

## Section 8

### Quality of life

## **Section 8: Quality of life**

### **Impact on quality of life**

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (53.85%). Other participants descriptions suggested that there was a mix of positive and negative impact on quality of life (19.23%), that there was overall a minimal impact on quality of life (11.54 %). that there was overall no impact on quality of life (7.69%), and that there was an overall positive impact on quality of life (3.85%).

The most common themes in relation to a negative impact on quality of life were the emotional strain (including family/change in relationship dynamics) (57.69%), emotional strain on themselves (42.31%), reduced capacity for physical activity/need to slow down (26.92 %), the financial strain (11.54%), and reduced having social interactions (11.54%)

The most common theme in relation to a positive impact on quality of life was that it brings people together and highlights supportive relationships (23.08%).

### **Impact on mental health**

In the structured interview, participants were asked if there had been an impact on their mental health. Most commonly, the descriptions suggested that overall, there was at least some impact on mental health (65.38%), other participants descriptions suggested that overall, there was no impact on mental health (23.08%).

### **Regular activities to maintain mental health**

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common response was highlighting the importance of family and friends in maintaining their mental health (26.92%). Other activities to maintain mental health included physical exercise (19.23%), mindfulness and/or meditation (19.23%), and remaining social and engaging in hobbies (19.23%). Some described no activities to maintain mental health (11.54%).

### **Regular activities to maintain health**

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common activities for general health were physical exercise or being physically active (50.00%), and understanding their limitations (34.62%). Other activities included complying with treatment/management (15.38%), maintaining a healthy diet (15.38%), maintaining a normal routine (15.38%), self care e.g. more rest, accepting help, pacing (15.38%), socialising with friends and family (15.38%), being organised and planning ahead (11.54%), and mindfulness and/ or meditation (11.54%).

### **Experience of vulnerability**

In the structured interview, participants were asked if there had been times that they felt vulnerable. The most common responses were that they felt vulnerable when having sensitive discussions (diagnosis, treatment decision) (30.77%), and vulnerable during/after treatments (19.23%). Other times when participants felt vulnerable included when feeling sick or unwell (11.54%), vulnerable because of interactions with the medical team (11.54%), and vulnerable in general (11.54%). Some participants described that they did not feel vulnerable (11.54%).

### **Methods to manage vulnerability**

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common response was self-help (resilience, acceptance, staying positive) to manage the feeling of vulnerability (30.77%). This was followed by support from family and friends to manage the feeling of vulnerability (7.69 %), and being supported by nurse or treatment team (7.69%).

## Impact on relationships

Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (30.77%). Other participants descriptions suggested that overall, there was an impact on relationships that was both positive and negative (23.08%), there was a positive impact on relationships (19.23 %), there no impact on relationships (15.38%), and that, there was an impact on relationships that was neither positive nor negative (7.69%).

The most common themes in relation to having a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships (34.62%), and that the dynamics of relationships changed due to anxiety, exacerbations and/or physical limitations of condition (23.08 %).

The most common themes in relation to having a positive impact on relationships from family relationships being strengthened (30.77%), and from people being well-meaning and supportive) (19.23%).

## Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Most commonly, the descriptions suggested that overall, there was a burden on their family (76.92%). Other participants descriptions suggested that overall, there was not a burden on their family (15.38%). The main reason that participant described their condition being a burden was from the mental and emotional strain placed on their family (38.46%).

## Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (61.54%), and that overall, there was no cost burden (34.62%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to needing to take time off work (38.46%), and the cost of treatments (26.92%). Other costs included diagnostic tests and scans (15.38%), cost of parking and travel to attend appointments (including accommodation) (15.38%), the cost of specialist appointments (15.38%), and public or private gap payments (11.54%). Where participants described no cost burden associated with their condition, this was because nearly everything was paid for through the health system (26.92%)

## Overall impact of condition on quality of life

Quality of life was rated on a Likert scale from one to seven, where one is Life was very distressing and seven is life was great. The average score was in the Life was a little distressing range (median=3.00, IQR=3.50).

## Fear of progression

The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated moderate levels of anxiety.

## Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (53.85%). Other participants descriptions suggested that there was a mix of positive and negative impact on quality of life (19.23%), that there was overall a minimal impact on quality of life (11.54 %), that there was overall no impact on quality of life (7.69%), and that there was an overall positive impact on quality of life (3.85%).

The most common themes in relation to a negative impact on quality of life were the emotional strain (including family/change in relationship dynamics) (57.69%), emotional strain on themselves (42.31%), reduced capacity for physical activity/needing to slow down (26.92 %), the financial strain (11.54%), and reduced having social interactions (11.54%)

The most common theme in relation to a positive impact on quality of life was that it brings people together and highlights supportive relationships (23.08%).

### **Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics**

*Probably the quality, maybe the part of a little bit of happiness has gone from the family.*  
Participant 013\_2023AULUC

*At the moment, it's not having a huge direct impact. It has an underlying impact in that everyone carries a little bit of grief knowing that it's not forever. I'm not going to do 88 years like my mother. That's it at the back of everyone's mind so it has a little bit of an impact but my quality of life is pretty good. My relationships are very good.*  
Participant 020\_2023AULUC

*It's affected my family. It's affected my children because my children live with my dad. My children have seen my dad really, really sick and sometimes his mental health's not so great trying to process all that stuff that he's not going to be around. It's really impacted-- I have a daughter with autism as well so for her to understand things is quite difficult so we've had to go through that. It's impacted on me because my whole life's changed but I wouldn't change it.*  
Participant 030\_2023AULUC

### **Participant describes negative impact on quality of life as a result of emotional strain on themselves**

*PARTICIPANT: Not for the kids. The kids are okay. The kids just take things on and just go with it. My husband, he said, "I don't think about it until you say something and then I remember, then I get sad." To me, it's like walking around with a gun pointed at my head all the time constantly...Are they going to pull the trigger? When is the trigger going to be pulled? Yes, it does affect it. I suppose I don't talk to my friends as much now. I let them come to me and of course, they've stopped doing that. I don't think I was a Debbie Downer, but I think they didn't want to hear about it. I am a talker and I need to talk about it. People don't want to hear. I understand that. My relationship with my mother is non-existent now. She didn't even care. [chuckles] She just went, "Oh." I don't think she understood. I don't know. I said to her, "I have terminal lung cancer, mom." "Oh, that's because you smoked when you were a teenager." "No. Mum, I didn't smoke when I was a teenager. You smoked when I was a teenager." She just didn't seem to care. I thought, "Okay, I'll see how long it takes her to ring me." Because if your kids said kid said, "Mum, I have got a terminal illness," you'd be ringing them pretty much every day just to say are you okay? Is everything okay? Anything I can do? 28 days [unintelligible] before I gave up.*  
Participant 002\_2023AULUC

*Yes, sure has. It affects everything. People can say like, "Oh yes, but you're not your cancer," but it's pretty much your full-time job because it's always in the back of your mind like, "How long have I got to live? How long is this tablet going to last?" I think until they have tablets that last for years and years, I think it's just an ongoing issue, the quality of life, from a psychological perspective.*  
Participant 004\_2023AULUC

*No and yes. [chuckles] It hasn't really affected quality of life or probably added a layer of stress. It's just me and my son, so it probably added a layer of stress, obviously for him and me in terms of caring for him, but I think main relationships with everyone else has been reasonable. I think, there's that concept with people when people find you've got a terminal illness and then all of a sudden you haven't died within 12 months, it's quite a surprise for people.*  
Participant 026\_2023AULUC

**Participant describes negative impact on quality of life due to a reduced capacity for physical activity/needing to slow down**

