

Section 10

Advice to others in the future: The benefit of hindsight

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Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common responses were that participants wished they had known what to expect from their condition (e.g. symptoms, side effects of medication) (n=11, 22.45%), and they wished they had known to be more assertive in relation to understanding treatment options and discussions about treatment (n=11, 22.45%). Other themes included participants described that there is nothing that they wished they new earlier (satisfied) (n=9, 18.37%), and wished they had know the early signs and symptoms of the condition (n=7, 14.29%).

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common theme was that they would have liked more time and personalised attention with specialists (n=10, 20.41%). There were 8 participants (16.33%) who would not change any aspect of treatment or care without giving a reason, and 8 participants (16.33%) who would not change any aspect of treatment or care because they were satisfied with care and treatment received. Other participants would have liked to have had a better understanding of their condition (n=6, 12.24%), and would have liked more support for side effects of treatment (n=5, 10.20%).

Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common responses were that participants wished they had known what to expect from their condition (e.g. symptoms, side effects of medication) (n=11, 22.45%), and they wished they had known to be more assertive in relation to understanding treatment options and discussions about treatment (n=11, 22.45%). Other themes included participants described that there is nothing that they wished they new earlier (satisfied) (n=9, 18.37%), and wished they had know the early signs and symptoms of the condition (n=7, 14.29%).

Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)

PARTICIPANT: Oh. I wish I'd known about blood in urine. Mm hmm. And maybe what it looks like an actual representation of what it really looks like. Because for women with gynaecological, you know, we don't always put it down to that. But, you know, to say that it could present, like, a UTI or something like that. You know, so those that would have been good.

INTERVIEWER: Because you would have gone to the doctor sooner.

PARTICIPANT: Yes.

INTERVIEWER: Yes. Okay.

PARTICIPANT: Cause I didn't have any pain at all, so I didn't think about it, you know, potentially being as UTI, because that's what I, you UTI down to. But, um, also after, I think, um, I would like to have known a bit more about the bag before I met with the stoma nurse two days before the surgery. No. Actually, I met her one day before the surgery and she marked up my stomach and basically said, this is likely where you're bag's going to be. But it would have been good to meet with them beforehand. And I suggest this to people that I talk to now. Ask for an appointment with the stoma nurse, get a bag, half fill it with water, stick it on your stomach and walk around with it. Try it with clothes that you wear, all things that, you could, you know, you can trial beforehand just to get a feel for things. I would have liked to have had that.

Participant 022_2022AUBLC

Oh, I wish I'd known the side effects of the BCG. That was never explained to me. I was just told that, I was just told I'd be having that. And it was the gold standard. And that may well be that that is most probably true. It is the best treatment. But there was no discussion whatsoever about side effects at any stage.

Participant 008_2022AUBLC

But. Um. Yeah. I don't know. Just probably the extent of the incontinence and the ongoing effect of that.

Participant 027_2022AUBLC

Yes. I wished I'd had a list of potential questions to ask somebody so that I could have gone through those and thought about that. That is now available. And I wished that, that I could have spoken to somebody that was similar to me that had in the bladder. And it wasn't you know, I didn't know how to access that then, but it is now available via via by BEAT. I can I can put people in contact with, you know, people that have had in a similar situation and they can talk with everyone's permission, of course, face to face. And I didn't I didn't have that. And I would really like towards that would have really helped me if I could have sat down with somebody over the phone or over Zoom and, you know, said, you know, okay, you have any ability to tell me what your life is like? And it would have put my mind at ease and and I couldn't do that back then.

