



# NO ONE OVERLOOKED:

Experiences of **older people** affected by cancer

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

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# INTRODUCTION

**One of the core principles underpinning the health and social care system in the UK is that access to – and appropriate delivery of – the best quality care services is available to everyone. This applies irrespective of race, age, sexual orientation, gender or gender identity, income, disability or religion. And yet, health consistently remains one of the great focal points of inequality<sup>1</sup> and a central concern in public health policy, especially when it comes to cancer.**

In 2015 the estimated number of people living with cancer in the UK is almost 2.5 million. Assuming that all existing trends in incidence and survival continue cancer prevalence is projected to increase to four million by 2030. Considering this, it is vital that the experiences of everyone living with and affected by cancer are taken into consideration so that no one is overlooked, ignored or poorly treated. Robust data about these experiences, therefore, is crucial.

Current methods for data collection about patient experience often target people living with cancer who are easily accessible. The analysis rarely stretches far enough to uncover hidden or latent needs as experienced by ‘too-frequently-ignored’ communities.

What’s more, such quantitative methods only provide a descriptive snapshot without explanations. The drivers of inequalities are likely to be complex and difficult to articulate, resulting in needs that are hidden. By definition, surveys only capture recognised current needs, not hidden or future needs.

Such a lack of evidence into people’s experiences will limit our ability to deliver services which truly reach every person living with or affected by cancer. The knock-on effects could include a lower take-up of services, later diagnosis, and an exacerbation of existing health inequalities.

# OLDER PEOPLE AND CANCER

## Older people make up a large – and growing – proportion of the UK population.

As the greatest risk factor for cancer is age, and more than 60% of everyone with a cancer diagnosis is aged 65 and over, it is critical to understand the needs and experiences of older cancer patients. Currently, some 1.3 million people aged 65 and over are living with cancer in the UK.

Evidence on the experiences of older people living with cancer remains scant. The main source of evidence is the national Cancer Patient Experience Survey (CPES). Since the first iteration of the survey in 2010, successive CPES reports have shown that age has

a significant impact on experiences of cancer services. Sometimes this impact is positive, sometimes it is negative. On many CPES questions, the most positive age group are those in the middle years of life or in early old age; but on some questions, the older age group (those aged 76 and over) are the least satisfied. These findings suggest that there may be important age inequalities<sup>2</sup> in cancer care. However, more research is necessary to fully understand what lies at the root of these results and how to identify ways of addressing poorer experiences and outcomes.

*Rodger, partner diagnosed with prostate cancer in 2003*



# WHAT WE'RE DOING: MACMILLAN'S ENGAGEMENT APPROACH

**There are several broad principles to our engagement approach aimed at tackling health inequalities:**

- To understand the complex issues driving health inequalities and to identify hidden needs, we need more qualitative research that targets specific seldom-heard-from groups of people affected by cancer.
- People affected by cancer are the experts in their experience, and should be equal partners in shaping the future of cancer care. We will support people affected by cancer to prioritise what the most important issues are, identify and test possible solutions, and influence decisions that lead to improvements.
- We will work with a range of partners (including people living with and affected by cancer, researchers, community partners, service providers, and policy makers) to understand needs and co-design solutions that work.

The experiences reported in this document are the first part of this engagement approach for older people affected by cancer. It builds on Macmillan's report, ***The Rich Picture: Older people with cancer***<sup>3</sup> (a document that collated the key available evidence about the numbers, needs and experiences of this community).

In this report we look in depth, in a qualitative way, at the experiences of a sample of older people living with cancer at different points of the cancer journey. Following this, we plan to work with people affected by cancer, policy-makers, commissioners and service providers to develop recommendations and develop interventions that will drive improvements in patient experience and reduce inequalities.

# METHODOLOGY

**To explore the experiences of older people living with cancer, the study was carried out using a bespoke online engagement forum that brought together 50 older people with cancer. Of these participants, 29 were women and 21 were men.**

The vast majority were aged between 65 and 84, but three were aged 85 and over. Many (19) lived in London and the South East, while the rest were distributed across other areas of England, with one participant living in Scotland and another living in rural Wales. Everyone had lived in Britain all or most of their life. The vast majority of the participants were married or in long-term relationships, but 12 lived alone. In terms of their cancer diagnosis and journey, the participants had a complex profile: almost half (23) were diagnosed with either breast or prostate cancer, 13 were diagnosed with one of the eight other most common cancers (colorectal, malignant melanoma, bladder, non-Hodgkin lymphoma, uterus, head and neck, lung and cervical cancer) and a further 18 had another type of 'rare' cancer<sup>4</sup>. As some participants had recurrences of cancer or had more than one cancer and were at different

stages of the journey for each cancer, it was not easy to allocate patients to a particular, single 'point in the cancer journey'. However, the majority of the participants (28) had completed their cancer treatment. Finally, in terms of their general health, 13 participants had a long-standing limiting condition (in addition to cancer) but the majority were fit and active.

In addition, the study included 24 healthcare professionals, diversity specialists and academics with an interest in equality, diversity and cancer.

Over a period of eight weeks, two professional researchers involved participants in 70 qualitative research and engagement tasks (see Appendix 1). Our main aim was to give a genuine voice to participants, and allow them to define and discuss the issues in their own terms.

# FINDINGS

**The findings are presented under the headings: emotional and psychological needs, physical needs, practical needs (including financial and information needs), underlying assumptions and perceptions, and end of life.**

We have presented the findings in this way as the boundaries between treatment (be it curative or palliative), recovery and post-treatment can sometimes be very fluid. Indeed, most of the experiences the participants living with and beyond cancer in our sample discussed (such as not feeling treated like ‘whole people’, lacking knowledge and information, poor communications, not feeling involved in decision-making, etc) were not confined to specific stages. The participants’ experiences also pertained to both primary and secondary care services, as well as to post-treatment and survivorship. Additionally, the same participant could have more than one cancer or have a recurrence, therefore they could be at different stages of the cancer journey simultaneously.

## **a. Emotional and psychological needs**

**The Rich Picture: Older people with cancer** highlighted a number of emotional and psychological needs, including:

- The most frequently reported psychological problems in older cancer survivors are anxiety, depression and loss.<sup>5</sup>
- Older people with cancer can be less likely than younger people to have a support system in place, often because they have lost close family members or do not live close to them.<sup>6</sup>
- Older people frequently report they are concerned that decisions made regarding their treatment lack fairness and transparency. They frequently feel that they are made excessively aware of the costs of treatment and whether they merit the expense of such treatments. This can lead to psychological distress.<sup>7</sup>

### **Communication**

Above and beyond receiving information on clinical matters, most participants in the sample wanted to be treated with empathy, compassion and care. They spoke of the need to not feel rushed, and to have personal introductions to the members of their clinical and nursing team (names, roles and contact details). They also mentioned the need for reassurance, and of wanting to sit in a quiet room afterwards (with a nurse, a cup of tea, and the opportunity to cry and ask emerging questions).