*During treatment, it's affected my life. I can't do what I would normally do. We've got a grandson and we were hoping to look after him once my daughter went back to work. I can't really do much of that at all at the moment, but my daughter had already prepared to get him into childcare. The timing was right because as soon as I start treatment, he got a place. He goes to childcare now and he's at the age where he benefit from it anyway. I'm just being able to do basic domestic stuff, which I was taking for granted for quite a while. At the moment, I can only do one little task at a time and just hope to achieve that one little task for the day because I just get [unintelligible]. Even just planning outings, I can't plan too much for the day. For example, we had a family celebration on Sunday, we had a christening and I wasn't sure if I could get there because I had a fear of actually going out and being with a crowd, but I was reassured. I spoke to my lung cancer nurse about it and she said, "The mental health too, you need to continue on, just be careful, wear a mask, et cetera." We managed to do that on Sunday, but just getting ready in the morning just took a lot out of me. I have to accept that that's what's going to happen for a while until the effects of this treatment wear off. It makes you more determined to get to the next one when you know you can get to one...You still want to be part of all of that. You don't want to just give up and hide away at home.*  
Participant 005\_2023AULUC

*Yes, mainly about the limitations post-op which we heard that would be shortlived. We regularly look after grandchildren and couldn't push the pram up the hill, couldn't push somebody on a swing, couldn't lift somebody up. We're quite busy, playful and I'm used to pulling my own weight around the house and in the garden, and [unintelligible] is limiting. It's just a matter of taking my time and I'm just not used to that. That's all.*

Participant 010\_2023AULUC

*PARTICIPANT: Like I said before, I was very fit, very active, physically out and about, and a hard-paced, fast-paced job. That's all slowed down. I'm managing to do things and I think I'm just learning to come to terms with the new me but that's all been pretty at times, quite confronting but I'm rolling with it. Just remind me the question again, how it affects.*

*INTERVIEWER: How it's affected your quality of life and that of your family?*

*PARTICIPANT: I think it's been a tough year for everyone. I'm just starting to come out of a bit of this haze, I think, and I'm realizing just how much it's impacted on my children and my husband but at the same time, we've all managed and we've all coped and we're all now the sun is starting to shine at last. I think we're all feeling a bit better. I wouldn't say minimally. It has impacted on my life and my relationships, but not in an horribly negative way. Let's say different, everything's different.*

Participant 025\_2023AULUC

**Participant describes a positive impact on quality of life as it brings people together and highlights supportive relationships**

*I guess, as I said, when I first started taking the medication, my quality of life was very affected. Probably the last year, it's been a great quality of life. I've been good. As far as family, some of them struggle, and most of them are quite good. It's brought us closer together. I think it did. It's been a good thing*

Participant 006\_2023AULUC

*PARTICIPANT: Of course, it has because, now, I've now only got one-and-a-half lungs. I get more fatigued more regularly and maybe that will change as it progresses. Because it's only been 18 months, or not even that, since I finished treatment. My libido's gone out the window, so I'm now trying to see a counselor, with my husband, to try and sort that part of things out. He's been very, very supportive, which I'm very grateful and very fortunate for. There are some people I haven't told that I've had lung cancer because of the stigma that surrounds it and how people treat you to say, "Oh, smoker, were you?", and give you grief. It's changed things, but it's actually probably helped me work out who's for real and who isn't, if that makes any sense. I'm extremely grateful to be alive, and I figure I'm here for a reason and, given a second chance, it's changed it a bit. Look, I don't look at it in a super bad way. I think it is the reason I'm alive.*

Participant 018\_2023AULUC

*Yes, definitely. We were staring potential death in the face. It was pretty confronting. I'd like to think that there have been positives that have come out of that in terms of appreciating each other and probably stronger relationships as a result of it, which is obviously a great outcome. It's certainly been a tough time for everyone in the family. More extended family as well, like my mother and sister back in COUNTRY.*

*It's been tough for everyone, particularly because it was COVID as well.*  
Participant 021\_2023AULUC

**Participant describes negative impact on quality of life as a result of financial strain**

*My marriage has now failed and my children have been impacted because they have to watch me get scans every four months and go through the stress of has mum got cancer this time? Has it come back? has it grown more? Is it still there? It's something that they shouldn't have to deal with either. Yes, it's just changed. Because we don't have that financially stable, we don't go on holidays like we used to. It's a big impact on the family.*  
Participant 007\_2023AULUC

*That goes back mainly because one, you're not always tired. You have chronic side effects, and also you've lost one income, correct?*  
**PARTICIPANT:** Yes. Exactly.  
**INTERVIEWER:** Anything else to add to that?  
**PARTICIPANT:** Just emotionally, I think because I have no support.  
Participant 027\_2023AULUC

**Participant describes negative impact on quality of life due to reduced social interaction**

*I struggle to do the grocery shopping now. I struggle to do housework now. My 29-year-old son lives with me. He is experiencing mental health issues. I don't like to go out because I'm afraid that I will get COVID or catch the flu or something stupid like that. I don't go out unless I have to.*  
Participant 003\_2023AULUC

*You know, there's a lot. Then just the emotional rollercoaster that we have to go on every three months. The quality of life is reasonable, we make the most of what we have, not what we don't have. If you're looking at what we don't have, [laughs] it would be significantly different in terms of, we would just be able to go and live a normal life. We'd be able to go out with friends more, and go out and have a late night, whereas now I can't because I get to have sensitive eyes at night, so we try not to go out at night. When I'm driving, and the reflection of the lights from the other cars—*  
Participant 015\_2023AULUC

**Table 8.1: Impact on quality of life**

Impact on quality of life	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Experience described suggests that there was an overall negative impact on quality of life	14	53.85	13	52.00	1	100.00	3	30.00	11	68.75	13	81.25	1	10.00
Experience described suggests that there was a mix of positive and negative impact on quality of life	5	19.23	5	20.00	0	0.00	3	30.00	2	12.50	3	18.75	2	20.00
Experience described suggests that there was overall a minimal impact on quality of life	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	1	6.25	2	20.00
Experience described suggests that there was overall no impact on quality of life	2	7.69	2	8.00	0	0.00	2	20.00	0	0.00	1	6.25	1	10.00
Experience described suggests that there was an overall positive impact on quality of life	1	3.85	1	4.00	0	0.00	0	0.00	1	6.25	1	6.25	0	0.00
No particular comment	1	3.85	1	4.00	0	0.00	0	0.00	1	6.25	0	0.00	1	10.00

Impact on quality of life	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Experience described suggests that there was an overall negative impact on quality of life	14	53.85	10	58.82	4	44.44	6	46.15	8	61.54	1	50.00	13	54.17	6	66.67	8	47.06
Experience described suggests that there was a mix of positive and negative impact on quality of life	5	19.23	4	23.53	1	11.11	2	15.38	3	23.08	0	0.00	5	20.83	1	11.11	4	23.53
Experience described suggests that there was overall a minimal impact on quality of life	3	11.54	1	5.88	2	22.22	2	15.38	1	7.69	0	0.00	3	12.50	0	0.00	3	17.65
Experience described suggests that there was overall no impact on quality of life	2	7.69	0	0.00	2	22.22	2	15.38	0	0.00	0	0.00	2	8.33	1	11.11	1	5.88
Experience described suggests that there was an overall positive impact on quality of life	1	3.85	1	5.88	0	0.00	0	0.00	1	7.69	1	50.00	0	0.00	1	11.11	0	0.00
No particular comment	1	3.85	0	0.00	1	11.11	1	7.69	0	0.00	0	0.00	1	4.17	0	0.00	1	5.88