Participant 032_2022AUBLC

Participant wishes they had known to be more assertive in relation to understanding treatment options and discussions about treatment

Yeah. Look would it would have changed the public versus private path. But we might have still ended up in private, but we would have journeyed down the public first. Yeah. And yeah, that's probably money and probably just, you know, an estimate of what this would cost on an annual basis to to treat if you kept down the private part. As I said, my wife told me this morning, you know, credible number was 65,000, um, to, to treat bladder cancer over it's over its lifetime out of pocket, that is. Yeah. Now if you'd said to me that in January I got holy crap. Oh, we better go. We better find something sustainable here and go down this path. You still want the urgency to want the quality care, but, you know, the public system has probably better qualified people. Cause they have to deal with everything they see, everything the private people would just do with a niche thing. They might be really

good at what they do. But I only see, you know, only do bladders, only do kidney stones or whatever might be one to get really good at that. But the public system have really broad robust surgeons have to deal with a lot more.

Participant 017_2022AUBLC

Well, I would like to have probably more information on bladder cancer. So that I did get leaflets. But, you know, let's face it, we don't really read as much as we should do. So, you know, I mean, before we did the operation for you know, I would like to have a clearer idea, you know, what if I did have a choice? Basically, I do feel as though I didn't have a choice, you know? Yeah. If you don't do this, then that's, you know, there's no other alternative or whatever, you know. So I won't say I was railroaded into it. But I, you know, it's it's afterwards you think, well, I wish I had a bit more sort of, you know, information. Then, you know, maybe try this for that before, you know. If you know, you were going to have a leg off? Well, you know, before that, is there a treatment for, you know, before you take the leg off?

Participant 023_2022AUBLC

Yes. I think the first time when I was diagnosed, it's a very shocking time. And I again repeated, you know, I wasn't giving almost very little information, you know, that what kind of cancer it is and what are the treatment options? What are the pros and cons? I was just given a phone call. I looked at it, look, we've found you've got cancer. And I think you should go for surgery and. I mean, it should be a face to face meeting with all information like this council. I had to dig for this Cancer Council booklet and you know, okay, so I think when they give the diagnosis, if that is to have a face to face meeting sit down, give me all the written information as much as possible so that the person can immediately start thinking, you know, what, what, what's happening?

Participant 028_2022AUBLC

Participant describes that there is nothing that they wish they knew earlier (satisfied)

No. No, not really. I guess I'd want a treatment that's effective. And I would, um. There's been no other sort of treatments more effective apparently in my type of cancer than the BCG. Um. So, no, I'm happy that I've had the treatment that I've had.

Participant 001_2022AUBLC

Uh, no, probably. As I said earlier, I think probably knowing a bit less is probably better at the initial stage when you're gonna get an operation than that because, um, you know, my friend, I go walking with,

and he's also in the same boat. His urologist said to him, You'll have a very poor standard to life once you get a stoma. And he said nothing's really changed for him, you know, apart from that little bit of extra time and effort that you've got to put in, um, managing it. Uh, but he's his doctor, in all was saying to him, you know, his standard of life, and I know mine's altered, but I don't think it's dropped. I've probably got to look at it differently. You know what? If I've lost a leg or an arm or something like that, I've got to look at life a little bit differently. But your life doesn't drop away because of that. It is going to change things a little bit. You know, I might not be able to do some thing, you transferred over other items. You know what? When I had my knees done and I couldn't run any of the, I couldn't really run anymore. I just, I walk and I swim and I kyack, you know? Yeah. Yeah, I'll just. I'll just change tack a bit. Yeah. Just staying positive. Yeah. and I know some people that need help to stay positive. You know, I'm one of the lucky ones. I've got a good outlook on life.

Participant 011_2022AUBLC

Um, oh, no. It's been a process of learning and dealing with it, no I found that, um, this is something that you learn and you get to. It's a journey, isn't it? So as I said you see some people who've, you know, like, diagnosed and they got to get their bladder removed within three weeks. And yeah, it's just a process of everyone's different, you know, I'm, I'm pretty happy with the treatment with that.