They talked of wanting doctors to listen to them, ask about their concerns and worries, and approach them as 'whole people' instead of mere 'patients'.

**'I was told that I had a lump on my ovary. I said, "Do you mean cancer?" and she said, "We don't like using that word". She said, "We are very sorry. Do you want to call someone?" and then left the room. Yes, I was on my own. Yes, I was devastated. I had no idea that it was anything like this.'**  
(Older woman affected by cancer, 65–79)

**'I wish the consultant had looked at me when he told me I had cancer. I wish he had bothered to look at my scan before I entered the room. I wish he had been able to answer at least one of my questions. I wish he hadn't jumped up and ran out of the room to ask someone else who to refer me to during my consultation instead of doing this before I entered to room. He frightened me.'**  
(Older woman affected by cancer, 65–79)

**'One oncologist did not even look at me. This I found very demoralising. Another made a comment that I would need another reconstruction, just as I was leaving the room. I was gobsmacked, and did not ask her why, but by that time it was too late anyway, as she was shooing me out of the door.'**  
(Older woman affected by cancer, 65–79)

Many participants reported that once the word 'cancer' was uttered, they could no longer hear anything else that was said. Feelings of shock, dread, panic, loss of control, disbelief, anger and deep sense of isolation were reported by most. Participants reported that they rarely communicated their

thoughts and feelings. Indeed, they often recollected how 'composed' they must have seemed, while they found themselves inwardly unable to cope, and surprised at this new vulnerability.

**'I didn't know what to do or who to call, having no-one special in my life and only cousins as relatives. That evening, I phoned two friends and they came round and we all cried. But that journey home alone was the loneliest I have ever felt.'**  
(Older woman affected by cancer, 65–79)

**'I am confident, fairly articulate, with developed social skills. However, I was as muddled, confused and, yes, scared as everyone else. Everyone needs consideration and kindness, not just the patients who go into 'vulnerable patient mode'. Health professionals should get behind the social veneer and treat everyone as a patient who needs careful care and explanations. They should not presume because we ask questions, we understand the answer!'**  
(Older woman affected by cancer, 65–79)

## Support

Many of the participants within our sample felt they would have benefitted from counselling or from speaking to other older cancer patients with the same condition. However, they were rarely directed to such services.

**'I wonder if hospitals could assist people getting together by providing some kind of networking – it shouldn't be too difficult with many people online these days ... I definitely found that talking to other people who've been through the process was invaluable.'**  
(Older woman affected by cancer, 65–79)

Both isolation and caring responsibilities made the cancer journey much more difficult for some of the participants.

**'My first thought when I was diagnosed the first time was how the family would manage if it was the worst scenario. In the second diagnosis, my chief concern was for my husband as he had then been diagnosed with dementia and I was his main carer ... My hospital care was very good, although it was 'cancer' centred. My husband was ill, so I did not have time to attend support groups. More support in the home and an understanding of the problems I faced caring for my sick husband would have gone a long way. These problems were both emotional and physical.'**

(Older woman affected by cancer, 80 and above)

**'I'm also an unpaid carer. I haven't mentioned this to hospital staff, as I'm not sure it's relevant. Perhaps they shouldn't be so coy about asking about personal circumstances, then they could respond more holistically. That was a very difficult part of my cancer experience.'**

(Older woman affected by cancer, 65–79)

**'My partner gave some support but he was rather overwhelmed by it and was working full-time, living an hour away and caring for his own elderly parents. Not easy for either of us.'**

(Older woman affected by cancer, 65–79)

The majority of participants in our sample tried to manage in isolation. This was especially true when they felt that others had already been very supportive during their treatment and they did not want to abuse their

kindness and generosity.

**'The main problems I had happened after the treatment/mastectomy, when I felt other people didn't really want to talk about the cancer as all the visits, hospital treatments, etc, had been going on a long time and I felt that people might get fed up with talking about it. Also, I was trying to get on with my life.'**

(Older woman affected by cancer, 65–79)

**'So many good, helpful people are there at the time of the event but they tend to fade away afterwards. Perhaps the cancer equivalent of AA meetings would be beneficial for support, understanding and continuity.'**

(Older woman affected by cancer, 65–79)

### Post-treatment and survivorship

For most patients (regardless of their demographic profile), cancer does not necessarily end when treatment does. However, this is often the point in the journey where the support needs may seem greatest. This is partly because these needs are the most unexpected (by patients, carers, employers and the wider community) and therefore they are the least catered for. In fact, the participants within our sample said they did not really have time to take stock of the full impact of their cancer until their medical treatment had ended. The reason for this was that until then, they had been intensely dealing with coming to terms with their diagnosis, making practical arrangements during treatments, and focusing on their most pressing physical needs.

**'I didn't anticipate the impact psychologically. I think that happened because of the end state – medically you've had the treatment, you're off on the road to recovery, but it's a road with no signposts. Had I known that bit, I'm not sure I could have been positive, but again, had I known that then, I would probably have taken it on board and figured it into my mind set.'**

(Older woman affected by cancer, 65–79)

For many in the sample, the survivorship period was also marked by a sense of isolation and loneliness. This, sometimes in combination with the practical and financial impacts of cancer and cancer treatment, dented many participants' self-confidence, altered their self-perception, and made it more difficult for them to move forward.

**'The past three years have made me feel very insecure. Operations, change of jobs, loss of job, second operation. It took a long time, but talking about my experiences has helped me come to terms with my illness. It has been hard to look forward to the future. I have been taking it each day at a time, but we are now planning ahead, talking about holidays, etc. I have never been a positive person. The glass is always half empty. I think my attitude has got worse since my illness. I am sometimes sharp with people, don't listen and argue at the slightest comment. I am working on this. I have always woken up feeling negative, but recently it's getting worse. Once I'm up, I am okay, could be better though. This is the most difficult time: I just want to enjoy life again, and I am getting there slowly, but I'm determined to succeed.'**

(Older man affected by cancer, 55–64)

## **Self-image**

For some participants within the sample, cancer and its treatments had impacted very negatively on their self-image, their feeling of being physically attractive, their interest in sex and their sexual performance.

Concerns and difficulties were noted mainly by men affected by prostate cancer, women who'd had mastectomies, women who had lost their hair, anyone with noticeable surgical scars or stomas, and anyone who'd put on a large amount of weight.

**'I feel the biggest worry is the change in me, I feel physically and mentally drained. I do have problems sexually and I am getting help from my doctor. I think it's a confidence issue, although I do look after myself and feel I can overcome that.'**

(Older man affected by cancer, 55–64)

**'It is only recently that I have openly acknowledged my serious issue with my negative body issue. I was aware of this before but it was more subconscious. Thus, I did not raise this as an issue when I received counselling. I think counselling before a double mastectomy would make a patient more at peace with their decisions if things go wrong. Post operation 'ugliness', I really don't know what can be done about that. Perhaps specialist counselling?'**

(Older woman affected by cancer, 65–79)

One man specifically joined the online engagement forum because he was interested in learning from the experiences of other men with prostate cancer who had also lost some of their

sexual functions. Yet, some participants in the sample believed that there was very little knowledge and advice among healthcare professionals about sexuality in old age.

