

Supplement 4: Illustrative Quotations

Key Themes	Illustrative Quotations
<p>Experiences of treatment</p> <p>Impact of treatment</p> <p>Initial treatments and support provided by clinical teams earlier in the trial were described as having resulted in small improvements for some participants' cancer symptoms. These symptoms mainly related to difficulties eating.</p>	<p><i>I know when I started, I had difficulty swallowing obviously with the oesophagus tumour and it was sort of every meal, every few mouthfuls was getting difficult and I did find in about two weeks into the first cycle, I was pretty much able to swallow normally. So, something positive is happening'. Participant 4 (2-3 months)</i></p> <p><i>I had a tube fitted in my arm yesterday, ready for the chemo on Friday, and I've got a feeding tube, so I don't have to worry about not getting enough nutrition in, so I think a lot of worries I had at the beginning have faded. Participant 6 (Baseline)</i></p>
<p>Side-effects from treatments</p> <p>Side-effects from chemotherapy</p> <p>Participants described common side-effects they experienced after receiving chemotherapy including muscular fatigue, pain and neuropathy in their feet, while most of which were expected some they were unexpected.</p>	<p><i>The side effects I've had are quite sore feet at one stage when I was on the chemotherapy, which was difficulty walking. Participant 7 (3 months)</i></p> <p><i>Cos everybody expected when I stopped the chemo, especially me. I thought that was it (laughs), you know stop the chemo and that's fine. And, then I stopped the chemo and I got ill (laughs). Patient 6 (6 months)</i></p>
<p>Four patients reported that during the trial their chemotherapy treatment had been changed or stopped due to pre-existing conditions, side-effects that they had experienced or that it was not making enough of a difference to their cancer</p>	<p><i>During the 1st cycle ... the pain in my feet and little bit sort of pins and needles like that, I think that's the worst side effect that I have experienced... Tiredness, you know, I just feel worn out... the other thing that I get is almost like fatigue in my thighs... I think one day where I felt sick which is just cleaning my teeth. Participant 4 (Baseline)</i></p> <p><i>I found the capecitabine taking those every day I think they were the hardest of the drugs that I was taking... I did notice with them the nausea and the sickness and the fatigue was massive. When, they put me on [another chemotherapy drug] ... I felt it was much gentler... unfortunate[ly] for me... having a blood clot... I think that was the worst thing... the blood clot was harder to recover from than the cancer (laughs)'. Participant 4 (3 months)</i></p>

outcomes. One participant described the unforeseen development of thrombosis after switching the types of chemotherapy they received due to the initial side-effects. This demonstrates the complexities some patients face when weighing up the side-effects of different chemotherapy regimens.

Side-effects from radiotherapy

The experience of receiving radiotherapy was reported by most patients as being physically and psychologically arduous. Difficulty and pain swallowing experienced after radiotherapy were the main side-effects described by several patients.

Companion: The last week of September that he couldn't eat... and that's why they stopped the treatment too early... and that tails off then because he has a dose of steroids and it boosted his appetite and it boosted everything.

*Patient: There were huge difference because of steroids... that was before all the, the pneumonia came on... that was again the weeks following the treatment which I believe happens. **Participant 1 (6 months)***

*After they took the test at the end of just one cycle and they said it hadn't made enough difference so it was being changed. **Participant 3 (2-3 months)***

The first chemo I was on, they had to change... I've got... Neuropathy... So, they changed it. And, another one was because of my kidneys. They changed that to a different one right at the very beginning.