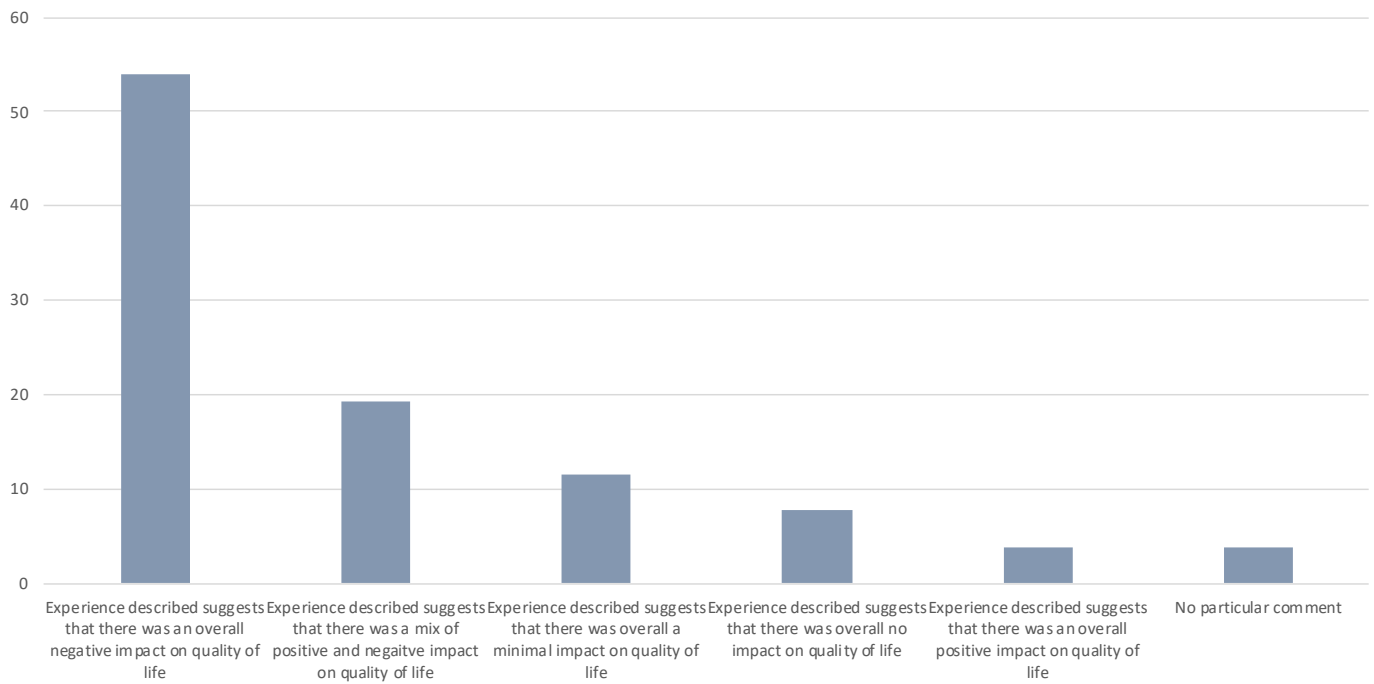


Figure 8.1: Impact on quality of life

Table 8.2: Impact quality of life – subgroup variations

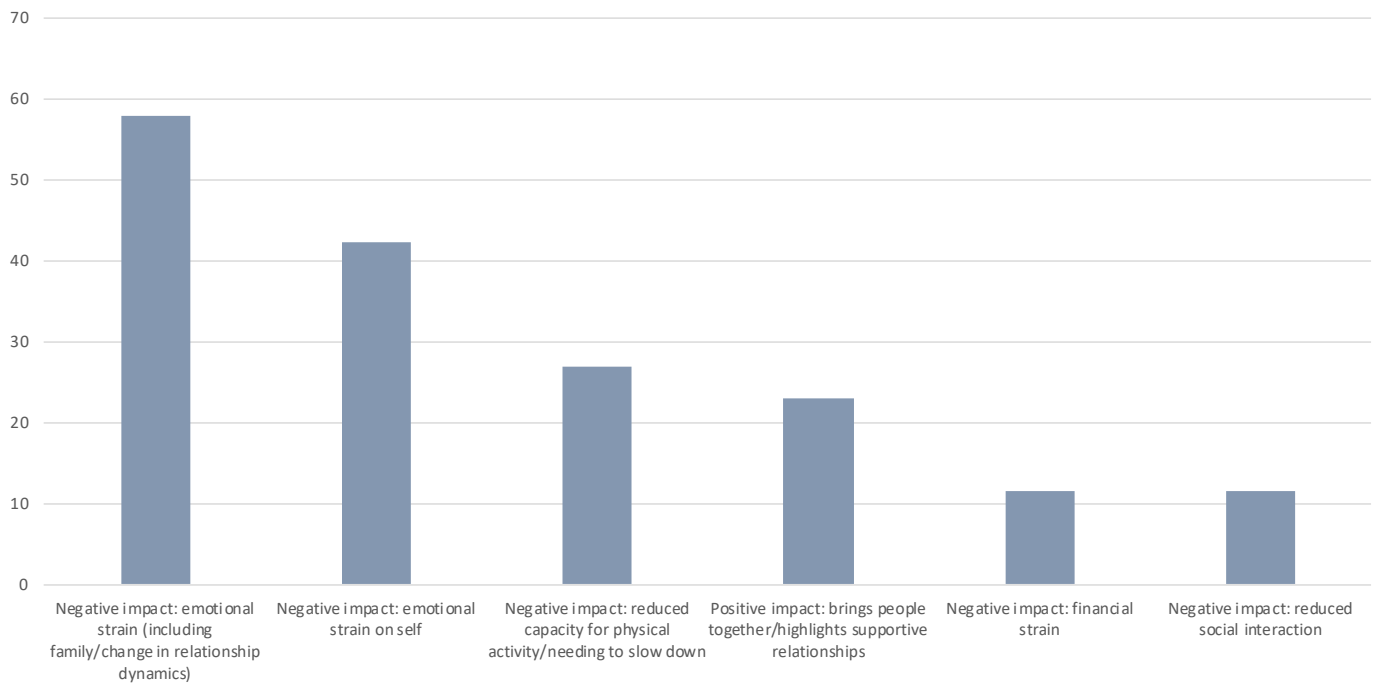
Theme	Less frequently	More frequently
Experience described suggests that there was an overall negative impact on quality of life	Non-metastatic Male	Metastatic Female Mid to low status Non-metastatic
Experience described suggests that there was a mix of positive and negative impact on quality of life	-	-
Experience described suggests that there was overall a minimal impact on quality of life	Mid to low status	Aged 65 or older
Experience described suggests that there was overall no impact on quality of life	-	Non-metastatic Aged 65 or older

Table 8.3: Impact on quality of life (Reasons)

Impact on quality of life (reasons)	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	15	57.69	14	56.00	1	100.00	5	50.00	10	62.50	12	75.00	3	30.00
Participant describes negative impact on quality of life as a result of emotional strain on themselves	11	42.31	10	40.00	1	100.00	3	30.00	8	50.00	8	50.00	3	30.00
Participant describes negative impact on quality of life due to a reduced capacity for physical activity/need to slow down	7	26.92	7	28.00	0	0.00	4	40.00	3	18.75	5	31.25	2	20.00
Participant describes a positive impact on quality of life as it brings people together and highlights supportive relationships	6	23.08	6	24.00	0	0.00	3	30.00	3	18.75	4	25.00	2	20.00
Participant describes negative impact on quality of life as a result of financial strain	3	11.54	3	12.00	0	0.00	0	0.00	3	18.75	3	18.75	0	0.00
Participant describes negative impact on quality of life due to reduced social interaction	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00

Impact on quality of life (reasons)	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	15	57.69	11	64.71	4	44.44	7	53.85	8	61.54	1	50.00	14	58.33	5	55.56	10	58.82
Participant describes negative impact on quality of life as a result of emotional strain on themselves	11	42.31	9	52.94	2	22.22	5	38.46	6	46.15	0	0.00	11	45.83	4	44.44	7	41.18
Participant describes negative impact on quality of life due to a reduced capacity for physical activity/need to slow down	7	26.92	5	29.41	2	22.22	4	30.77	3	23.08	0	0.00	7	29.17	2	22.22	5	29.41
Participant describes a positive impact on quality of life as it brings people together and highlights supportive relationships	6	23.08	5	29.41	1	11.11	2	15.38	4	30.77	1	50.00	5	20.83	2	22.22	4	23.53
Participant describes negative impact on quality of life as a result of financial strain	3	11.54	3	17.65	0	0.00	2	15.38	1	7.69	0	0.00	3	12.50	1	11.11	2	11.76
Participant describes negative impact on quality of life due to reduced social interaction	3	11.54	3	17.65	0	0.00	0	0.00	3	23.08	1	50.00	2	8.33	1	11.11	2	11.76



**Figure 8.2: Impact on quality of life (Reasons)**

**Table 8.4: Impact on quality of life (Reasons)– subgroup variations**

Theme	Less frequently	More frequently
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	Male Aged 65 or older	Female
Participant describes negative impact on quality of life as a result of emotional strain on themselves	Non-metastatic Male Aged 65 or older	Aged 35 to 64
Participant describes negative impact on quality of life due to a reduced capacity for physical activity/need to slow down	-	Non-metastatic
Participant describes a positive impact on quality of life as it brings people together and highlights supportive relationships	Aged 65 or older	-
Participant describes negative impact on quality of life as a result of financial strain	Non-metastatic Male Aged 65 or older	-
Participant describes negative impact on quality of life due to reduced social interaction	Male Aged 65 or older Trade or high school	University

## Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. Most commonly, the descriptions suggested that overall, there was at least some impact on mental health (65.38%), other participants descriptions suggested that overall, there was no impact on mental health (23.08%).