**‘Sex and the over 80s is hardly ever enquired into, on the assumption that it isn’t there. It might be. Don’t be party to killing it off because of embarrassment or assumptions. Advice on new ways to express an old attraction is humane and rehabilitative after cancer. I have no idea what the sexual repertoire of the over 80s might be, but anyone might like advice after pelvic radiation or abdominal surgery.’**

(Academic/researcher)

## b. Physical needs

**The Rich Picture: Older people with cancer** highlighted a number of physical needs, including:

- Even when corrected for tumour characteristics and co-morbidities, studies indicate that older people are less likely to receive intensive investigation and treatment, and are more likely to be admitted as emergencies.<sup>8</sup>
- Older people are less likely to receive radical surgery than younger people.<sup>9</sup>
- Radiotherapy is used less often on older patients.<sup>10</sup>
- People with cancer aged 65 or over are significantly under-represented in cancer clinical trials.<sup>11</sup>



## Age as a risk factor

Older participants in the sample tended not to be aware that age itself is a key risk factor for cancer. They were aware of various lifestyle factors (eg. smoking, drinking, obesity and being overweight, diet, and physical activity), but not specifically of age. Because they underestimated the risk in their age group, they may have been less alert to the signs of cancer as a result, leading to potential delays in diagnosis. There was, however, a much greater awareness of the risk of breast and prostate cancer than of other cancers more common in old age (such as ovarian, bladder, lung, pancreatic and colorectal cancers).

**'Where is the National Awareness and Early Detection Initiative (NAEDI) work that targets men and women aged over 75, who are at greatest risk of cancer? Older people may not know that cancer is even a possibility. Older women at risk of breast cancer often don't know increasing age is a key risk factor.'**  
(Academic/researcher)

**'The skin cancer was a surprise. The prostate cancer seems to be 'par for the course' for many elderly men.'**  
(Older man affected by cancer, 80 and above)

## Symptoms

Many participants reported difficulties in identifying signs of cancer. In the context of comorbidities, the normal aches and pains of ageing, and a general decrease in memory and attention span, the focus on the discrete symptoms for each cancer is problematic at prevention stage. This is in stark contrast to an incidence of recurrence or secondary cancer, when survivors should indeed

be given detailed lists of symptoms to watch out for.

**'We may have additional ailments like arthritis, rheumatism and dementia that complicate matters and may mask cancer symptoms and make it more difficult to identify them.'**

(Older woman affected by cancer, 65–79)

**'Despite my medical background, I was unaware of ovarian cancer symptoms. I just thought it was symptoms of getting older and something I would have to put up with.'**  
(Older woman affected by cancer, 65–79)

## Diagnosis

The majority of participants in our sample reported being diagnosed within 14 days of first seeing their GP (due to an urgent GP referral because of suspected cancer). This was most likely to be the case for those with breast, prostate or skin cancer. However, a large minority of participants had been to their GPs on several occasions before being referred to a specialist. The problems were especially serious for cancers that are less common in the population as a whole, but either frequent in old age (eg. lung, bowel, ovarian, and bladder cancers), rare or asymptomatic.

**'Once a tumour was suspected, I saw a colon consultant within a few days and the gynaecologist consultant within a week. However, it took six months and several visits to the GP to get to that point. It was frustrating to know something was wrong and not getting a diagnosis for six months. By the time I had symptoms, the cancer was already advanced [Stage 4].'**  
(Older woman affected by cancer, 65–79)

**'Because I looked well, the early GP consultations were not taken seriously enough and my condition was put down to being post-menopausal and related to age rather than requiring further investigation. It was only when I was referred to a female GP that things changed for me and womb cancer was diagnosed after referral – and 10 months on from my initial consultation.'**

(Older woman affected by cancer, 65–79)

Given that many health problems tend to increase with age, some participants within our sample (especially those with less common cancers) were diagnosed incidentally, while already in hospital being seen for other conditions or undergoing tests for other complaints.

**'The doctor called it an 'incidentaloma'. "What's that?", I asked. "Oh, a tumour that shows up when we're not even looking for it.'"**

(Older man affected by cancer, 65–79)

A number of participants were also diagnosed through the emergency route, either because they were not referred by their GPs (despite numerous appointments) or because they found themselves suddenly unwell, having hitherto been asymptomatic.

**'For 18 months, I went to my old GP. For months, I was breathing with difficulty. He was more worried about my cholesterol level than my voice or breathing. I had blood tests that did not pick up cancer. I came downstairs one day, got out of breath and someone called an ambulance. That was a Thursday. On Friday, I had SOS surgery to enable me to breathe. A biopsy was done. On the following Tuesday,**

**I was told I had Stage 4 throat cancer. An operation was scheduled for the following Friday.'**

(Older man affected by cancer, 65–79)

These findings are in line with national evidence on the routes to diagnosis of cancer patients.<sup>12</sup>

### Postponing treatment

In our sample, a handful of participants opted to postpone their treatment. This was the case when they were about to have invasive surgery or to start a course of chemotherapy (usually for the second time), which they knew would be taxing. They preferred to enjoy greater 'quality of life' for some time or to tend to family obligations before starting their treatment.

**'I had three resections of the bowel caused by adhesions and the histology report said the cancer has spread to the surface of the liver. The oncologist wanted me to restart the chemo in June but I was so sick of it all, I said I wanted to travel as much as I could before it killed me. I am currently on my last trip to visit good friends in the USA and due to start on Carbo/Caelyx on 24 October.'**

(Older woman affected by cancer, 65–79)

**'I waited a year for the operation to remove my colon. My daughter was getting married that year so I had a lot to keep me occupied to start with. After the wedding, I told her and she was devastated and scared she was going to lose me. But it is only then that I had the operation. I understood that my cancer was not life-threatening and that other people were more important.'**

(Older woman affected by cancer, 65–79)



**'Prior to having a second cell transplant, I discussed with my consultants the possibility of delaying it as I felt I needed a little more quality of life before undergoing this procedure again. Based on our discussions, I decided to postpone it for a short period, enjoy the summer months and have the treatment in the period November to January. A decision that I do not regret at all.'**

(Older man affected by cancer, 65–79)

### **c. Practical needs**

**The Rich Picture: Older people with cancer** highlighted a number of practical needs, including:

- Fewer older people receive information from hospital staff about financial help and benefits than other age groups.<sup>13</sup>
- There is a lack of information and knowledge given to older patients and carers regarding their follow-on care.<sup>14</sup>
- Older patients are less likely to seek additional information to

that provided by their healthcare professionals. For example, many older patients with breast cancer say that they would prefer to receive information face-to-face from healthcare professionals rather than from leaflets or websites.<sup>15</sup>

- Of those who need it, fewer people receive information about financial help and benefits from hospital staff than any other age group. Around 48% of those aged over 75 received this information compared to around 83% of those aged 16-25 and over 60% of those aged 26-65.<sup>16</sup>
- Older people are particularly likely to be sensitive to the stigma associated with means-testing of certain benefits.<sup>17</sup>

### **Finances**

With some exceptions, the participants in our sample rarely experienced serious financial setbacks as a result of their cancer. Most were financially at ease, married, independent, active and well supported by their spouse. However, the participants who lived alone, were unwell, poorer or not

independent talked of not wanting to 'trouble' relatives or friends by asking them to drive them to or accompany them on their appointments. Participants with caring responsibilities also found it difficult to attend appointments. With lower levels of energy, these additional logistical problems deterred some from seeking medical appointments. These issues impacted across the entire journey.

