until softened. 3. Add the tomato sauce, Italian sausage, mushrooms, and spinach. 4. Simmer for 10 minutes. 5. Top with cheese and herbs. 6. Serve hot.

By [Name]

For more recipes, visit [Website]

6. The views of people affected by cancer: prevention and awareness

Many people felt they had not accessed much information in terms of cancer prevention except in very general terms – if you eat more fruit and vegetables, don't smoke, and drink moderately then you are less likely to develop cancer. People often don't follow these guidelines anyway – 'cancer is something that happens to other people'.

Vision for 2017

- **There is better awareness of the symptoms and the wider impacts of cancer through national education campaigns. These dispel the myths and stereotypes associated with cancer. They are informative and interesting, and use a plain English no-nonsense approach that reaches across the generations. It is supplemented by targeted education work in schools.**
- **People receive regular 'health MOTs' to ensure that cancer symptoms aren't missed. This is an annual, non-invasive health check for all ages, designed to pick up any abnormalities.**
- **There are training camps for people who are most at risk to help them to give up smoking, take exercise etc. People who want to change their lifestyle, but lack the knowledge, confidence or inclination to do it on their own can sign up, or might be referred by their GP.**
- **Super nutritional foods are available that prevent cancers forming. There's a tax on unhealthy, carcinogenic foods.**

'A screening programme, you get a letter saying drop in at your nearest diagnosis centre.'

'Finding people who are possibly at risk, at high risk.'

7. Cross-cutting themes

As well as identifying how specific aspects of cancer care would need to change in 2017, the participants highlighted some fundamental changes that would need to be made across the whole system in order to deliver their future vision. These cross-cutting themes included:

Providing people with cancer with all the information they need to make decisions and take control of all aspects of their cancer journey

For example this would include providing a full information pack at diagnosis – including up-to-date, personalised information – that could be shared with friends and family and available in different formats. It would provide people with:

- Information about their type of cancer and treatment options.
- A key to technical terms.
- Information on a range of treatment options and their repercussions/side effects with regular updates.
- Contact details for local support groups and other emotional support.
- Information about benefits and financial support.
- Suggestions about where to go to find out more information for example reliable websites.

People with cancer would also need to be given:

- A patient passport. This would be a summarised version of their medical notes, which they can carry with them to all appointments across all departments, saving the need to repeat information each time. Full notes would also need to be accessed electronically by consultants. After each consultation any new information would be added to the patient's copy.

- Support from a key worker team of three or four people to help navigate the system. This team would be made up of professional nurses and doctors who are 'matched' to the cancer patient in terms of their experience and the profile of the patient. One member of the team would always be on call to ensure that the person with cancer has somebody to turn to at all times.

Changing the relationship between patients and health professionals

This would ensure that people with cancer are treated:

- As individuals, with dignity and respect.
- As equal partners in choices about their treatment.

Medical professionals would be mentored by someone who has been affected by cancer, who provides them with evaluative comments, and helps them to become more sensitive and reassuring to the patients.

Ensuring continuity of care and a more joined-up service

This could be achieved by:

- Encouraging all agencies to work together.
- Ensuring care is provided by the same team throughout the cancer journey.

'I think continuing to see the same oncologist is very important for a patient... I said, "Look, can I just see you and nobody else? You've taken me through this treatment; you've explained everything to me. I've got my trust in you. When I come in for checkups can I just see you?".'



8. Conclusions – people affected by cancer's top ten priorities for cancer care in 2017

At the end of each deliberative workshop, the participants were asked to rate all the ideas they had discussed. The top ten ideas from all the workshops are listed below in order of priority:

1. Regular non-invasive checks to detect cancer early

This includes shorter-term ideas such as an annual health MOT to pick up any abnormalities as well as longer-term ideas for example using advanced technology to reduce the risk of human error in detection.

2. Specialist cancer centres

Cancer is diagnosed and all investigative tests are carried out on the same day in the same place. Referral through a GP is not required so anyone can visit the centre if they are worried about a symptom. People affected by cancer, and their carers, are able to access up-to-date information via digital libraries.

3. Holistic healing centres

Centres or retreats are available for people with cancer and their families and carers. These centres focus on the person with cancer and their carer in a holistic way. They provide an opportunity for people to get away from it all for a day, a week or longer and really concentrate on getting better. They have a very healing environment – lots of plants, water features, a wholefood nutritious cafe, chill out rooms with reading materials and music, relaxing and complementary therapies and counselling or lifestyle advice. The staff in the healing centres focus on the positive elements in people's lives and advise on ways to maximise them. A free nutritional consultation will provide people with a personalised plan to make positive changes to their diets.

4. Key workers for cancer patients

Upon diagnosis, cancer patients are immediately assigned a key worker team of three or four people who they see each time. This team is made up of professional nurses and doctors who are 'matched' to the cancer patient in terms of their experience and the profile of the patient. The key worker team are given training in helping the cancer patient through the experience, for example explaining the various steps they will undertake, remaining positive, being a good listener, offering practical information and support for the emotional, practical and financial impact of cancer. One member of the team is always on call to ensure that the person with cancer always has somebody to turn to.

5. A campaign to inform and educate the public about cancer and destigmatise the condition

This campaign aims to dispel the myths and stereotypes associated with cancer. It shows the wider emotional, practical and financial impact a cancer diagnosis can have. It targets schools and workplaces as well as reaching the general public. It is informative and interesting and uses a plain English, no-nonsense approach.