Participant 5 (3 months)

*Because of what the radiotherapy does, it sort of burns all the inside and it's very difficult to swallow... but that was the worst thing to be perfectly honest with you, the thing is I would like to be able to eat like I used to, but at the moment I can't but I am getting there... definitely tons better now. **Participant 2 (2-3 months)***

*With the radiotherapy... I was completely and utterly flat out, nothing mattered at all... You can't win it at any point... you can't concentrate or want anything, you feel bad if there is no pain, nevertheless you feel dreadful. **Participant 1 (6 months)***

*Once radiotherapy started I could feel then that the inflamed and the tumour and the oesophagus, I could feel that it sort of was creeping back to where I was before and it just got a little harder to swallow but not to the extent that I couldn't eat. **Participant 4 (6 months)***

*It's worse right now but then we've only just finished radiotherapy, it's very tender right now, it's burning from inside out... the consultant did say... I've been trying to get on pulses, semi solids... It's not how thin or thick it is it's the texture of it, whether it'll slide down or it won't slide down, so every now and again I experiment sending something down there. Sometimes I can do it but this particular week it's been difficult, but the consultant explained to me "I'm full up of chemo and I'm full up of radiotherapy and everything's pretty raw right now". **Participant 8 (3 months)***

I just have a slight problem with swallowing sometimes but that's they say that's to do with the radiation but it didn't stop me eating what I want, I just have to make sure I chew it properly that's all. **Participant 9 (6 months)**

Recovery after chemoradiotherapy

After the completion of chemoradiotherapy, during the recovery period, participants experienced symptoms which ranged from mild to severe, having physical and psychological outcomes. Nausea, as well as fluctuations in appetite, weight and energy levels were reported by participants, often relating to pain and issues swallowing. Some participants recalled having to adapt to the fatigue caused by difficulty sleeping and pneumonia. Participants' symptoms tended to lessen over time, and when they had received support to reduce these symptoms they usually recalled noticeable improvements. It was not always possible to differentiate between the longer-term impact of chemotherapy or radiotherapy treatments, as participants described their symptoms more generally.

I lost my appetite a bit, but, ... that's come back now, and ... I am starting to regain weight... I still have problems digesting food ... some foods just get stuck in my oesophagus, and that is still a little bit painful. **Participant 7 (3 months)**

I had pneumonia... I started with the infection as soon as I finished the chemo... I was in hospital for a week. And, I had about four different courses of antibiotics and they just weren't working on the pneumonia. And, I felt worse with that than I had been through all the treatment. And, I was just starting to get better before we went away... within days I suddenly was much, much, much better. **Participants 6 (6 months)**

I had trouble sleeping for quite some time and that sorted itself out now and can sleep perfectly well now without any paracetamol at all, so night-time is good. **Participant 1 (2-3 months)**

The treatment make[s] you very tired... I have to rest a lot and whilst, I think to myself I feel really good today lets go out. When I have out a couple of hours I have to come home, even now you know it tires me, but that's fine. Things improve on a daily basis and hopefully it will continue to improve. **Participant 2 (3-6 months)**

I had some constipation, I have to admit and that's been an issue throughout... I had to listen to my body and you know rather than fighting sleep, rather than thinking that you know I am going to battle this, sometimes you just got to shut your eyes and think you know what I will sleep all day, doesn't matter. **Participant 4 (2-3 months)**

The fatigue, the tiredness... did seem to last a little bit longer than I really anticipated... you know some days I didn't feel like lifting my head off the pillow... I think the fatigue was a biggest one for me. **Participant 4 (6 months)**

I'm getting stronger in myself as well, so. And, the treatment has gone and I'm getting taste back, so I can taste things better than I did. You know cos just drinking. Just drinking water, it wasn't very nice, but it's alright now. Participant 5 (2-3 months)

I had nausea, tiredness has been the biggest one for me... it's slowly improving, I'm not dropping off to sleep as I'm talking to people type of thing now, but that was happening, (chuckling)... I've started to eat again, tiredness is the main thing, but nothing that I can't cope with and was expected, they told me that I would be, my body's going to, gotta kind of repair itself a bit now... I'm still taking the anti-nausea medications, but I have reduced them... I've still got the RIG feeder in, so, I'm trying to wean myself, at the moment, off it. So, I'm starting to try and take some of my medications orally, instead of through the tube. I'm on a lot less medication than I was. Participant 6 (3 months)

I was sleeping up to 17 hours a day ... which is... I've spoke to the people down there and they say that's a natural side effect, but it happens. Participant 7 (3 months)

Treatment impact over time

Participants reflected on their cancer treatment journey and how their symptoms had changed over time, including facing adversity throughout treatment regimens gradual improvements.