**'There is an interplay of different things. We have more time but less energy. We may no longer drive and friends are older too, so getting around is much more difficult if family are not nearby. Caring for a partner may take precedence over our own health concerns.'**

(Older woman affected by cancer, 65–79)

### Level of involvement

Some participants commented on the fact that older people are often less assertive, more likely to trust their doctor, to feel that 'doctors know best' and to be happy to go along with their decisions. They also felt that this attitude needed to be challenged and that older patients needed to be empowered to ask more questions and to demand more of their doctors. They felt this was especially important as many older people are not able to navigate the health service by themselves or access information and support on their own.

However, in our sample, the 'doctor knows best' attitude was not prevalent. On the contrary, most participants were uneasy about being assigned the role of 'patient' and all but one wanted to be involved in decisions about their treatment and care. They recognised the expertise of professionals, but believed they needed to be genuinely consulted and involved in decisions about their

treatment, not just merely informed about decisions made elsewhere about them.

**'I have largely been an onlooker at the dramatic spectacle of my various conditions and treatment. This is hard to take. I want to be fully involved, treated as an equal participant in the drama. This is not simply about choice, but about informed choice ... Other than requesting the briefest of summaries of my current symptomatic condition, none of my doctors have, at any stage, asked me if there is anything I would like to say or ask. They have never encouraged me to contribute to the discussion. None of them have appeared in the least interested in hearing from me. It is demeaning and disempowering. It is probably also clinically negligent, as it fails to explore the patient's side of the story.'**

(Older man affected by cancer, 65–79)

**'I was diagnosed with prostate cancer. After a bone scan and MRI scan, I was told that my lymph nodes were clear. A second MRI scan was taken in six months later. I was then told the cancer had spread to my lymph nodes and this would prevent me receiving radiotherapy or an operation. I was not happy because they were comparing images from different cameras and hospitals. The differences were very minute. I paid to see a consultant privately for a second opinion and the scans showed my lymph nodes were clear and I should be allowed to receive radiotherapy – the treatment I wanted.'**

(Older man affected by cancer, 65–79)

The participants who had been fully informed and consulted on their needs and preferences found the experience positive and empowering; they were less distraught overall and had a sense of control over their condition and treatment. They were much happier with the care they received than those who were not fully informed and consulted.

**'My consultant actually talked about monitoring my health as a joint partnership, which felt enormously supportive.'**

(Older woman affected by cancer, 65–79)

**'I have received clear and honest answers to my questions, and my views have been taken into account when issues of management were decided on. I have seen no one who treated me just like a set of cancer symptoms but rather as someone who could and wished to be informed and involved in what was happening ... I have nothing but praise for my doctors.'**

(Older man affected by cancer, 65–79)

### **Practical support and assistance**

Participants in the research felt very strongly that, as a counter for the potential vulnerability of illness and old age, older cancer patients should systematically be offered to be accompanied by health advocates or 'cancer buddies'. They felt this to be especially important for patients who do not have access to a Clinical Nurse Specialist.

**'To be old and to be ill both undermine our ability to speak for ourselves, to understand complex information, to absorb unwelcome news, to question advice, and to explore alternatives. To be both**

**old and ill is doubly challenging. So older patients should have the support of a partner, a buddy, a personal advocate.'**

(Older man affected by cancer, 65–79)

**'People who cannot assert their needs should have an advocate, whether it is your partner, family member or very good friend, a chaplain or someone from the local cancer advocacy service. Someone who is with you for appointments and can discuss what was said with you afterwards. Someone who helps you track your treatments and medication and can encourage you to speak up and back you up if you have any questions or concerns. We need to be told about advocacy and support services when they do exist, for this to be offered without waiting for us to ask.'**

(Older woman affected by cancer, 65–79)

### **Discharge arrangements**

Very few participants had had a proper discussion with their doctors about their long-term needs or a holistic needs assessment, and no one was aware of any geriatric input at this point. Virtually no one had received a treatment summary on discharge – although once patients heard that this was possible, they typically found this to be an excellent idea and were prompted to request one. Similarly, no one was given a 'care plan'.

**'No discussion at all, apart from the GP telling me to get on with my life. Didn't know getting a treatment summary was an option. I have no named person but if I need help, I need to go through my GP – but don't.'**

(Older woman affected by cancer, 65–79)

**'My consultant told me I was now discharged and he wouldn't expect to see me again. I felt abandoned and told him so but he said the stoma nurses were on hand if I needed any follow up. I wasn't aware that I could get a treatment summary. The hospital stoma nurses are no longer available to me without a GP referral, so there is no key worker.'**

(Older woman affected by cancer, 65–79)

Similarly, relatively few participants had a named person whom they knew, who was familiar with their medical history and who they felt comfortable to contact if the need arose – except for their GP. They would have liked to be able to discuss their cancer-related concerns in depth with someone, to be able to get advice, to be guided through complex services and to be made aware of what relevant advice and help was available to them.

**'I would like to have a named person who knows my medical background that I could speak to if I'm in trouble or just need reassuring.'**

(Older woman affected by cancer, 65–79)

**'I emailed the Consultant Radiologist asking if he could explain to me why my CT scan in April said I was clear yet one in June said the cancer had spread. Sadly he didn't reply ... That's when you feel you would need someone at the hospital, someone who knows you, who can find things out for you.'**

(Older woman affected by cancer, 65–79)

### Recurrence and detection

Many participants reported that they had deep anxieties about the possible recurrence or spread of their cancer. They felt powerless because they did not know how to recognise the signs of cancer, despite sometimes having explicitly asked their doctors for such information.