Participant 044_2022AUBLC

Participant wishes they had know the early signs and symptoms of the condition

Well, I wish I did now. And to this day, I'm absolutely, totally convinced that my nocturia and very frequent urination from about age 35. Was was the reason that I got bladder cancer because I don't smoke, never had one cigarette in my life. I never work in areas where there's chemicals and things like that, which apparently is. So I didn't have any sort of risk factors for getting cancer. The I'm totally convinced that the fact that I was 30 years was 20 years, 30 years going to the toilet regularly at night. And I reckon that must have had something to do with the. So I didn't, I had no information or didn't even know, never even knew there was a bladder cancer. All I knew was that I thought I had prostate problems, which I had checked out when I was 45. And they said. He said, you haven't got prostate problems. That was when I was 45 and I had this PSA test on blood tests over the years, which was less than one. So I just thought I was unlucky and that I had this bladder frequency problem. If doctors had said, well, you know. I don't. I'm just totally

convinced that's the reason I got this bladder cancer. Totally convinced. It's the only thing I can think of. Just the I've had a bladder irritation. So for so many, many years. So just a little bit of information beforehand would have been was the doctors had said you should go and see urologist so-and-so, a doctor GP a few times about it. They should always this is you know, you'll get out of it. I'll just do the bladder retraining, one doctor advised me that can offer what is maybe a bit more information about risk factors and all that sort of thing.

Participant 021_2022AUBLC

Probably because I, I sort of had blood in the urine from, oh, maybe ten years ago or more than that. But at different stages, and then it would go away and. If I and I did go to that doctor once and have a CT scan and they said they couldn't find anything, that was maybe 2010, 2012 or something. So if I'd known that that's what it could have been, I think I would have been more vigilant in going, because I think when I when it was diagnosed, it had been there for quite a while, he said.

Participant 025_2022AUBLC

Oh, I mean. I wish I had of known what blood in your urine meant

Participant 040_2022AUBLC

Participant does not describe anything they wish they had known earlier (no reason given)

Oh, well, no, I don't think so.

Participant 012_2022AUBLC

No, not at all.

Participant 031_2022AUBLC

Participant wishes they had known to be more assertive through the diagnostic process

I wish I knew that UTIs were actually a symptom of cancer. Um, unfortunately, I was female. I was 24 at the time. I was having recurring UTIs and everyone just said, no, it's fine. Don't even worry about it. You're not male, you're not older, you don't actually meet the criteria of anything sinister. So yeah, I wish I just knew the side effects so I could maybe speak up more about my health and have, you know, just something that I could say, look, no, this is an issue,

and it turned out to be cancer. And yeah, I was kind of surprised a lot of people.

Participant 009_2022AUBLC

Oh, diagnosis. Um, I guess. I don't think we could have picked it up any earlier because there was no blood in the urine the year before. Just three weeks wouldn't have made a difference. I guess. I guess we should have got a referral to a specialist in Newcastle earlier because he said he thought we should have had chemo two months before we did so. I mean, it might not make any difference, but it's all just. Yeah. Anyway, it is what it is.

Carer 005_2022AUBLC

Participant wishes they had known more about what support was available to them

Probably about the incontinence, about how severe the incontinence can be. And what kind of help that there is out there for incontinence

Carer 001_2022AUBLC

Um. Not really. Everything happened so quickly for me, but I certainly found it reassuring to to have to make the acquaintance of the support group that I was just talking about, the one that is run by Coloplast. Because when I was in the hospital, the stoma nurse, I mean the state hospital I was in was in the city, in HOSPITAL. I am not sure if you're familiar with CANCER CENTRE, but in in normal times I would have probably been put into LOCATION hospitals, which is quite close, but the stoma nurse in the in the city. He said I'm your stoma nurse now and you know if you need me help. And I tried to contact him a couple of times just because there was something little happening that was worrying me and I couldn't get hold of it because he's so busy. So I found that when I went to this support group run by Coloplast two of the people there were nurses from LOCATION stoma nurses and they said, I can make appointments to see them if if I need to. And that was really reassuring because I was the stoma nurse in the city obviously, and the private hospital is incredibly busy. And also the practicality of going to see him would be really not not that easy. So I found it really, really helpful to know that there's two nurses in LOCATION which is just like five minute drive away, that I can make appointments to see if I need to.