**Experience described suggests that overall, there was at least some impact on mental health**

*Like I said, The first two months, I was a wreck. I wanted to cry. I was crying every other day and then I'd wake up in the night and think about it and just felt terrible, terrible down. Well, it's like they'll give you a death sentence, but now I have got myself out of it and I'm not thinking that way anymore. I've just*

*changed my own way of thinking really. I'm just trying to think the best. Miracles do happen. [crosstalk] Participant 001\_2023AULUC*

*PARTICIPANT: Oh yes, definitely. I'm a lot stronger now. I think with something like lung cancer, people are not supportive and that affects-- some people are not supportive, either friends or family or whatever because they just assume you've brought it on yourself, and that does affect your mental state. Or people that say the wrong things, it does affect your psychology when people are like that.*

*INTERVIEWER: Have you done anything to look after your mental and emotional health in these times?*

*PARTICIPANT: Yes, I joined a number of lung cancer forums with patients who've also got the stage 4. It's just been a marvelous source of support, it's just been*



*amazing. There's just so much kindness and support in these forums, it's incredible.*  
Participant 004\_2023AULUC

*PARTICIPANT: Yes, it has. This time around especially because it's a lot more confronting this time not knowing where this treatment will take you. I was hoping that I would have lasted a lot longer on [unintelligible] because I would read stories about some people even lasting 10 years. I always had that hope, but I only lasted the 18 months or 20 months. That was a shock because I was just cruising along and scans were looking good. I wasn't really having any symptoms until I started having the visual issues.*  
Participant 005\_2023AULUC

**Experience described suggests that overall, there was no impact on mental health**

*No, I'm fine. I'm all good. This is the card I've been dealt. I'm good. I'm putting practical things in place. It is what it is. Now, I'm fine*  
Participant 006\_2023AULUC

*I'm probably more emotional than I used to be. I tell people, more, how I feel or what I think, and not in a bad way. [laughs] How I feel about things and what*

*have you, which I think we always say, "Oh, we should have told them we love them," or "we should have said this," I just to do that now. I just do that now. Things are certainly a little bit more emotional. I'm ever so much more grateful and I practice different, I suppose, practices, every day, of being grateful and seeing the joy in small things. I don't tolerate rules. I never really did, previous to this, anyway, but now it's even less. I stand my ground. I speak my mind. I advocate for myself because I know that nobody else will.*

Participant 018\_2023AULUC

*No, well, see, I'm quite surprised that I haven't had any major breakdowns. I think that's my nursing. It is what it is and I just carry on. I'm probably a lot luckier than most in that I haven't gotten metastasis. It could have been better but does that make sense? I feel luckier than most. My mental health I think is doing okay. I think if I was falling apart, I would have sought help from somewhere but I haven't needed to. I've got great friends around me despite the fact I haven't been working. Whilst I'm getting a bit bored now, I've not been bored. I've had so many people call in and so many people have been there for me and my family are excellent. I've got a beautiful family.*

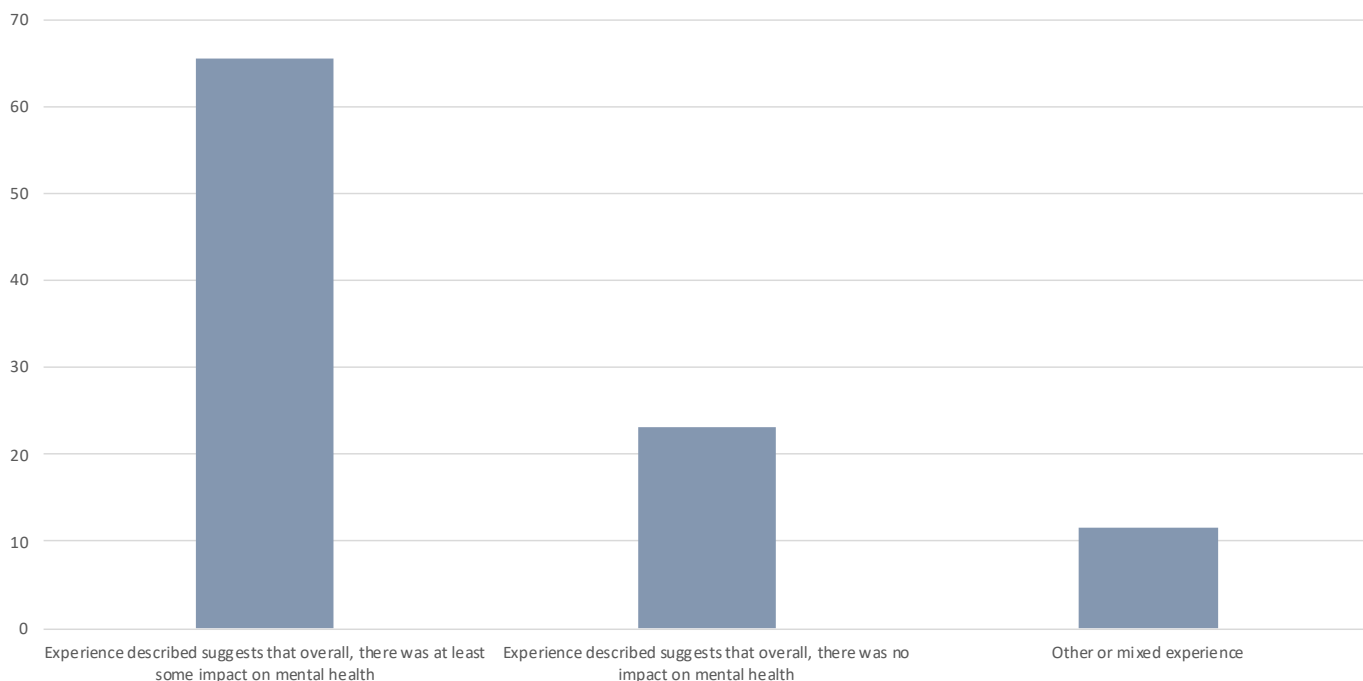
Participant 025\_2023AULUC

**Table 8.5: Impact on mental health**

Impact on mental health	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Experience described suggests that overall, there was at least some impact on mental health	17	65.38	16	64.00	1	100.00	5	50.00	12	75.00	13	81.25	4	40.00
Experience described suggests that overall, there was no impact on mental health	6	23.08	6	24.00	0	0.00	4	40.00	2	12.50	5	31.25	1	10.00
Other or mixed experience	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	1	6.25	2	20.00

Impact on mental health	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Experience described suggests that overall, there was at least some impact on mental health	17	65.38	12	70.59	5	55.56	8	61.54	9	69.23	1	50.00	16	66.67	7	77.78	10	58.82
Experience described suggests that overall, there was no impact on mental health	6	23.08	3	17.65	3	33.33	3	23.08	3	23.08	1	50.00	5	20.83	2	22.22	4	23.53
Other or mixed experience	3	11.54	1	5.88	2	22.22	2	15.38	1	7.69	0	0.00	3	12.50	0	0.00	3	17.65



**Figure 8.3: Impact on mental health**

**Table 8.6: Impact on mental health – subgroup variations**

Theme	Less frequently	More frequently
Experience described suggests that overall, there was at least some impact on mental health	Non-metastatic Male	Female Mid to low status
Experience described suggests that overall, there was no impact on mental health	Metastatic Male	Non-metastatic Aged 65 or older

## Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common response was highlighting the importance of family and friends in maintaining their mental health (26.92%). Other activities to maintain mental health included physical exercise (19.23%), mindfulness and/or meditation (19.23%), and remaining social and engaging in hobbies (19.23%). Some described no activities to maintain mental health (11.54%).