**'I have asked why I and others like me seem not to have instruction in just what to look for, but was fobbed off with remarks about how "self-examination doesn't really work" and, "you will have a mammogram". I did ask twice for specific instruction but got only evasion. I believe that a few minutes' instruction might be very helpful.'**

(Older woman affected by cancer, 80 and above)

**'The main problem was NHS staff telling me to get in touch if I had any symptoms but, when I asked what they might be, I got no real answers. This was more worrying than anything for a while. I kept wondering what might be important and what might not. I got sent quickly for tests last year when I found blood when I went to the toilet and told to keep an eye on things, and here we are again!'**

(Older woman affected by cancer, 65–79)

**'My colon is removed so I have to assume there will be no symptoms in that area but how do I know the cancer is not lurking elsewhere? It is always in the back of my mind it could crop up elsewhere.'**

(Older woman affected by cancer, 65–79)

**'I don't know what symptoms to look out for and, now that you raise the matter, I had better find out. I wonder who knows?'**

(Older man affected by cancer, 65–79)

### **Information**

There appeared to be very little lifestyle information and support specifically tailored for older people living with cancer. The key reason was that the advice was simply too generic to be

of any real practical use to individual patients. They needed a personalised assessment and very specific guidance on what would work for them.

**'Physio and exercise: 'exercise regularly but don't overdo things' is not good enough. What kind, where, when, for how long? Who tells you that you can get GP referrals to your local leisure centre? Who tells you about Survivorship Assessments and cancer rehab classes where they exist? You may have to source this info yourselves.'**

(Older woman affected by cancer, 65–79)

### **d. Underlying assumptions and perceptions**

***The Rich Picture: Older people with cancer*** highlighted a number of underlying assumptions and perceptions, including:

- While approximately 35% of young women report being worried about wasting a doctor's time this figure is closer to 70% for older women. Older women are therefore more likely to be diagnosed at a later stage as many of them will delay visiting the doctor when they suspect something is wrong.<sup>18</sup>
- For many older people with cancer, their biggest concerns are being able to take care of themselves and feeling they are still in control of their health and decisions. Cancer treatment may interfere with their ability to cook and eat independently, wash and bathe independently, and walk, drive or access transportation.<sup>19</sup>

- Many older people felt that professionals did too little to uncover information from them which would have helped in planning their follow-on care. It was felt that professionals neglected to ask about the type of support network the patients had.<sup>20</sup>

### Attitudes to aging

The participants in our research – especially those diagnosed in their 70s and 80s and those with prostate or breast cancer – were more likely to feel that illness was part of growing older.

**‘Neither cancer was devastating. The skin cancer was a surprise but the hospital has been wonderful. I have had a check-up every four months since 1986 (recently reduced to every six months). The prostate cancer seems to be ‘par for the course’ for many elderly men, and I was lucky not to have the active version.’**

(Older man affected by cancer, 80 and above)

**‘I am amazed at the things people elect to do when faced with limited time, but we have had a good life and I am quite content to chug along as we are. I do not have any sense of ‘unfinished business’ for myself, my husband or my sons and their families.’**

(Older woman affected by cancer, 65–79)

National cancer screening programmes have upper and lower age limits which differ over different cancers. Those who are older than the upper age limit can usually choose to opt back in to each programme. For those that don’t, there is a risk that cancer could be missed

and, as a result, could be diagnosed at a more advanced stage, once cancer becomes symptomatic and more difficult to cure.

**‘A diagnosis of cancer in an older person is very unlikely to be a screen-detected early diagnosis because of upper age limits on screening. So cancer gets diagnosed only once it is symptomatic, often at a very advanced stage, when it is more likely to be incurable.’**

(Academic/Researcher)

Upper age restrictions on cancer screening contributed to the low awareness that old age is a risk factor. This led some older people to assume that they were no longer at risk of cancer when they got older, since they were no longer called in for screening.

There was also some lack of clarity on the reasons why the age restrictions on screening varied in different parts of the UK and concern that financial factors, rather than strictly clinical considerations, might account for these differences.

**‘Why does screening stop after a certain age? There is a lot of debate about screening ages. It is different in different parts of the UK. Why? It is confusing and it makes you think that you are not at risk after a certain age, or maybe that the NHS does not want to spend money on older people.’**

(Older man affected by cancer, 65–79)

### Barriers to presentation

In addition to practical barriers, there was some limited evidence of attitudinal barriers to early presentation among the participants within the sample.



In a handful of cases, participants delayed making an appointment with their GP to investigate abnormal symptoms.

**'I should have listened to my inner voice and been more proactive and returned sooner, but I didn't want to bother the doctor.'**

(Older woman affected by cancer, 65–79)

Except in a very small number of cases, participants in our sample were unable to say whether they had been refused treatment or services specifically because of their age, but assumed that they had not. They often felt that this was because they were comparatively young, 'fit', 'alert', 'able to stand up for themselves', 'articulate', 'middle class', 'educated', 'informed', 'aware of their rights', 'strong enough to say "no" to doctors', etc.

**'I may have received better treatment than others. I live in an area where the local hospital is a major teaching hospital with excellent Urological and Oncology Depts. As a result, the quality of the facilities and the level of care provided were of the highest level. Being a [retired] doctor, I was very aware of the nature of my condition and its management, and was familiar with the setting in which I was being treated. This helped in being able to establish a good relationship with those responsible for my care, and become very much a partner in the decision making process.'**

(Older man affected by cancer, 65–79)

## Chronological age and treatment options

However, participants were worried about other older people, and about themselves in the future, should their own physical or mental health deteriorate. They talked about older people who are elderly, frailer, less confident or assertive, poorer, those living alone or in communal establishments and those with no family nearby and no one to advocate for them. They were also concerned about older people with multiple or complex conditions or mental health difficulties, those who are not mobile, and those who cannot use computers to access information or support. They were not sure that these people were getting the quality of treatment and care they deserved. In some cases, these concerns were based on witnessing how older relatives had been treated.

**'I have not experienced favourable or unfavourable treatment on account of my age. I am 68, articulate, well informed and able to speak up for myself. Even so, I have sometimes struggled to be heard by doctors who don't listen. This experience suggests that if I was older, less articulate or more ill, I could expect poorer treatment and consideration. That is an uncomfortable thought. Esteeming age should be a matter of professional pride and practice. Why can't we be confident that it is?'**  
(Older man affected by cancer, 65–79)

**'If you have no family looking out for you, either because they live somewhere else or are working during the day, all sorts of things can be happening on the ward or at home ... My mum was treated**

**very badly in another part of the country when she was in hospital with lung cancer in a very advanced state. I had to stay with her all day to make sure she could eat, asked for her to have a drip when she got dehydrated from not eating or drinking and other issues around her diet.'**

(Older woman affected by cancer, 65–79)

A key concern, among the participants with cancer, healthcare professionals, diversity specialists and academics, was that healthcare professionals used patients' chronological age in making clinical decisions, and that this could easily lead to under-treatment. This was perceived partly to be due to age discrimination and partly a matter of assumptions about older people made by healthcare professionals when making treatment decisions.