Participant 043_2022AUBL

Table 10.1: Anything participants wish they had known earlier

Wish they had known earlier	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)	11	22.45	5	25.00	3	30.00	1	7.14	9	20.45	2	40.00	6	35.29	5	15.63
Participant wishes they had known to be more assertive in relation to understanding treatment options and discussions about treatment	11	22.45	3	15.00	4	40.00	3	21.43	10	22.73	1	20.00	3	17.65	8	25.00
Participant describes that there is nothing that they wish they knew earlier (satisfied)	9	18.37	4	20.00	2	20.00	3	21.43	9	20.45	0	0.00	2	11.76	7	21.88
Participant wishes they had know the early signs and symptoms of the condition	7	14.29	1	5.00	3	30.00	2	14.29	6	13.64	1	20.00	2	11.76	5	15.63
Participant does not describe anything they wish they had known earlier (no reason given)	4	8.16	2	10.00	1	10.00	1	7.14	4	9.09	0	0.00	2	11.76	2	6.25
Participant wishes they had known to be more assertive through the diagnostic process	4	8.16	2	10.00	1	10.00	0	0.00	3	6.82	1	20.00	2	11.76	2	6.25
Participant wishes they had known more about what support was available to them	3	6.12	1	5.00	0	0.00	1	7.14	2	4.55	1	20.00	2	11.76	1	3.13

Wish they had known earlier	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)	11	22.45	7	24.14	4	21.05	5	33.33	6	18.18	5	25.00	6	21.43
Participant wishes they had known to be more assertive in relation to understanding treatment options and discussions about treatment	11	22.45	6	20.69	5	26.32	2	13.33	9	27.27	2	10.00	9	32.14
Participant describes that there is nothing that they wish they knew earlier (satisfied)	9	18.37	3	10.34	5	26.32	0	0.00	8	24.24	2	10.00	6	21.43
Participant wishes they had know the early signs and symptoms of the condition	7	14.29	5	17.24	2	10.53	2	13.33	5	15.15	2	10.00	5	17.86
Participant does not describe anything they wish they had known earlier (no reason given)	4	8.16	2	6.90	2	10.53	2	13.33	2	6.06	3	15.00	1	3.57
Participant wishes they had known to be more assertive through the diagnostic process	4	8.16	3	10.34	1	5.26	4	26.67	0	0.00	2	10.00	2	7.14
Participant wishes they had known more about what support was available to them	3	6.12	2	6.90	1	5.26	1	6.67	2	6.06	2	10.00	1	3.57