At the time during the treatment ... I've felt really, really, really ill, worse than before I started the treatment... The treatment was tough... I have [had] a lot of symptoms, side-effects from it. But those have finished now, so obviously things are improving... when it finished I was having problems... but each day I'm getting better. Participant 5 (3 months)

I'm just feeling better every day and my eating is improving all the time. Participant 6 (6 months)

I feel a lot better. Obviously the time I was diagnosed it was a bit of a bolt out of the blue and I was left you know in big, big shock. So, the fact that they've now said to me that the cancer's gone, it's obviously a huge relief. Participant 7 (6 months)

In some instances, however, participants described the reality of the unexpected longer-term side-effects of the illness and treatment, emphasising the need for ongoing support and updates from healthcare professionals.

I was quite euphoric all the way through the treatment and it was after the treatment ended that I sort of thought it's all over now. The fatigue, the tiredness [will] all be going and it did seem to last a little bit longer than I really anticipated and unfortunately the wound with the blood clot still hasn't healed. Participant 4 (6 months)

Patient: No interest at all in checking my general condition which could have changed because of the treatment ...

Companion: And you just hope that all the drugs are compatible...

They all interact with each other and that is another hurdle. Who knows?...

*Patient: It's thousands of, it's thousand of trials. How can you do it, interaction of drugs is a massive problem being tackled all the time. **Participant 1 (2-3 months)***

Information and support needs after treatment

Concerns were raised by several participants and their companions regarding what would happen post-treatment, as they felt that there was less information and support available than before and during their treatment. A need for further and more timely information and updates from healthcare professionals regarding potential longer-term side-effects including rare events such as blood clots and recovery timescales post-treatment was also expressed by participants.

*We actually felt we have huge information on side effects during treatment but virtually nothing on after [treatment]. **Companion of Participants 1 (2-3 months)***

When it comes to this particular type of blood clot I had, there was nothing, no description there and I suppose if I could sort of say anything about the website- that's the one thing they missed because all the symptoms I read about were symptoms that were associated the side effects of the drugs as well.

Participant 4 (6 months)

*The fortnight before we draw the line for the end of treatment as to how things are likely to move on and likely tests and however... some sort of framework... As it is, we haven't got any date at all for anything beyond next Friday, week Friday, nothing at all... We didn't have a cohesive view on the whole thing presented by one person anyway, it was bits and pieces. **Participant 1 (2-3 months)***

*Companion: Its general advice be kind to yourself for few months (coughs) and then you should begin to feel stronger or sleep more than you would have done so that your body recover. So the body has had fair hammering... It isn't just the 10 weeks when you take the chemotherapy challenge is it? It's much bigger picture. **Participant 1 (2-3 months)***

It's all been a bit strange because, I had to come off the initial chemotherapy drugs. It was sort of we will have to take you off the trial but still keep collecting the data from the trial and I understood that because... I think trials have to be very specific and if you stay outside the guidelines then it does blur the data... I don't know whether I will be monitored a little bit extra. I don't know whether I am assuming when I go back to check up in six months there would be the same questionnaires and the same sort of things.

Participant 4 (6 months)

Participants described difficulties with eating and dietary needs, and expressed the

One thing that I asked all along was really about how much I could eat, we have been asking, haven't we? You sort of [know] it is going to get more difficult, is my throat going to be smaller, will it get bigger again,

importance of being provided with relevant information regarding how the disease or treatments impacted on these fundamental needs.