**'At my local hospital, there certainly appears to me to be 'age discrimination'. I was told at the beginning of my journey that if you are aged 70 or older, or have a life expectancy of less than 10 years, certain procedures would not be available to you. As yet, I have not experienced any discrimination, but as I am now 72, I certainly could come under the umbrella of '10 years or less life expectancy.'**  
(Older man affected by cancer, 65–79)

**'I recall being offered adjuvant chemo and being told if I was older and not as fit, it may not have been offered. This would have an impact on others, not me, but I did think it seemed unfair to them. I did wonder what would have happened if I had been 75 and not 65?'**  
(Older woman affected by cancer, 65–79)

Some in the sample explained that this could be due to the lack of evidence on the clinical response of older cancer patients (itself due to the lack of recruitment of older patients into clinical trials), as well as well-intended specialists seeking to minimise the potential harm caused to patients by aggressive treatment. However, concerns remained that decisions were too often made based on assumptions by doctors rather than clinical evidence, and also without the informed consent and full involvement of older patients (or their proxies). It was deemed imperative to carry out more clinical and social research on the elderly.

**'Whenever there is research with older people, it's all low-hanging fruit ... We should promote much more actively clinical trials among the elderly to improve the evidence base ... There is an under-developed clinical research agenda in elderly people with cancer, resulting in badly researched treatment options in the very elderly, in a disease of ageing.'**

(Academic/researcher)

For the participants in our research, the most important issue was that they (either themselves personally or their families or proxies if they could no longer decide for themselves) should be fully informed of all their treatment options and told of the potential benefits and risks, so that they could make informed decisions. They wanted to be reassured that every aspect of their treatment and care, across the entire cancer journey, was designed to promote their best interests.

**'Age is just a number. Why should the NHS give age as a reason for either withholding more expensive**

**treatment or not operating on someone?'**

(Older woman affected by cancer, 65–79)

**'I think that the patient should be taken into account by health professionals. Not just the condition, not a collection of symptoms, not simply test results, not only the treatment, but the whole patient – a real person just like them, someone with a body, a mind, values, feelings, fears and dreams. There is no place in the NHS for negative discrimination on grounds of a patient's identity. If a patient's age, needs, abilities and disabilities, beliefs, sexuality or language call for enhanced or different care and treatment, it should be provided. Health professionals must listen as well as talk, to understand special needs. That entails knowing the individual patient, not simply their socio-demographics.'**

(Older man affected by cancer, 65–79)

**'Age and perhaps complex health issues are relevant to treatment. Some of the treatments are so aggressive; it's hard even for a 'healthy' body to cope with. However, all treatment options must be discussed with the patient, if possible, or relatives. Health professionals must always be guided by the best interests of the patient. This is what I expect now and in the future for myself.'**

(Older woman affected by cancer, 65–79)

## **e. End of life**

### **'Dying well'**

While more and more people survive cancer, death from cancer remains a reality for many older people. Many of

the participants found it difficult to talk about end of life and to discuss their concerns and preferences. Only 16 out of 50 participants answered questions about what 'dying well' would mean to them.

**'Can't think about this too much. I don't want to die. I want to be with my family here in this life. I hope I can stay at home right until the end. I'm sorry that is all I can say right now.'**  
(Older woman affected by cancer, 65–79)

In terms of older people's wishes and preferences, it seems that almost all the participants wanted to die in a manner that resembled as closely as possible how they lived. This can mean with loved ones around them, usually at home, without pain, with dignity, in a 'homely' environment, and with as much control over the situation as they could have.

**'Friends that 'have died well' seemed to not change that much when they were close to death as when they were well. So maybe my answer to your question is that I hope I die as I live, if that makes sense.'**  
(Older man affected by cancer, 65–79)

**'For me to die well, I must first feel that I have lived well. I try as much as I can to make the most of this extra time I have been given.'**  
(Older man affected by cancer, 65–79)

For some, there was a great deal of concern and care for those around them. They wanted to ensure that they would not burden them with their death, but also that the circumstances of their death would enable their loved ones to express their love and care.

**'Thinking about 'dying well' relates both to myself and those closest to me. For myself, in common to most others I'm sure, I would wish to have a death free from great physical discomfort and suffering, be at peace with myself and without a fundamental change in my personality and ability to relate to those around me, and be well cared for in a setting in which I felt 'at home'. For those closest to me, I would wish that the manner of my death would be free from undue suffering and personal demands, and experienced in a way that they would feel they had been able to contribute to my comfort and peaceful end through the expression of their support and love.'**  
(Older man affected by cancer, 65–79)

### **Over-treatment against a patient's wishes**

While participants were concerned with possible under-treatment and poorer access to services (as discussed earlier), they were also worried about over-treatment and the artificial prolongation of their life. In the same way that they argued for the right of all patients to be treated as fully and aggressively as they wanted to, they argued that all patients should have the right to decline treatment if they wish to.

**'I expect equality for all in pain control, dignity, and end of life care. Equality does not always mean to save life at any cost. Individual circumstances need to be taken into consideration. For example, is it fair to subject elderly people to surgery and chemo to extend life for a short while? I would want to make my own decision and, if not capable, then trust my family.'**  
(Older woman affected by cancer, 65–79)

**'If a person wants to be treated, then they should be. If not, then this should be respected as well.'**

(Older woman affected by cancer, 65–79)

### **Lack of planning for 'end of life'**

Only a few of the participants who answered questions on end of life had made practical arrangements and explicitly communicated their wishes to their family and healthcare professionals. Those who had made such arrangements were typically elderly participants (those aged 80 or over), those with recurrent or secondary cancers, those with life-threatening cancers, or those undergoing treatment. They reported that having 'their affairs in order' brought them a good deal of peace of mind.

**'Although, at the age of 87, I still enjoy life, I have made arrangements for my funeral – chosen the hymns and the readings, as well as preparing other necessary information both for the funeral and, more generally, for my wife. Like everyone else, I hope to die quickly when the time comes – this is part of 'dying well'.'**

(Older man affected by cancer, 80 and above)

**'I would like to die organised and tidy and to take as much stress out of it as possible for those left. I have a funeral plan paid for, Living Will, Power of Attorney and Order of Service in place. My mother had severe dementia, I learnt from that experience. I strongly believe that I should be able to control my own peaceful exit.'**

(Older woman affected by cancer, 65–79)

**'I have produced a first draft of 'Advanced Care Planning' with my lovely hospice nurse. This has been circulated now to family members and we have discussed it with them and the implications. It felt quite good to have made a first stab at it.'**

(Older woman affected by cancer, 65–79)

But many respondents in this older sample (including an 85-year-old woman with a life-threatening cancer) still did not have adequate, explicit and formal arrangements in place. They typically felt that they 'ought' to be dealing with this, but simply could not face the prospect.

**'I would want to have my affairs in order, to declutter my home and the masses of stuff and paperwork I have in it. This would clear my mind and give some peace of mind.'**

(Older woman affected by cancer, 65–79)

**'I know that I ought to be thinking about this but I don't seem to address it effectively at present, ie, I prefer not to dwell on this.'**

(Older woman affected by cancer, 80 and above)

### **Uneven quality of care in different settings**

All participants in the sample wanted to have some control over where they would die.