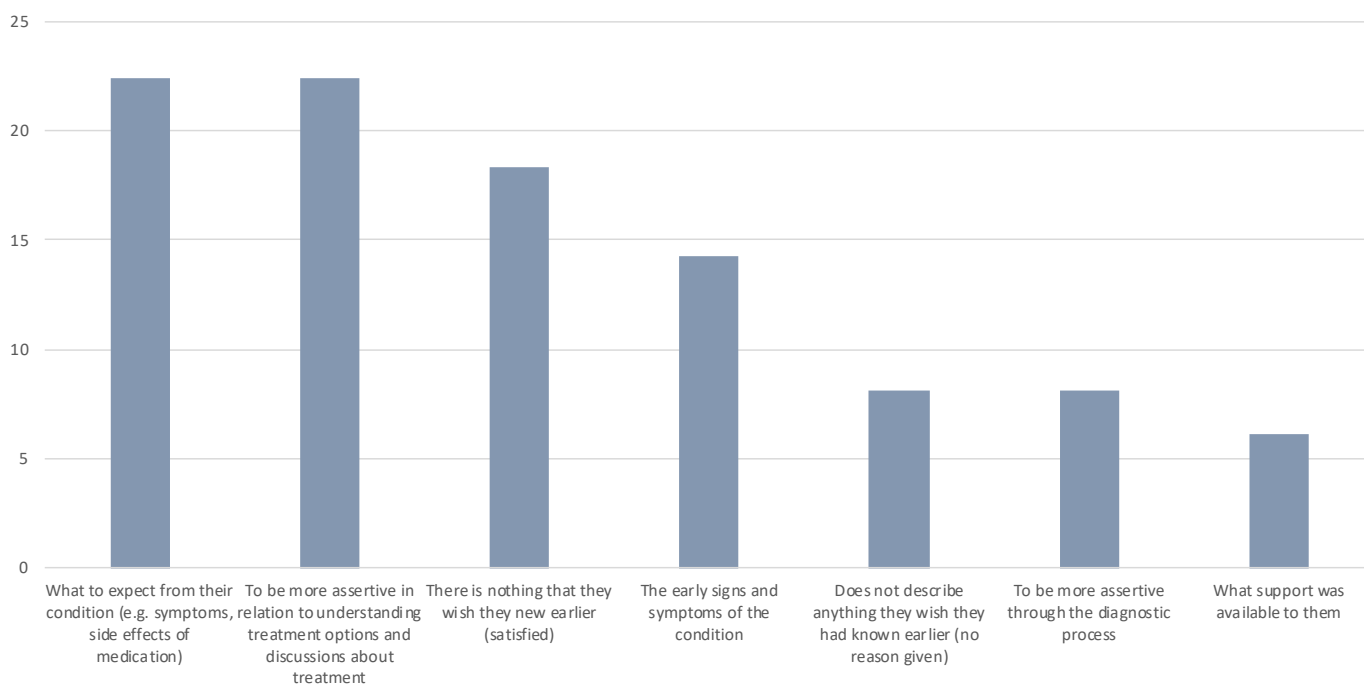


Figure 10.1: Anything participants wish they had known earlier

Table 10.2: Anything participants wish they had known earlier – subgroup variations

Wish they had known earlier	Reported less frequently	Reported more frequently
Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)	Advanced (Stage IV)	Carer to someone with bladder cancer Female Regional or remote
Participant wishes they had known to be more assertive in relation to understanding treatment options and discussions about treatment	Mid to low status	Invasive (Stage III)
Participant describes that there is nothing that they wish they knew earlier (satisfied)	Carer to someone with bladder cancer Regional or remote	-
Participant wishes they had know the early signs and symptoms of the condition	-	Invasive (Stage III)

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common theme was that they would have liked more time and personalised attention with specialists (n=10, 20.41%). There were 8 participants (16.33%) who would not change any aspect of treatment or care without giving a reason, and 8 participants (16.33%) who would not change any aspect of treatment or care because they were satisfied with care and treatment received. Other participants would have liked to have had a better understanding of their condition (n=6, 12.24%), and would have liked more support for side effects of treatment (n=5, 10.20%).

Participant would have liked more time and personalised attention with specialists

Um. I wouldn't change anything. I would love to have changed like the communication side of things with my doctor, but I don't think that was ever going to change. So yeah, probably just more being involved in my treatment plan and actually knowing what was going on. Like, for example, when I had my partial bladder removed, partial bladder removal, I was never told that they were going to be removing some of my lymph nodes around the bladder, around the pelvis or wherever it is. Um, and when he told me that they removed some lymph nodes and they said, keep it all, it looks fine, don't worry about it. But if I do come back cancerous, we're going to have to do chemotherapy. That really scared me because I didn't actually know that they had intentions of removing it, even though it's just a precaution. I would have, just like if they actually had a bit more communication with me, have, you know, exact step by step what was going to happen.

Participant 009_2022AUBLC

Well, the treatment is what the treatment is. So I can't really say I want to be treated. Clinically any different? I mean, the diagnosis is what it is and you follow the the recommended approach. It's just that how. You know, I look, I sound like a broken record. It's coming back just to the way that you want to just chooses to do, to communicate the the messaging of of what I'm dealing with and what my options are. It's very aloof, standard, standoffish and drip fed based upon what you need to know when you need to know it. And don't don't concern yourself with anything else right now other than what I've just told you.