Several participants described a high level of personal support from clinical and third sector services, which made a significant impact on their trial experience. They described how they had received support relating to their quality of life and practical needs, which they may not have accessed from healthcare professionals.

Patient outlook and quality of life

Psycho-social impact of treatments

The psycho-social impact that some patients experienced in the first few months following treatment included disinterest or

*how much will I be able to eat? Will I be able to eat properly at the end and I think that all out questions have been like that. **Participant 3 (2-3 months)***

*I have phone calls from the clinical nurse... sometimes just to ask how I am, he's helped to make appointments for me when I've had problems making them myself. And he's managed to make everything seamless from one thing to another, which I greatly appreciated, because I was a bit all over the place, especially at the beginning of diagnosis... if [clinical nurse] thought that maybe I wasn't getting something, that the Oncologist was saying to me... maybe sometimes I was lacking a bit of understanding and he always made sure that I left that room, understanding everything. **Patient 6 (3 months)***

*Age Connect, Age Concern one of those we have used their advice a few times. Just popped in and seen them... has been very, very good as a system for us. **Participant 4 (6 months)***

*The medical staff have really been great, and ... I've got all the information ... all I need to do is pick the phone up and I know I can speak to somebody with any questions ... I have been in contact and ... am on various forums with Macmillan, ... which ... my wife and I have accessed quite frequently ... just to view other peoples' experiences, which has been good, because obviously whatever side effects you're having, there's always somebody else who's had them as well... it reinforces and puts you at ease really to see other people have gone ... through the same thing. **Patient 7 (3 months)***

*Somebody did contact us from Macmillan right at the very, very start. He went through all sort of social things like... carers allowance and things like that and that's one of the things that I got to say that we were very, very grateful for... The information was fantastic and you know lots of the sites were really really good... I think I read along from the Macmillan website because that was quite sympathetic. **Participant 4 (2-3 months)***

*Things that I would have done, I am a cellist, I play cello and other things and no way completely uninterested, stopped, books and all I read stopped. **Participant 1 (2-3 months)***

lack of energy to participate in hobbies and social activities that they had previously.

*I suppose it has affected my social life ... I don't really [go out]... at the moment, I've only just started going out perhaps socially a little bit more. **Patient 7 (3 months)***

*In my previous life basically, I was able to do a bit... of online communicating with people not that I felt like chatting to them but you know, I could keep [up] with things... to be done by phoning them, or writing to them, or visiting. **Participant 3 (2-3 months)***

Gradual improvements to quality of life

Participants explained how the treatment had impacted on their quality of life overall. Their physical health post-treatment had placed restrictions and strains on their everyday routines. At times they felt they had relied heavily on their family for support with daily activities. Gradual improvements to participants' health and well-being related to readapting and regaining their capacity to participate in previous routines and social activities.

*My wife has done everything for me and is very, very protective... I do think it would have been lot tougher if I had been on my own. My daughter stepped in and did all the work... she moved heaven and earth to make sure that for the last three months she was available... There were days when I [said] "it's okay, let me drive" and getting back into that was a biggish step but now I am back into driving. **Participant 4 (6 months)***

*I've seen a daily improvement, day on day something else seems to improve... I could eat things today that I couldn't eat yesterday. It's an ongoing thing but it's an onwards and upwards kind of feeling. Today I'm going to my granddaughter's birthday and tomorrow I'm going out with friends. I couldn't do that a couple of months ago... starting to get back to normal now. **Participant 6 (3 months)***

*I say we are completely together, and I have completely depended on (names wife)... I been thinking very much about this, see people on a walk, people who are old, and they have nobody at home and they have to go back to an empty house as well and that's terrible you know at the end of the day its absolutely awful and I have been much aware of this and seen this kind of and there are simply people who are by themselves... how would I have coped that it not been for the kind of relationship. **Participant 1 (3 months)***

*My middle daughter, the nurse, when I didn't know what I was doing at the very beginning, she came with me to the, to the clinics and to the meetings... and asked the questions that I didn't know what to ask or wasn't aware to ask at the time. **Participant 8 (3 months)***