### Participant describes the importance of family and friends in maintaining their mental health

*I told you that I had anxiety catastrophized so my poor husband co-opted a lot. Before I often talked about being dead and I'm going to die so I don't care about doing this anymore but I've since I've got over that. I think that it was good for my mental health to be able to talk that sort of shit. To say, "Oh, well [inaudible] and I'm going to be dead soon anyway." My husband, he's a great foil for that if you know what I mean. He can [unintelligible] back to me without sounding flippant or that he doesn't care. I wouldn't really say that my mental health has suffered because of it.*  
Participant 010\_2023AULUC

*I'm probably more emotional than I used to be. I tell people, more, how I feel or what I think, and not in a bad way. [laughs] How I feel about things and what have you, which I think we always say, "Oh, we should have told them we love them," or "we should have said this," I just do that now. I just do that now. Things are certainly a little bit more emotional. I'm ever so much more grateful and I practice different, I suppose, practices, every day, of being grateful and seeing the joy in small things. I don't tolerate rules. I never really did, previous to this, anyway, but now it's even less. I stand my ground. I speak my mind. I advocate for myself because I know that nobody else will.*

Participant 018\_2023AULUC

*No, well, see, I'm quite surprised that I haven't had any major breakdowns. I think that's my PROFESSION. It is what it is and I just carry on. I'm probably a lot luckier than most in that I haven't gotten metastasis. It could have been better but does that make sense? I feel luckier than most. My mental health I think is doing okay. I think if I was falling apart, I would have sought help from somewhere but I haven't needed to. I've got great friends around me despite the fact I*

*haven't been working. Whilst I'm getting a bit bored now, I've not been bored. I've had so many people call in and so many people have been there for me and my family are excellent. I've got a beautiful family.*

*Participant 025\_2023AULUC*

#### **Participant describes the importance of physical exercise**

*PARTICIPANT: Yes, I do. I go for that walk every day and have a moment to try going to the carers group. I've got someone that comes to the house to look after the girls. My girls are still very young, they're 11 and 12, [crosstalk] 13 now. Then I started trying to-- you just caught me, I'll go to hydro...I use the girls' NDIS so I can leave the house. Now my husband works from home on Friday, so I can go off and do shopping...I can grab a coffee or something on a Friday*

*Participant 027\_2023AULUC*

*PARTICIPANT: I was going to hydrotherapy, but I had to stop that after this latest diagnosis and I won't be able to go back till next year because I've got to be careful too about being in the water. I'm taking anesthesia, but also, just being aware of exposure to bacteria. I was doing that, going to Pilates, which I think in the next few weeks, I can start looking at going back to that. Now I was considering doing some yoga, going back to yoga because I'd worked at a fitness routine for a while, so I was going to at least once a week. I was going to Zumba Gold, hydrotherapy, Pilate. I was trying to do something, some sort of a routine exercise. I just do it once a week.*

*INTERVIEWER: It definitely sounds like staying active is helping for you.*

*PARTICIPANT: Yes, it does. Even I started going back to Lift last week, and this week, I've been for the second time today and I'm booking for tomorrow. There's days where you wake up and you're feeling a bit flat, but I know that as soon as I finish the session, I feel so much better. I know there's real advantages in continuing with that. I remember a friend of mine, she went through breast cancer treatment about seven years ago and I told her how I was exercising and she goes, "Oh, really?" She said, "I slept through my chemo." I found that really surprising. She said she just slept through that. Obviously, she wasn't getting any encouragement to do some exercise program to help her through it.*

*Participant 005\_2023AULUC*

*PARTICIPANT: I have treatment and I'm trying to exercise because I had about four months where I didn't do any*

*and exercise was always important to me. We actually got a higher spin bike and put it in our room.*

*INTERVIEWER: Excellent*

*PARTICIPANT: That's been great through winter. It's been a really cold winter here. I've got a normal bike which I*

*ride.*

*INTERVIEWER: Road bike?*

*PARTICIPANT: I haven't been able to. I jump on the bike and get some sessions in.*

*INTERVIEWER: Excellent. Do you listen to music field or is there a program that you watch?*

*PARTICIPANT: When I'm writing, I listen to music. Music is really important to me.*

*INTERVIEWER: Excellent. All right.*

*PARTICIPANT: I love music.*

*INTERVIEWER: [inaudible 00:54:53].*

*PARTICIPANT: Actually, yes. Now planning a few holidays has really helped my outlook*

*Participant 024\_2023AULUC*

#### **Participant describes using mindfulness and/or meditation**

*Like I said, The first two months, I was a wreck. I wanted to cry. I was crying every other day and then I'd wake up in the night and think about it and just felt terrible, terrible down. Well, it's like they'll give you a death sentence, but now I have got myself out of it and I'm not thinking that way anymore. I've just changed my own way of thinking really. I'm just trying to think the best. Miracles do happen.*

*Participant 001\_2023AULUC*

*It definitely impacts it in a major way. I seek help from the Cancer Council of Queensland and do a mindfulness meditation course with [unintelligible], and then I do yoga retreats whenever I can. Hopefully mostly twice a year, once or twice a year. Or I do meditation as well. I try to keep physically active and, and meditate to counteract stress and anxiety.*

*Participant 007\_2023AULUC*

*PARTICIPANT: Oh, absolutely. It's probably the biggest impact for me. That's bigger than physical for me. Mental and emotional health, especially now in this new treatment, this new treatment makes all that work. That basically is the biggest side effect. I obviously try and exercise again. I do yoga once a week.*

**INTERVIEWER:** Talk to your psychologist regularly?  
**PARTICIPANT:** Yes, correct. I try and meditate when I need to. What else do I do? I call people, I talk to people, and I'm involved in support groups.  
 Participant 015\_2023AULUC

**Participant describes the importance of remaining social and taking part in their hobbies**

*I make soap. I'm starting a cosmetic formulation course in July. That's about it. I tend to isolate myself from people because I don't feel like I can talk to them*

*without bringing them down, so to speak. I just do my thing really. I don't take on board anything that I don't have to. I only talk to friends that I know that I can trust and who understand where I'm coming from. That's about it.*  
 Participant 003\_2023AULUC

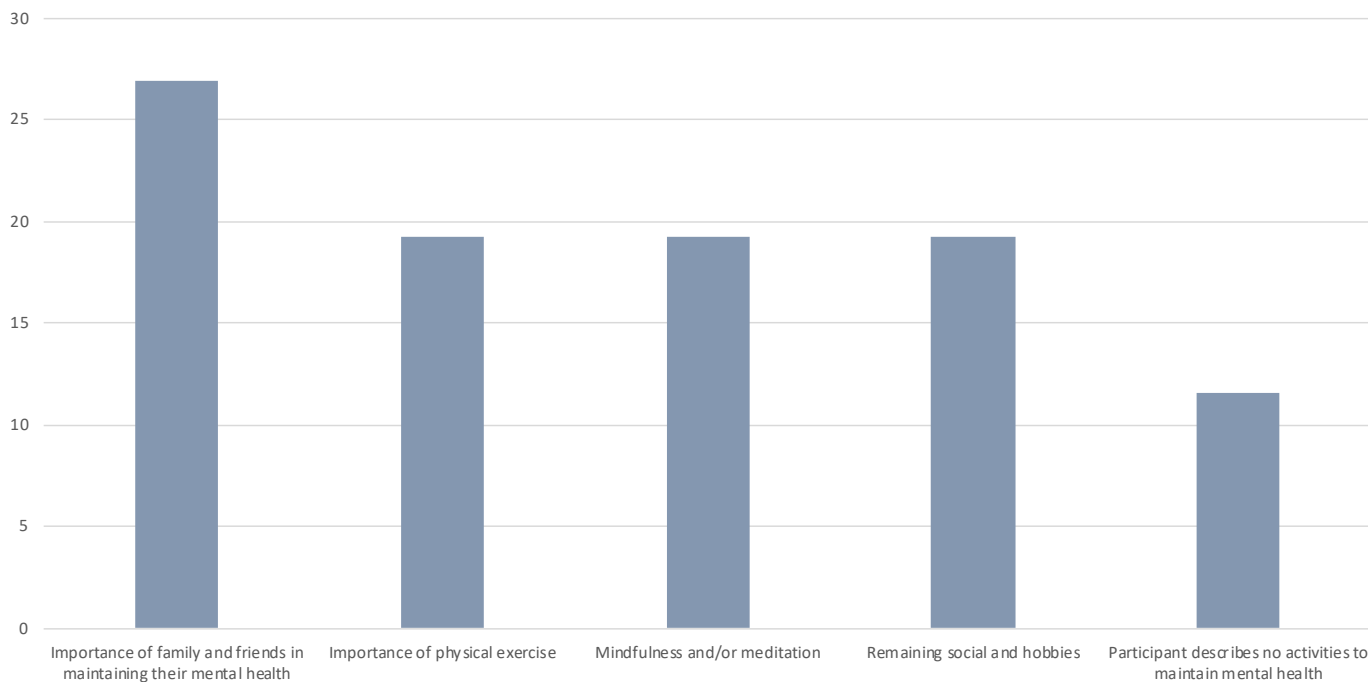
*Yes, I've probably already answered that. I think about it every day and I deal with it through looking after my own mental health and all the things I discussed; physical activity and appreciating people and places and nature and all that stuff.*  
 Participant 021\_2023AULUC