Participant 017_2022AUBLC

Oh, the only thing I would change is that the clinics would be longer. In other words, the time spent with

with the doctor or with the the carers, that's with your stoma nurse or your doctors, was allocated longer. But I know they've got the, they've got deadlines they've got to do and then god knows what else, the other patients to see, etc.. All that I'm saying is that you know the length of the consultation be longer.

Participant 037_2022AUBLC

Participant would not change any aspect of their care or treatment/satisfied with care and treatment received

No, not really. As I said, I, I, thank my lucky stars every day. I had excellent care and excellent and excellent treatment. And you know, anyone facing what I faced, you know, my urology nurse when I met her before my surgery explained to me that, you know, the first four days are not going to be good and you're just going to have to follow instructions and you just going to have to do it no matter what. And, you know, it was so very true. It would have been nice to speak to another patient that had been through that and, you know, explained to me that, you know, this is you know, this is very true and this is what's going to happen.

Participant 032_2022AUBLC

So they were, they were pretty good. Um, as I say, there was, I had a preferred nurse, um, because I thought she, she lent me more dignity because I felt very vulnerable having, you know, that being catheterised so often. And it did and it didn't seem to get me better, to be honest. So I didn't get immune to it really. Um, so, but I, I think overall they were tremendous. Really.

Participant 036_2022AUBLC

Only the ones I've already mentioned. But everything else has been amazing. Like, um, where he receives BCG and cystoscopy. Nope, that's all been fabulous.

Carer 003_2022AUBLC

Participant would not change any aspect of their care or treatment (no reason given)

No, not really. I don't know what I would change. I don't know what would make it any different.

Participant 003_2022AUBLC

Care or treatment? No. No, I wouldn't change anything.

Participant 033_2022AUBLC

Participant would have liked to have had a better understanding of their condition

Maybe just a bit more explanation.

Participant 013_2022AUBLIC

Um. Probably wouldn't have been in a hurry to get out of hospital. Probably would argue that quite a bit. [CROSS TALK]. It's not that you really like that idea. And probably. Yeah. More information about, um. catheterising. Um. Having to having to self cathertise would have been, would have been more helpful. I as said that it was the information that we got. From. Coloplast was was more helpful than what we got out of the health department.

Participant 040_2022AUBLIC

No, I don't think I think I've been really well-cared for. No. I mean. I don't know what else they could have done or anyone could have done so. No. Nothing. Nothing more than perhaps a bit more information, but. That. Yeah. Yeah. About other options. But I don't know that there are many other options. Mhm.

Participant 025_2022AUBLIC

Participant would have liked more support for side effects of treatment

PARTICIPANT: So and I've just talked to a 74 year old lady who was diagnosed with cancer and spoke to her before her operation and gave her some hints and tips and things like that.

INTERVIEWER: Excellent.

PARTICIPANT: She wanted to know before we went into hospital and I suggested the bag and she did all of those things. And I've spoken to her numerous times after her also. She's incredible, constantly positive and fantastic. But she she really liked the practical side of things and really appreciated having a bit of a heads up around that before she got through them. So really, I'm the more that that sort of stuff can happen, the better I think.

Participant 022_2022AUBLIC

Because it's one of the I think if they remove your bladder, then you a nephro tube to as well. It's very invasive and it's, um, very discomfort. And you need to find practical ways to deal with it because it's just kept around your leg. And that's in the beginning you're afraid it will leak and it will drop off down there, fall off. And I was so unhappy that I designed my own. It's like a a like a lycra short, but I stitched pockets on it. And then I could put the the the bag I

could put in there. So that gave me so much joy. But I couldn't find anything on the market like that, and I think lots of people would be helped with that as well, because when you have something strapped to your leg, it's it hurts at a certain stage. And with my Lycra shorts, when I put that in the pockets, I sticth on. Yeah. Then you're. Yeah. It's like, uh. Yeah, it's very comfortable and it gives you confidence. But that's something, uh, I share to a lot of people. But yeah, I think other people could benefit from something like that as well. And that's the experience. And when you talk to people, you can give that advice that there are other ways to deal with it. Yeah, and I never think there's so many things. Tips and tricks that could be way better explained than on an A4.