6. A full information pack for every cancer patient at diagnosis

A standard pack / DVD of accurate and up-to-date information is offered to every person upon diagnosis. There is an insert for each specific type of cancer. The pack or DVD would include:

- Information about your cancer.
- Glossary of key terms.
- Information on the range of treatment options.
- A plan of what you can expect from your treatment options.
- Contact details for local support groups.
- Information about benefits and finances.
- Details of websites you can look to for further information.

7. A patient passport

Summarised medical notes which can be taken to all appointments and across all departments, saving the need to repeat information each time. Full notes could also be accessed electronically by consultants in different departments.

8. Community drop-in centres

The centres provide information, advice and guidance on issues related to cancer for people with cancer and carers for example benefits or work related issues. There is also access to emotional support through in-house counsellors. People can find out about and join support groups, who can hold meetings there. The community centres are located anywhere that's easily accessible in a community.

9. Cancer buddy/mentor

When diagnosed, people with cancer and their families are offered a 'buddy'. This is someone local to them who has had cancer themselves, and for carers it would be someone who has also been a carer. Cancer buddies support the person with cancer and their families through the experience. They offer an opportunity to talk and can also offer guidance and advice. Anybody willing to become a buddy would be able to register their interest. People would be matched up based on characteristics such as location, type of cancer, age and gender.

10. Specific treatment for example a cancer pill

This is a targeted, tailor-made drug treatment with no side-effects for each individual. It enables home-based treatment and care.

9. Taking up the challenge

Macmillan's response by Ciarán Devane, Chief Executive

First of all I would like to thank all the people who gave us their time to help with this project, or to participate in the research. This report could never have been written without their help. The findings clearly show what people affected by cancer want and need. Above all, they want to be treated as individuals, not 'cancer patients', and they want to be able to live their lives as normally as possible with the right support available for themselves and their family.

Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial support and campaign for better cancer care. We aim to act as a source of support and a force for change.

Over the next few years, we will take action to put in place much of what people affected by cancer say they need and want. In fact, we are already prioritising a number of areas, including information and support, healing environments, and financial support and advice. We will push for many of the other ideas to be implemented, either by pioneering services ourselves or by influencing others to take appropriate action, particularly governments and the NHS across the UK. We will share the ideas that fall outside of our remit with others who specialise in these fields, in particular suggestions for new drugs, treatments and diagnostic and screening technologies.

Listed below are some of the things we will be doing over the next three years to turn the vision of 2017 set out at the beginning of this report into a reality.

What will we do to improve emotional support for people affected by cancer?

- We will work with the Department of Health in England to develop a national cancer survivorship initiative. This will address the needs for information, emotional support and self-care when people are living at home after treatment. We will look to develop similar initiatives across the rest of the UK.
- We will pilot services that involve volunteers as buddies and advocates, and we will develop emotional and practical support services for carers.
- We will increase the number, diversity and quality of self-help and support groups across the UK and expand opportunities for people to help themselves and each other through online support.

What will we do to improve practical support for people affected by cancer?

- We will have a benefits advice service in every Primary Care Trust or equivalent across the UK to help people access statutory benefits and other grants. We will expand the financial support and advice we provide by telephone and email and also develop a simple website that will enable people affected by cancer to find out about the benefits they are entitled to.
- We will lobby for better financial information and support for people affected by cancer through our Better Deal campaign. This has a number of strands including better access to benefits, better travel and parking costs, and making it easier for people affected by cancer to get travel insurance.
- We will launch a new programme to help people to return to work after cancer. We will run a campaign, commission research, produce resources for employers and health professionals, and pilot new employment services for people with cancer.

What will we do to improve physical support for people affected by cancer?

- We have already funded over 100 Macmillan environments that provide a healing and comforting space for people affected by cancer to receive information, treatment and care. Over the next three years we will seek to push up overall standards by developing an Environmental Quality Mark and awarding it to cancer centres and facilities that meet the gold standards that people affected by cancer deserve.
- We will help people to manage the side effects of treatment through programmes enabling better self-care and management of symptoms such as lymphoedema and breathlessness.
- We will push for the transition between palliative and end-of-life care to be better managed and for earlier discussions to ensure that end-of-life care is better coordinated.

What will we do to change the way services are provided for people affected by cancer?

- We will develop information materials to help people affected by cancer find their way through the system and cope with the practical and emotional impact of cancer. We will aim to ensure people with cancer receive timely and tailored information, as well as receiving support to interpret that information at key points on the cancer journey.
- We will work with the Department of Health in England and other cancer charities to roll out 'information prescriptions' so that health and social care professionals are able to provide personalised information to patients and carers. We will also explore how applicable the model is to other nations of the UK.
- We are calling for the NHS to introduce routine care plans for people affected by cancer that will result in better coordination and planning of supportive care.

The findings from this report reinforce the message that people affected by cancer place as much importance on personalised care, information and support as they do on improvements in treatment and medical advances. This is central to everything that Macmillan is working towards and we will be working with and for people affected by cancer to make sure that current and future Cancer Plans across the whole of the UK reflect this balance of need.

Ciarán Devane

Chief Executive, Macmillan Cancer Support

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. 1.2 million of us are living with it. We are all affected by cancer. We can all help. We are Macmillan.

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