**Table 8.7: Regular activities to maintain mental health**

Regular activities to maintain mental health	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes the importance of family and friends in maintaining their mental health	7	26.92	7	28.00	0	0.00	5	50.00	2	12.50	6	37.50	1	10.00
Participant describes the importance of physical exercise	5	19.23	5	20.00	0	0.00	1	10.00	4	25.00	3	18.75	2	20.00
Participant describes using mindfulness and/or meditation	5	19.23	5	20.00	0	0.00	1	10.00	4	25.00	5	31.25	0	0.00
Participant describes the importance of remaining social and taking part in their hobbies	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	3	18.75	2	20.00
Participant describes no activities to maintain mental health	3	11.54	3	12.00	0	0.00	3	30.00	0	0.00	2	12.50	1	10.00

Regular activities to maintain mental health	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes the importance of family and friends in maintaining their mental health	7	26.92	5	29.41	2	22.22	3	23.08	4	30.77	1	50.00	6	25.00	2	22.22	5	29.41
Participant describes the importance of physical exercise	5	19.23	4	23.53	1	11.11	3	23.08	2	15.38	0	0.00	5	20.83	2	22.22	3	17.65
Participant describes using mindfulness and/or meditation	5	19.23	4	23.53	1	11.11	1	7.69	4	30.77	1	50.00	4	16.67	1	11.11	4	23.53
Participant describes the importance of remaining social and taking part in their hobbies	5	19.23	4	23.53	1	11.11	2	15.38	3	23.08	1	50.00	4	16.67	2	22.22	3	17.65
Participant describes no activities to maintain mental health	3	11.54	1	5.88	2	22.22	2	15.38	1	7.69	0	0.00	3	12.50	2	22.22	1	5.88



**Figure 8.4: Regular activities to maintain mental health**

**Table 8.8: Regular activities to maintain mental health – subgroup variations**

Theme	Less frequently	More frequently
Participant describes the importance of family and friends in maintaining their mental health	Metastatic Male	Non-metastatic Female
Participant describes using mindfulness and/or meditation	Male Trade or high school	Female University
Participant describes no activities to maintain mental health	Metastatic	Non-metastatic Aged 65 or older Mid to low status

## Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common activities for general health were physical exercise or being physically active (50.00%), and understanding their limitations (34.62%). Other activities included complying with treatment/ management (15.38%), maintaining a healthy diet (15.38%), maintaining a normal routine (15.38%), self care e.g. more rest, accepting help, pacing (15.38%), socialising with friends and family (15.38%), being organised and planning ahead (11.54%), and mindfulness and/ or meditation (11.54%).

### Participant describes being physically active

*I need to keep fit, and I do yoga each week to keep my body moving and [unintelligible] twice a week. I get, like I said before, weekly massages and acupuncture. All of those things keep my body functioning and my lungs clear so that I don't get chest infections again.*  
Participant 007\_2023AULUC

*I probably just maintain, which is actually probably the hardest bit when you're feeling tired, but maintaining physical fitness, keeping busy, walking and exercises, stuff like that. I would do a lot more of that stuff like yoga and stuff like that if I wasn't working full-time and it didn't come with the cost.*  
Participant 026\_2023AULUC

*I'm a baby boomer, so we all think we'll live forever and we stay young forever. I'm a fairly positive person. I've had prostate cancer, I've had eye surgery, and I had another surgery on my bladder, and I've had bypass surgery, I had hernia surgeries. I've had quite a few surgeries over the years and I'm still here, which is good. At the moment I'm doing a fitness program through Deakin University, and I'm probably fitter now than I was 20 years ago. The only problem, I suffer from chronic fatigue, which is at the moment, this week, it's affecting me. I haven't been doing strenuous work around the house and exercise. I'm a bit going backwards as far as my fitness because of this chronic fatigue thing, but then I'll hopefully*

*recover in the next few days. Sometimes it lasts a day, sometimes a few days, sometimes a few weeks. I never know. I just roll with it.*  
Participant 028\_2023AULUC

### Participant describes the importance of understanding their limitations

*As I say, it's going to be a gradual reintroduction of some of the things that up to now I haven't been able to do. Getting back into the gardening, being more physical with the grandkids, getting back into the housework that my husband's taken over. Is that the sort of thing you mean?*  
Participant 010\_2023AULUC

*No, there's no great adjustment. Just at my age, it comes with it too because the lung cancer has slowed me down a bit. That's about all.*  
Participant 012\_2023AULUC

*Yes, at this point, it's not really stopping me from doing much on a day-to-day basis. I mean, it's slowed me down definitely, but yes, it's not really affecting me day-to-day.*  
Participant 014\_2023AULUC

### Participant describes the importance of complying with treatment

*I go to yoga. I go on big long walks with my friends, and obviously, I take your sleeping tablet and the antidepressant. I'd really love to get off the antidepressants because you don't have the highs and the lows and you just flat line at okay and that's just not me. You lose a little bit of empathy. Maybe that's a good thing because it stops you from crying. Obviously, psychologists. Just help with everyday things like grocery shopping. I do order online and then go and pick it up. You just trying to continually conserve your energy because it's tiring. It's just debilitating. Whether it's the cancer or the medication, it is exhausting. Walking through the essential, I know there are walking clubs out there for people with lung cancer but I'd rather leave them to*

*the older people at this stage because I'm a young 50-year-old but I was 47 when I was diagnosed. My kids had gone from being told and growing to living with it.*

*Participant 019\_2023AULUC*

*I have reduced things that I do on a day-to-day basis, but I can sort of do the things. I just monitor my temperature and just taking my vitamins, and sometimes Panadol and sometimes Nurofen, that's how I deal with it.*

*Participant 004\_2023AULUC*

#### **Participant describes maintaining a healthy diet**

*I've got to try and keep myself as fit as possible, which I try. Make sure I try and walk every day. Well, my naturopath said Infrared Sauna's really good. I'm doing that. I'm just trying to keep myself and I'm trying to eat as healthy as I can*

*Participant 001\_2023AULUC*

*Well, that's the only thing because I always eat well anyway. I probably just made it a little bit more refined by making vegetable and fruit pieces every day, instead of drinking a lot of coffee like I used to. I now drink more healthier food and juice, which the body needs right now to help it through this, but other than, nothing. I'm hanging out for my first read, I'm waiting.*

*Participant 017\_2023AULUC*

#### **Participant describes the importance of maintaining a normal routine**

*As I say, it's going to be a gradual reintroduction of some of the things that up to now I haven't been able to do. Getting back into the gardening, being more physical with the grandkids, getting back into the housework that my husband's taken over. Is that the sort of thing you mean?*