**'A good death is pain free, dignified and takes place in peaceful surroundings, hospice or home, definitely not hospital.'**

(Older woman affected by cancer, 65–79)



**'I would want to be comfortable, sympathetically cared for in an attractive room with a view to the outside, and able to see family and close friends if strong enough to do so: a good hospice would seem to fit the bill.'**

(Older man affected by cancer, 65–79)

Two participants wanted to die alone in a hospice to avoid burdening their loved ones with the distress of seeing them pass away and to be 'helped' by nurses to pass away.

**'As and when my time comes, I do not want any of the family there to witness the ending hours. So I would like to have any medication available to me so I just fade away peacefully, like going to sleep but never waking up. This may be best in a hospice surrounded by the angel nurses who make passing easier ...'**

(Older woman affected by cancer, 65–79)

**'I would like to die fairly quickly and not linger on. I do not wish to be a burden on anybody; lingering deaths cause your immediate family too much of an inconvenience.'**

**I have told my family just let me die and don't feel you need to hold any bedside vigil, etc, for me.'**

(Older man affected by cancer, 65–79)

Some in the sample suggested that all patients should have the right to choose where they will spend their final days. However, they did not think that older cancer patients would access the same quality of end of life palliative care and other forms of support in all environments.

**'I work in a hospice and I don't see a lot of difference between older and younger people. I think the meaning of dying well is different for each person. One person may accept not having 24-hour care at the end of life if they can die at home with their dog next to them; another may only feel safe if they can die in hospital/hospice/nursing home and have their symptoms managed as aggressively as possible. [What matters is that all hospices can provide for these different needs].'**

(Health practitioner)

### **Inadequate pain control**

The themes of pain and pain control also dominated the responses of participants. For those prepared to discuss end of life, pain control was a clear priority. The thought of being in pain in the final days of life was a difficult and terrifying one.

**'I have been giving a lot of thought to this one. To 'die well', to me, means lying in my bed in no pain, with my husband, son and daughter with me. 'In no pain' being the operative phrase! Pain is what I'm frightened of.'**

(Older woman affected by cancer, 65–79)

**'I hope to die at home, pain free, and quickly. My worst nightmare is a lingering death.'**

(Older woman affected by cancer, 65–79)

**'I would hope to be fully alert but free from pain.'**

(Older woman affected by cancer, 65–79)

### **Emotional and spiritual support for patients and loved ones**

Some professionals within the sample agreed that provisions for end of life tended to focus predominantly on the immediate physical health needs of the dying, rather than on their emotional and spiritual needs. They also agreed that the focus was largely on the patients themselves, and that more could be done to support carers and loved ones.

**'There must be a lot that can be done to prepare cancer patients psychologically to begin to think about their own mortality, by providing sensitive emotional support, information, financial help, reassurances that loved ones will be supported, etc. Psychologically and practically, death raises many questions both for the dying person and for those who care for or about them. Facilitating informed choice for patients and carers must be paramount, but there is also a need to address the more complex issues around finding meaning and purpose, and reaching a resolution or closure to enable everyone to make sense of the situation and to move on well.'**

(Academic/researcher)

Information, advice and support should not end with the death of the patient. Older cancer patients want to minimise the burden of their death on their loved ones. Knowing that the latter will be supported after their death – with practical arrangements, emotional and spiritual services – would be reassuring to older patients reaching the end of their life. It would also help carers and loved ones to cope with the many difficulties surrounding death.

# WHAT MACMILLAN WANTS TO DO

**We know that this is only part of a much bigger story around the experiences of older people living with and affected by cancer.**

In order for this work to continue to explore and understand the needs of older people with cancer, Macmillan wants to:

- continue to work with older people living with and affected by cancer, using their experiences to identify health inequalities and variation in experience. Together we aim to co-design solutions, and influence decision-makers at local, regional, and national levels to tackle health inequalities.
- continue our work with multiple partners and stakeholders within the community to develop and strengthen our knowledge around the experiences of those who are living with and affected by cancer.
- continue to provide support for older people living with and affected by cancer to develop their skills, resources, and confidence to self-organise and use their experiences to influence decision-makers.

## WHAT CAN I DO?

Macmillan is currently working with a newly established Expert Reference Group (ERG) for older people. A taskforce made up of older people affected by cancer is exploring how they can feed in their experiences to shape the work of the ERG's programmes. With this in mind, we would like to invite older people living with and affected by cancer, as well as health and social care professionals, to join this taskforce.

If you would like to get involved and help shape the future of cancer care for older people, please contact us at [researchlearning@macmillan.org.uk](mailto:researchlearning@macmillan.org.uk)

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# References

1. The Institute of Health Equity. Fair Society, Healthy Lives: Marmot Review <http://www.instituteofhealthequity.org/Content/FileManager/pdf/fairsocietyhealthylives.pdf>
2. Cancer inequalities are 'the differences between individuals' cancer experience or outcome which result from their social-economic status, race, age, gender, disability, religion or belief, sexual orientation, cancer type or geographical location.' (Report of the All Party Parliamentary Group on Cancer's Inquiry into Inequalities in Cancer, 2009).
3. <http://www.macmillan.org.uk/Documents/AboutUs/Research/Richpictures/update/RP-Older-people-with-cancer.pdf>
4. The numbers add up to more than 50 because some patients had more than one type of cancer.
5. Holland J, et al. Psycho-oncology. 2010. OUP, New York.
6. Cancer.Net. Cancer in older adults. American Society of Clinical Oncology, USA. 2010. [www.cancer.net/sites/cancer.net/files/cancer\\_in\\_older\\_adults.pdf](http://www.cancer.net/sites/cancer.net/files/cancer_in_older_adults.pdf) (accessed September 2014)
7. BRAP/Macmillan Cancer Support. Walking into the unknown – Survivors and carers speak out on discrimination and inequality in cancer care services. 2011.
8. Foot C, et al/The Kings Fund. How to improve cancer survival: explaining England's relatively poor rates. 2011. [http://www.kingsfund.org.uk/publications/cancer\\_survival.html](http://www.kingsfund.org.uk/publications/cancer_survival.html) (accessed September 2014)
9. NCIN. Major surgical resections, England 2004-06. [www.ncin.org.uk/view.aspx?rid=540](http://www.ncin.org.uk/view.aspx?rid=540) (Accessed September 2013)
10. Turner N, et al. Cancer in old age – is it inadequately investigated and treated? British Medical Journal. 1999. 319: 309-12.
11. Cancer.Net. Cancer in older adults. American Society of Clinical Oncology, USA. 2010. [http://www.cancer.net/sites/cancer.net/files/cancer\\_in\\_older\\_adults.pdf](http://www.cancer.net/sites/cancer.net/files/cancer_in_older_adults.pdf) (accessed September 2014)
12. [http://www.ncin.org.uk/publications/data\\_briefings/routes\\_to\\_diagnosis](http://www.ncin.org.uk/publications/data_briefings/routes_to_diagnosis)
13. NHS England. Cancer Patient Experience Survey 2013. The Impact of Age. <http://www.qualityhealth.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports> (accessed September 2014)
14. BRAP/Macmillan Cancer Support. Walking into the unknown – Survivors and carers speak out on discrimination and inequality in cancer care services. 2011.
15. Breakthrough Breast Cancer. APPG on Breast Cancer. Age is Just a Number. 2013. <http://www.breakthrough.org.uk/sites/default/files/media/Campaigns/Age%20is%20just%20a%20number%20-%20APPG%20report%20on%20older%20people%20and%20breast%20cancer.pdf> (accessed September 2014)
16. NHS England. Cancer Patient Experience Survey 2013. The Impact of Age. <http://www.qualityhealth.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports> (accessed September 2014)
17. Roberts E, et al/The Kings Fund. Briefing note: Age discrimination in health and social care. 2000. <http://www.kingsfund.org.uk/publications/age.html> (accessed September 2014) (64)
18. Breakthrough Breast Cancer. APPG on Breast Cancer. Age is Just a Number. 2013. <http://www.breakthrough.org.uk/sites/default/files/media/Campaigns/Age%20is%20just%20a%20number%20-%20APPG%20report%20on%20older%20people%20and%20breast%20cancer.pdf> (accessed September 2014)
19. Cancer.Net. Cancer in older adults. American Society of Clinical Oncology, USA. 2010. [http://www.cancer.net/sites/cancer.net/files/cancer\\_in\\_older\\_adults.pdf](http://www.cancer.net/sites/cancer.net/files/cancer_in_older_adults.pdf) (accessed September 2014)
20. BRAP/Macmillan Cancer Support. Walking into the unknown – Survivors and carers speak out on discrimination and inequality in cancer care services. 2011