*It's been very tiring ... my wife and I, we do like to do a little bit of walking and that. I obviously haven't been able to do anything like that. **Participant 7 (3 months)***

Adaptation and normality

Regaining a sense of normality was important but complicated for several participants when re-adapting to life after treatment, as their daily lives had been significantly impacted by their experiences of cancer and treatment. Some participants explained that they struggled to readjust to life after treatment, due to the change in outlook that they needed to make or the extra support that they had been provided with during their trial until that point but was no longer receiving.

*I think there was a feeling of... as if you were left on your own. You get that initial feeling because the 12 weeks of treatment were so intense... we were in the hospital everyday, sometimes twice a day and then you know it's off you go then. It been couple of months now rest, recuperate relax, get back to normal life and I found that quite a strange statement and I got to admit that's perhaps the hardest thing to do now was getting back to normal life. **Participant 4 (6 months)***

*The days and the nights are not the same at all and you don't see people and you miss all your normal, normal things that you do certain days and certain, lose all your fixed points (laughs). **Participant 1 (6 months)***

*I have found that because we actually went in on Saturday night, for the first time it was to a function, a dinner and I said "I am coming but I don't know how long I can stay" and we stayed until 12'oclock, had a really nice time and then the next day I went out again to a food ... Had a fabulous weekend it was really nice, to break the mould to being ill.... I probably paid for that because I had couple days where I have needed to rest a lot, you know, that's fine. **Participant 2 (3-6 months)***

*I do think back fondly because you sort of make acquaintances with people... I saw the same people 5 weeks, every day of the week. We got to know each other, we got to chat, we got to talk about our cancer, we got to talk about our treatments and how tired we were. You know we got to sympathise and carers got a chance to talk to carers and have laugh and have a little fun and have a giggle and what you have been doing today, bit of gardening you know those sort of things and roaring with laughter sometimes so that's, that's how I have handled it. **Participant 4 (6 months)***

*Well you got to keep cheerful. It's not... been easy. It's been bit of a struggle getting back to normality but... we getting there.... It been couple of months now rest, recuperate relax, get back to normal life and I found that quite a strange statement and I got to admit that's perhaps the hardest to do now was getting back to normal life... I am sort of getting to the point where I am starting to feel better my wife is noticing that I am feeling better ... I do a little bit of help around the house and do little things... So that's the thing now getting back to normality. **Participant 4 (6 months)***

*I am getting back to normality then. **Participant 7 (3 months)***

Positive outlook after treatment

Several participants described how they attempted to sustain a positive outlook about their survival prospects and their circumstances overall, as a coping mechanism. Thus, being provided with adequate support and information aided their positive outlook.

Impact of COVID-19 pandemic Vulnerability and isolation

*I'll tell you one thing that I don't know whether you come across this a lot, but when I went to see the consultant he told me that the cancer had gone I expected to feel quite elated, but I didn't... if anything I felt sort of a bit down and I don't know why... And, my wife felt the same as well. **Participant 7 (6 months)***

*Physically, I probably feel better, I feel good, no problems... I am getting back to normal, I am really where I was before the treatment. My social life and my family life, yes, is back to where it was, it's normal, quite happy it didn't make any different after the treatment. **Participant 9 (6 months)***

*Things improve on a daily basis and hopefully it will continue to improve. I don't like it (laughs)... yeah a lot (laughs), yeah but that's fine you know, there will come a day when it will be fine and I will be able to go [out] again, so I will just wait for that day. **Participant 2 (3-6 months)***

*Mentally... I have got no problems at all, never had, also with treatment I didn't have any difficulties that way, I knew what was happening, I was aware of it, and all it was about just waiting for the outcome. **Participant 9 (6 months)***