*Participant 010\_2023AULUC*

*We had really good systems in place. As soon as dad got cancer, as a carer, we changed the way that he took his medications. We now pack them in a blister pack. There's-- Oh, I don't know, I'm lost for words. Sorry. We've started a routine where he has a shower in the morning, not the evening because his breathing's a little bit better. It's just about planning as a carer. I've had to plan a little bit more than what I probably did with dad but I guess respecting him as a person and him as an adult as well and as my dad.*

*Participant 030\_2023AULUC*

#### **Participant describes the importance of self care e.g. more rest, support for housework etc.**

*I need to get more sleep. I probably used to get by on six hours sleep and I find now I need minimum of eight, some days nine hours sleep. I am walking and-- I finally got walking go to gym regularly. I think that helps my mental health more than anything, but it does help my breathing a bit. I'm trying everything. I don't know how I'll go back at work, going up a flight of stairs if I have to rush around. That's when I get into trouble. If I pace myself with everything, I can do everything but I have to slow everything down.*

*Participant 025\_2023AULUC*

*I'm a baby boomer, so we all think we'll live forever and we stay young forever. I'm a fairly positive person. I've had prostate cancer, I've had eye surgery, and I had another surgery on my bladder, and I've had bypass surgery, I had hernia surgeries. I've had quite a few surgeries over the years and I'm still here, which is good. At the moment I'm doing a fitness program through Deakin University, and I'm probably fitter now than I was 20 years ago. The only problem, I suffer from chronic fatigue, which is at the moment, this week, it's affecting me. I haven't been doing strenuous work around the house and exercise. I'm a bit going backwards as far as my fitness because of this chronic fatigue thing, but then I'll hopefully recover in the next few days. Sometimes it lasts a day, sometimes a few days, sometimes a few weeks. I never know. I just roll with it.*

*Participant 028\_2023AULUC*

#### **Participant describes socialising with friends and/or family**

*As I said, I've now quit work, I've sold out my house, I've sorted out all my affairs and I live on a farm. I do a lot of gardening. I do a lot of knitting, I do some painting. I do a lot of relaxing, traveling, spend time with the family.*

*Participant 006\_2023AULUC*

*I go to yoga. I go on big long walks with my friends, and obviously, I take your sleeping tablet and the antidepressant*

*Participant 019\_2023AULUC*

*The both what I do is I exercise regularly. Soon after my diagnosis, we got a dog because we used to have dogs, and I thought this was great. This gives a reason that you get up and go each day because she's not going to let you lie in bed and be miserable. It's*

*keeping up my social relationships, making sure I keep in contact with friends, family, and meet up with them. That's very important to me, too. I love my cycling, and getting back on the bike after I had my brain surgery was so important and I do that socially, as well. I love it. I love exercise, so getting up and keeping up exercise it has been very important mentally and physically great for me and helps me manage a whole lot of things. I haven't really changed life to work around the minor side effects of the drugs. The one thing I did change was obviously working because physically I'm more tired. At times, I will be kind to myself and let myself have an [unintelligible 00:36:52] if I need it, and not push myself when I really, really feel tired.*

*Participant 020\_2023AULUC*

### **Participant describes the importance of being organised and planning ahead**

*I think I just need to fulfill my duty towards the kids, and that's it. You see, again, for me, it's also the collective. I pace myself, I organize myself. I think the thing I have to do every day is to focus on the care of the kids, and if I focus on the care of the kids, I will survive longer.*

*Participant 023\_2023AULUC*

*We had really good systems in place. As soon as dad got cancer, as a carer, we changed the way that he took his medications. We now pack them in a blister pack. There's-- Oh, I don't know, I'm lost for words. Sorry. We've started a routine where he has a shower in the morning, not the evening because his breathing's a little bit better. It's just about planning as a carer. I've had to plan a little bit more than what I probably did with dad but I guess respecting him as a person and him as an adult as well and as my dad.*

*Participant 030\_2023AULUC*

### **Participant describes using mindfulness and or meditation to maintain their health**

*I have a heap of vitamins that I take every day. I exercise nearly every day, either walking or at the gym or whatever because HIIT exercises have been proven to be the best form of exercises to prevent re-occurrence. I ate pretty well, previously, but I now try to eat as organically as possible. I drink filtered water. I don't drink any of the council waters whatsoever. Just stuff like that, I try to do. I have a mantra or a meditation that I go through every day because I believe the mind is very powerful and makes a difference. I still and will continue seeing my Reiki healer and my massage person because I still have a lot of tension that builds up in my muscles from worrying about, "Is it coming back?" Especially leading up to scans and things like that. I take a lot of vitamins. I have to take these tablets at night for my neuropathy and deal with the fatigue that comes with that and manage that sort of thing. I have to sleep with white noise because of the ringing in my ear. Because I can't get to sleep otherwise. If I get five hours sleep, that's a bonus. I've just adjusted to "This is how things are with me. This is how much I can do and how much I can't do, and then I have to stop because I know that I'll be too tired," so bits and pieces like that every day.*

*Participant 018\_2023AULUC*

*Well, mindset stuff, again, physical health stuff. Trying to keep myself as active as I can, which I do in any cases. That's me. Yes, I think that probably covers it.*

*Participant 021\_2023AULUC*

**Table 8.9: Regular activities to maintain health**

Regular activities to maintain general health	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes being physically active	13	50.00	13	52.00	0	0.00	6	60.00	7	43.75	10	62.50	3	30.00
Participant describes the importance of understanding their limitations	9	34.62	9	36.00	0	0.00	5	50.00	4	25.00	8	50.00	1	10.00
Participant describes the importance of complying with treatment	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	4	25.00	0	0.00
Participant describes maintaining a healthy diet	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	4	25.00	0	0.00
Participant describes the importance of maintaining a normal routine	4	15.38	3	12.00	1	100.00	1	10.00	3	18.75	3	18.75	1	10.00
Participant describes the importance of self care e.g. more rest, support for housework etc.	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	2	12.50	2	20.00
Participant describes socialising with friends and/or family	4	15.38	4	16.00	0	0.00	0	0.00	4	25.00	4	25.00	0	0.00
Participant describes the importance of being organised and planning ahead	3	11.54	2	8.00	1	100.00	0	0.00	3	18.75	2	12.50	1	10.00
Participant describes using mindfulness and or meditation to maintain their health	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	1	6.25	2	20.00

Regular activities to maintain general health	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes being physically active	13	50.00	9	52.94	4	44.44	6	46.15	7	53.85	1	50.00	12	50.00	3	33.33	10	58.82
Participant describes the importance of understanding their limitations	9	34.62	7	41.18	2	22.22	3	23.08	6	46.15	1	50.00	8	33.33	3	33.33	6	35.29
Participant describes the importance of complying with treatment	4	15.38	4	23.53	0	0.00	0	0.00	4	30.77	1	50.00	3	12.50	2	22.22	2	11.76
Participant describes maintaining a healthy diet	4	15.38	2	11.76	2	22.22	2	15.38	2	15.38	0	0.00	4	16.67	2	22.22	2	11.76
Participant describes the importance of maintaining a normal routine	4	15.38	1	5.88	3	33.33	3	23.08	1	7.69	0	0.00	4	16.67	0	0.00	4	23.53
Participant describes the importance of self care e.g. more rest, support for housework etc.	4	15.38	2	11.76	2	22.22	2	15.38	2	15.38	0	0.00	4	16.67	0	0.00	4	23.53
Participant describes socialising with friends and/or family	4	15.38	4	23.53	0	0.00	2	15.38	2	15.38	1	50.00	3	12.50	2	22.22	2	11.76
Participant describes the importance of being organised and planning ahead	3	11.54	1	5.88	2	22.22	2	15.38	1	7.69	1	50.00	2	8.33	1	11.11	2	11.76
Participant describes using mindfulness and or meditation to maintain their health	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	0	0.00	3	12.50	0	0.00	3	17.65