Participant 005_2022AUBLIC

Well, when I was bleeding, I wish I knew about the Falxseed. But the flaxseed oil and the oregano, because I would have saved money, saved me 34 days of bleeding, you know. And that was definitely on the cards. Um, but again, as I said, the doctors didn't really want to know about it because that something they don't learn at university so that I'm one of those, you know

Participant 042_2022AUBLIC

Participant would have stopped or changed treatment sooner

I keep coming back to say I didn't have private health. I got, I went through the public system. Sometimes I go through them myself, now. I go, well, if I'd had private health coverage, would that have made a difference to me? Would it? Would that have given me quicker access with. Without, without? Having an idea of what was actually happening to me at the time. I did not know because I still felt I still felt fine. And that's that's the insidious part about the whole process is that, yeah, this cancer is growing in you, but you feel there's nothing wrong. There's literally nothing wrong.

Participant 035_2022AUBLIC

Not one. I survived. Yes. Yeah. So I wouldn't I wouldn't go down. As I said earlier, I wouldn't go down the same track as having BCG. But I'm seeing so many problems with that. I end up having it out anyhow. I'm quite happy to have the bladder removed that don't worry about it

Participant 038_2022AUBLIC

Oh, no, as I said, you know, like you still think about whether they should have gone for the extra treatment or, you know, went have you bladder

removed like straight away as a sort of the decision. Yeah. Like you said, he was sitting there in the office with me and he said, which way you want to go with?

You know, like you sit there within 10 minutes, you're gonna make a life changing decision. Participant 044_2022AUBL

Table 10.3: Aspect of care or treatment they would change

Anything to change about treatment or care	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant would have liked more time and personalised attention with specialists	10	20.41	6	30.00	1	10.00	1	7.14	8	18.18	2	40.00	3	17.65	7	21.88
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	8	16.33	2	10.00	2	20.00	3	21.43	7	15.91	1	20.00	3	17.65	5	15.63
Participant would not change any aspect of their care or treatment (no reason given)	8	16.33	4	20.00	2	20.00	2	14.29	8	18.18	0	0.00	2	11.76	6	18.75
Participant would have liked to have had a better understanding of their condition	6	12.24	2	10.00	3	30.00	1	7.14	6	13.64	0	0.00	3	17.65	3	9.38
Participant would have liked more support for side effects of treatment	5	10.20	2	10.00	1	10.00	2	14.29	5	11.36	0	0.00	3	17.65	2	6.25
Participant would have stopped or changed treatment sooner	4	8.16	2	10.00	0	0.00	2	14.29	4	9.09	0	0.00	0	0.00	4	12.50
Participant would have liked better communication with specialist	3	6.12	3	15.00	0	0.00	0	0.00	3	6.82	0	0.00	2	11.76	1	3.13

Anything to change about treatment or care	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant would have liked more time and personalised attention with specialists	10	20.41	7	24.14	2	10.53	1	6.67	8	24.24	2	10.00	7	25.00
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	8	16.33	3	10.34	5	26.32	1	6.67	7	21.21	2	10.00	6	21.43
Participant would not change any aspect of their care or treatment (no reason given)	8	16.33	5	17.24	3	15.79	2	13.33	6	18.18	5	25.00	3	10.71
Participant would have liked to have had a better understanding of their condition	6	12.24	4	13.79	2	10.53	5	33.33	1	3.03	4	20.00	2	7.14
Participant would have liked more support for side effects of treatment	5	10.20	3	10.34	2	10.53	0	0.00	5	15.15	1	5.00	4	14.29
Participant would have stopped or changed treatment sooner	4	8.16	2	6.90	1	5.26	1	6.67	2	6.06	2	10.00	1	3.57
Participant would have liked better communication with specialist	3	6.12	3	10.34	0	0.00	1	6.67	2	6.06	1	5.00	2	7.14