*We are not doom mongers... I don't particularly think it will [be] good, it will [be] bad. It will be as it is. I really don't think I am bothered in that sort of sense at all what's going to happen. It's just a treatment. **Participant 1 (2-3 months)***

*I... try to keep healthy, try to keep active you know and I also try to have a very positive outlook ... I think that's the huge thing during the situation is to be positive, to be hopeful. I constantly say to people I have not got the time to worry, I haven't got the energy to worry. I need all my energy now to look after myself to get better. Its pointless panicking, its pointless crying, its pointless breaking down and saying what if and why and I think a big part was accepting that, yes I got cancer, yes I going to have to go through the treatment... I think a lot of the stories about the treatment were horrendous. I haven't felt that as yet. **Participant 4 (2-3 months)***

*I feel a lot better. Obviously the time I was diagnosed it was a bit of a bolt out of the blue and I was left you know in big, big shock. So, the fact that they've now said to me that the cancer's gone, it's obviously a huge relief. **Participant 7 (6 months)***

Some participants reflected on how the pandemic may have intensified the sense of isolation and stress that other patients felt during their treatment process, although these participants did not feel personally affected in this way.

When you were sat in radiotherapy and chemo, some people probably needed somebody with them in chemo, I didn't... but there were people that were a lot sicker than I was I suppose pre- Covid you could have a friend with you to keep you company through the day. Participant 8 (3 months)

It's not nice sometimes when you've got to go through things on your own, where you like having your partner sitting outside the door, but I don't think it's affected my treatment. Participant 6 (3 months)

When we were filling in the clinic surveys... isolation wouldn't have been isolation if it hadn't have been for Covid... Covid had an influence on everything... From times of clinics to staff levels to... it was an influence on everything. Participant 8 (3 months)

The pandemic caused an increased sense of vulnerability and cautiousness amongst cancer patients. However, the comprehensive social restrictions put into place for infection control, and the vaccination programme at times, eased the sense that some of these participants missed out on their usual social activities.

I haven't been out since the beginning of Covid... it's been isolation all the way... if everybody else wouldn't have been in isolation as well, I suppose it would've affected me more but because everybody else was in isolation... I don't suppose it bothered me that much, no, I was quite comfy that everybody else was stuck in as well. Participant 8 (3 months)

Everybody's been really cautious around me; you know any family members that were coming here were doing lateral flow tests before. And, I still wear a mask wherever I go... we went away on holiday other people weren't wearing masks, when they were going to the bar or the restaurants, but I was. There is a bit of anxiety, but I'm double vaccinated. I still go to shops and stuff, but I do get a bit of a rumbly tummy if I'm around people and they've not got masks on. Participant 6 (6 months)

I've read ... which could have made me more vulnerable to Covid... to counter that ... I had my two vaccines ... quite quickly because... of the cancer I've had, so that most probably countered that bit ... the stress of that ... against catching the Covid. Participant 7 (3 months)

You've gotta wear masks and things like that... So, obviously you couldn't go out as much... Whilst you're going through treatment I didn't wanna go anywhere anyway, so the.... Coronavirus didn't affect me, very, very little. Participant 7 (6 months)

Potential Improvements

Sharing information among peers

Opportunities for participants and their caregivers to share information regarding

I think there should be opportunities where people that have been through [cancer treatment]... share maybe positive experiences, can also point people in the direction you know? ... I think there is an

their experiences of cancer and their treatment pathway through peer support networks were suggested as a means of improving patient knowledge.

Follow up information

Follow up information regarding the participants' current cancer status, as well as results from the trial, were desired by a participant, who felt that they were unsure about their personal outcomes or how this related to the wider trial.

opportunity there maybe a support network of people's needs, need to be arranged. Participant 4 (6 months)

Did they tell me it was a 70/60 chance... they said to me they can burn it away... if it's not burnt away why not, you know what I mean? I think it should be followed up and I suppose my question to follow onto that would be, would we, the participants be able to see the outcome of your survey? Participant 8 (3 months)