# Appendix

Below is an overview of the engagement exercises that participants took part in.

## Final Task Plan

### Macmillan research into inequalities in experiences of cancer services

WEEK	TASK TITLES	ALLOCATION	RESPONSES
Wk 1.1.	Getting to know you	All participants	Open
Wk 1.2.	Your needs and expectations of this community	All participants	Open
Wk 1.3.	How did you hear about us?	All participants	In private
Wk 1.4.	Overview of your cancer	PLWC only	In segment
Wk 1.5.	Thinking about cancer	All participants	In segment
Wk 1.6.	Getting the language right	All participants	In segment
Wk 1.7.	The Wheel of Life	PLWC only	In private
Wk 2.1	I am ...	PLWC only	In private
Wk 2.2	A picture is worth a thousand words	PLWC only	Open
Wk 2.3.	Your body	PLWC only	In private
Wk 2.4.	Take a peek and share	PLWC and Professionals	In segment
Week 2.1.	Life at work	Professionals only	In segment
Week 2.2.	A picture is worth a thousand words	Professionals only	In segment
Week 2.3.	Working on health and equality	Professionals only	Open
Week 2.4.	Case study: Sam	Professionals only	Open
Wk 3.1.	Dear Diary ...	PLWC only	In private
Wk 3.2.	Tips to doctors	PLWC only	In segment
Wk 3.3.	Your initial reaction	PLWC only	In segment
Wk 3.4.	Timing can make a big difference	PLWC only	In segment
Wk 3.5.	Navigating the system	PLWC only	In segment
Week 3.1.	Breaking the news	Professionals only	Open
Week 3.2.	Late presentation and diagnosis	Professionals only	Open
Week 3.3.	Late treatment	Professionals only	Open
Week 3.4.	Case study: Omar	Professionals only	Open
Wk 4.1.	Holistic approach to individual needs	PLWC only	In segment
Wk 4.2.	Information and resources for patients	PLWC only	In segment
Wk 4.3.	Involvement in decisions about care: survey	PLWC only	In private
Wk 4.4.	Involvement in decisions about care: survey	PLWC only	In private
Wk 4.5.	Involvement in decisions about care: blog	PLWC only	In segment
Wk 4.6.	Thinking about the end of life	PLWC only	In segment
Wk 4.7.	Thank goodness ...	PLWC only	In segment
Week 4.1.	Holistic approach to individual needs	Professionals only	In segment
Week 4.2.	Information and resources for patients	Professionals only	In segment
Week 4.3.	Involvement in decisions about care	Professionals only	In segment
Week 4.4.	Case study: Susan	Professionals only	In segment

WEEK	TASK TITLES	ALLOCATION	RESPONSES
Wk 5.1.	The impact of cancer on people around you	PLWC only	In segment
Wk 5.2.	Support for people who care about you	PLWC only	In segment
Wk 5.3.	Adjusting to life once treatment is over	PLWC only	In segment
Wk 5.4.	Being active in the community	PLWC only	In private
Wk 5.5.	Then and now	PLWC only	In segment
Wk 5.6.	On balance, I feel ...	PLWC only	In private
Wk 5.7.	Bin it!	PLWC only	In segment
Week 5.1.	The impact of cancer on people around older cancer patients	Professionals only	In segment
Week 5.2.	Support for people who care for cancer patients	Professionals only	In segment
Week 5.3.	Adjusting to life once treatment is over	Professionals only	In segment
Week 5.4.	Being active in the community	Professionals only	In segment
Wk 6.1.	Should 'equality' matter?	PLWC only	In segment
Wk 6.2.	Discrimination based on age a) What else could explain poorer experiences or outcomes? b) What else could explain poorer experiences or outcomes? c) What else could explain poorer experiences or outcomes?	PLWC and Professionals	In segment
Wk 6.3.	Your public health campaign	PLWC only	Open
Wk 6.4.	Why do perceived inequalities exist?	Professionals only	In segment
	Managing difficult situations	Professionals only	In segment
Wk 6.5.	Your public health campaign	Professionals only	Open
Wk 7.1.	Your shout	PLWC and Professionals	Open
Wk 7.2.	Top three lessons	PLWC and Professionals	Open
Wk 7.3.	A cup of tea with your doctor	PLWC only	In segment
Wk 7.4.	Message in a bottle	PLWC and Professionals	In segment
Wk 7.5.	I pledge ...	PLWC and Professionals	In private
Wk 7.6.	The last word	PLWC and Professionals	Open
Week 7.3.	Professional engagement and capacity building	Professionals only	Open

'Open' means that all participants assigned this activity can see and comment on other participants' posts.

'In segment' means that if participants share a segment, they can see and comment on other participants' posts.

'In private' means that no one apart from the posting participant can see the answer. Some tasks can ONLY be set as private (such as 'Mark Up' tasks or surveys).

When you have cancer, you don't just worry about what will happen to your body, you worry about what will happen to your life. Whether it's concerns about who you can talk to, planning for the extra costs or what to do about work, at Macmillan we understand how a cancer diagnosis can affect everything.

No one should face cancer alone. So when you need someone to turn to, we're here. Right from the moment you're diagnosed, through your treatment and beyond, we're a constant source of support, giving you the energy and inspiration to help you take back control of your life.

For support, information or if you just want to chat, call us free on **0808 808 00 00** (Monday to Friday, 9am–8pm) or visit **macmillan.org.uk**