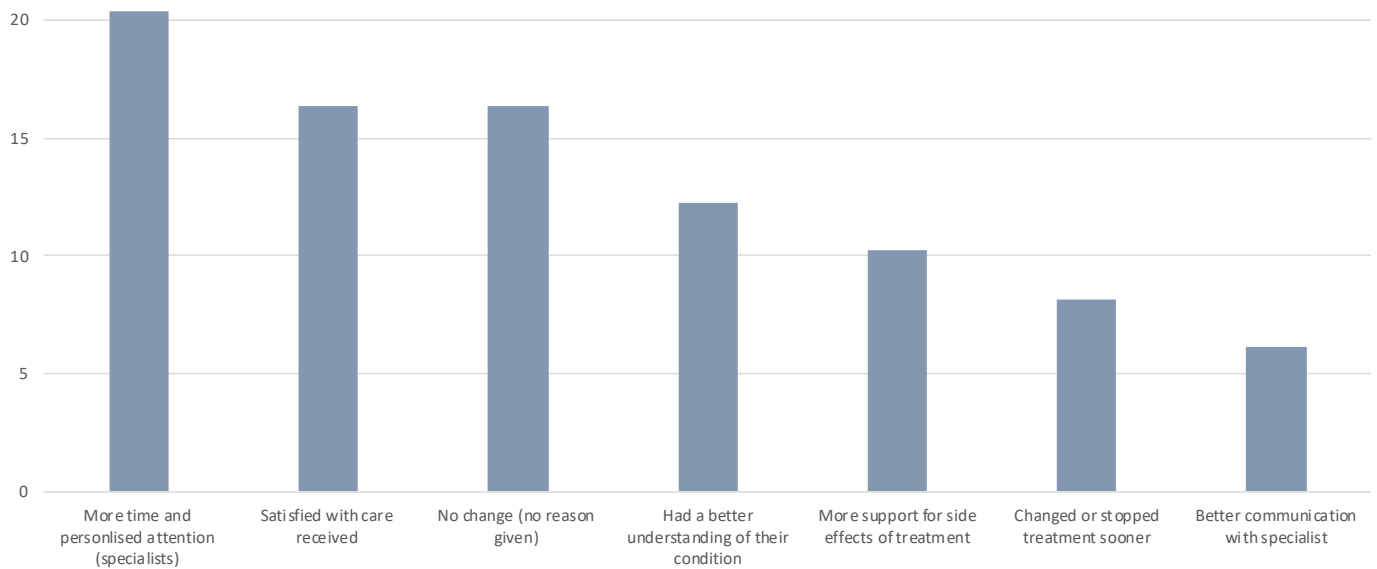


Figure 10.2: Aspect of care or treatment they would change

Table 10.4: Anything participants wish they had known earlier – subgroup variations

Anything to change about treatment or care	Reported less frequently	Reported more frequently
Participant would have liked more time and personalised attention with specialists	Invasive (Stage III) Advanced (Stage IV) Regional or remote Mid to low status	Carer to someone with bladder cancer
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	-	-
Participant would not change any aspect of their care or treatment (no reason given)	Carer to someone with bladder cancer	-
Participant would have liked to have had a better understanding of their condition	Carer to someone with bladder cancer	Invasive (Stage III) Regional or remote
Participant would have liked more support for side effects of treatment	Carer to someone with bladder cancer Regional or remote	-
Participant would have stopped or changed treatment sooner	-	-
Participant would have liked better communication with specialist	-	-