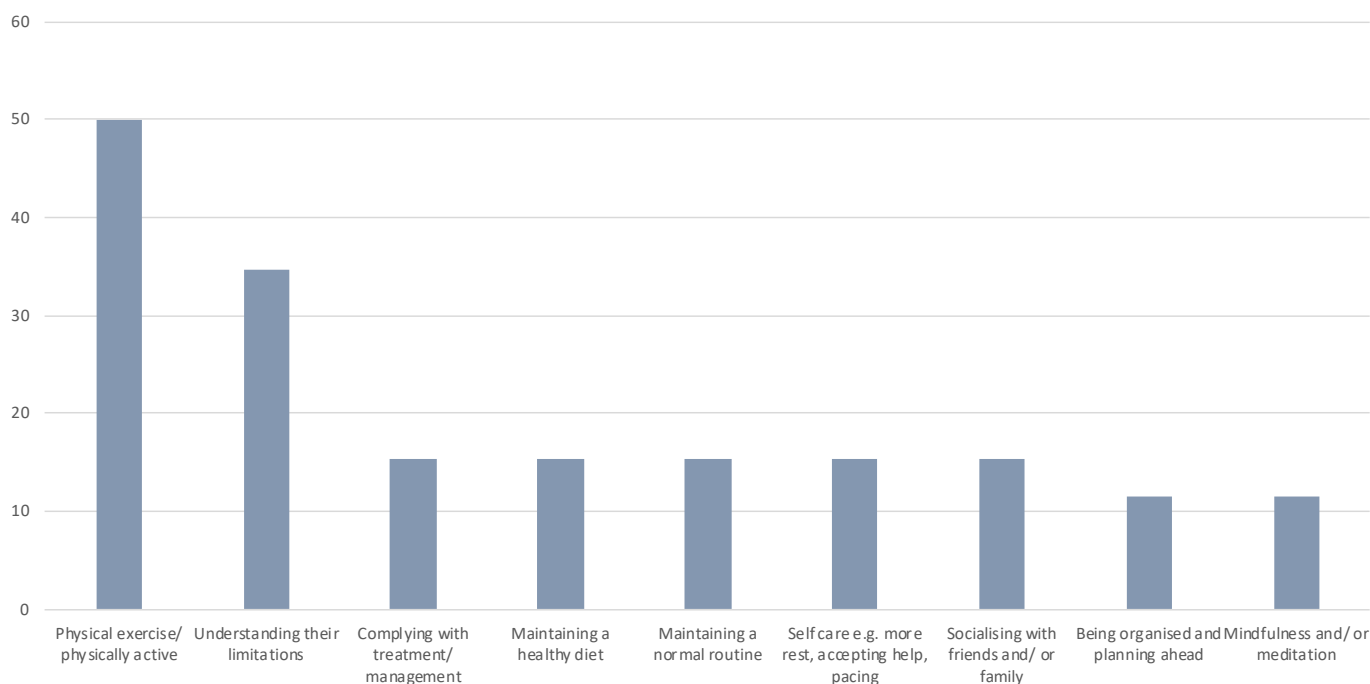


Figure 8.5: Regular activities to maintain health

Table 8.10: Regular activities to maintain health – subgroup variations

Theme	Less frequently	More frequently
Participant describes being physically active	Male Mid to low status	Female
Participant describes the importance of understanding their limitations	Male Aged 65 or older Trade or high school	Non-metastatic Female University
Participant describes the importance of complying with treatment	Male Aged 65 or older Trade or high school	University
Participant describes maintaining a healthy diet	Male	
Participant describes the importance of maintaining a normal routine	Mid to low status	Aged 65 or older
Participant describes the importance of self care e.g. more rest, support for housework etc.	Mid to low status	
Participant describes socialising with friends and/or family	Non-metastatic Male Aged 65 or older	
Participant describes the importance of being organised and planning ahead	Non-metastatic	Aged 65 or older
Participant describes using mindfulness and or meditation to maintain their health	Mid to low status	

## Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. The most common responses were that they felt vulnerable when having sensitive discussions (diagnosis, treatment decision) (30.77%), and vulnerable during/after treatments (19.23%). Other times when participants felt vulnerable included when feeling sick

or unwell (11.54%), vulnerable because of interactions with the medical team (11.54%), and vulnerable in general (11.54%). Some participants described that they did not feel vulnerable (11.54%).



**Participant describes feeling vulnerable when having sensitive discussion, for example at diagnosis or when making treatment decisions**

*Now. As soon as they find that mass or nodule in your lung, that's when you become vulnerable*  
Participant 003\_2023AULUC

*Every time there's a progression, apart from when you first get diagnosed and then every time there's a progression, or there's like a wait-and-see or you've got symptoms, that's when you feel vulnerable.*  
Participant 004\_2023AULUC

*Probably right at the beginning because I didn't know what was going to happen.*  
Participant 013\_2023AULUC

*Probably just at the start before the doctors even know how bad it is.*  
Participant 026\_2023AULUC

**Participant describes feeling vulnerable while having treatments or the period following treatments**

*Yes, quite often. In particular, I felt vulnerable when somebody's doing brain radiation to your head. That's the most vulnerable I felt. Very scary.*  
Participant 007\_2023AULUC

*This time I ended up in hospital. My biggest concern, these days they're trying to get you out of hospital as fast as possible, which some ways it's good. In my experience, I don't mind being in hospitals. I'm in no rush to go home. I live alone. My son lives virtually next door to me, so I'm alone but not alone. I've always asked to stay a bit longer. If I could, I've always tried to get an extra day or two in hospital. This time around because of the complications with my lung draining or whatever, not draining properly, they kept me there. Instead of five days I ended up being there for nine days. That was good.*  
Participant 028\_2023AULUC

**Participant describes feeling vulnerable when feeling sick or unwell**

*Well, basically, there was a few times-- Most of the time I was on, what do you call drugs-- High dosage drugs. It was only a few weeks ago that my wife and I were talking and she said sometimes she'd visit me and I didn't even know where I was because I was allowed to have this drug every four hours because of*

*the pain. Oh, I can't remember the name of it. I was getting two types of pain relief, both drugs, and one I can have every four hours, and trust me, I was having it every four hours. It was because of my esophagus. It wasn't my lung, it was my esophagus was the main problem. After the chemotherapy and radiation, the tumor was shrinking, and everything was happy. The problem with my case was the esophagus, the burn, and that led to loss of weight, loss of appetite, and having to take barbiturates or whatever they are on high dosage.*

Participant 012\_2023AULUC

*I was very vulnerable when I was really sick with the chemo, really vulnerable. I really felt dreadful because they do give you a list of "Let us know when this happens, that happens." I'd ring-- I rang twice and said, "Well this is happening," and both times the response was you need to go to an emergency department and that was my multidisciplinary team providing assistance. I knew that was COVID and I'm neutropenic. You're not going to go and sit in an emergency department, are you?*

Participant 025\_2023AULUC

**Participant describes feeling vulnerable because of interactions with the medical team**

*PARTICIPANT: Yes, totally. When you don't know what's going on or you sit there and like for an example, one of the radiation oncologists, we had to meet them on [unintelligible 00:33:16], and it wasn't my regular. It was with another guy, and he said, "How you feeling?" I said, "I'm still pretty short on breath." Because radiation does make you very short on breath. I kept having this goal in my head of "I'm moving myself forward to being cancer free. I'm moving myself forward. He was like, "That could be as good as it gets. You may not get you better. You could just be like this for the rest of your natural life." Then I got a bit teary and, bang, the next thing, he was talking to the nurse and saying, "We want NAME to see a psychologist." It's like as soon as you get emotional, they just, "Oh, how's your mental health?" You think, "My mental health is not too bad, all things considered. You, be given all this news and go through everything I've gone through and see how your mental health is." I thought it was okay, but they just brush you straight off to a psychologist, instead of just having a conversation with you.*

Participant 018\_2023AULUC

*In the hospital? Yes, definitely. Even there's no toothbrushes in the hospital. This is just disgusting, but I was in theater roads and had my period and I was bleeding everywhere. That was the last line, but it was like, what is going on here? Just little things like that.*

*It was a very bad hospital thing. If it wasn't that bad, I may have been a lot more better when I left the hospital, but I was an absolute mess when I left the hospital.*

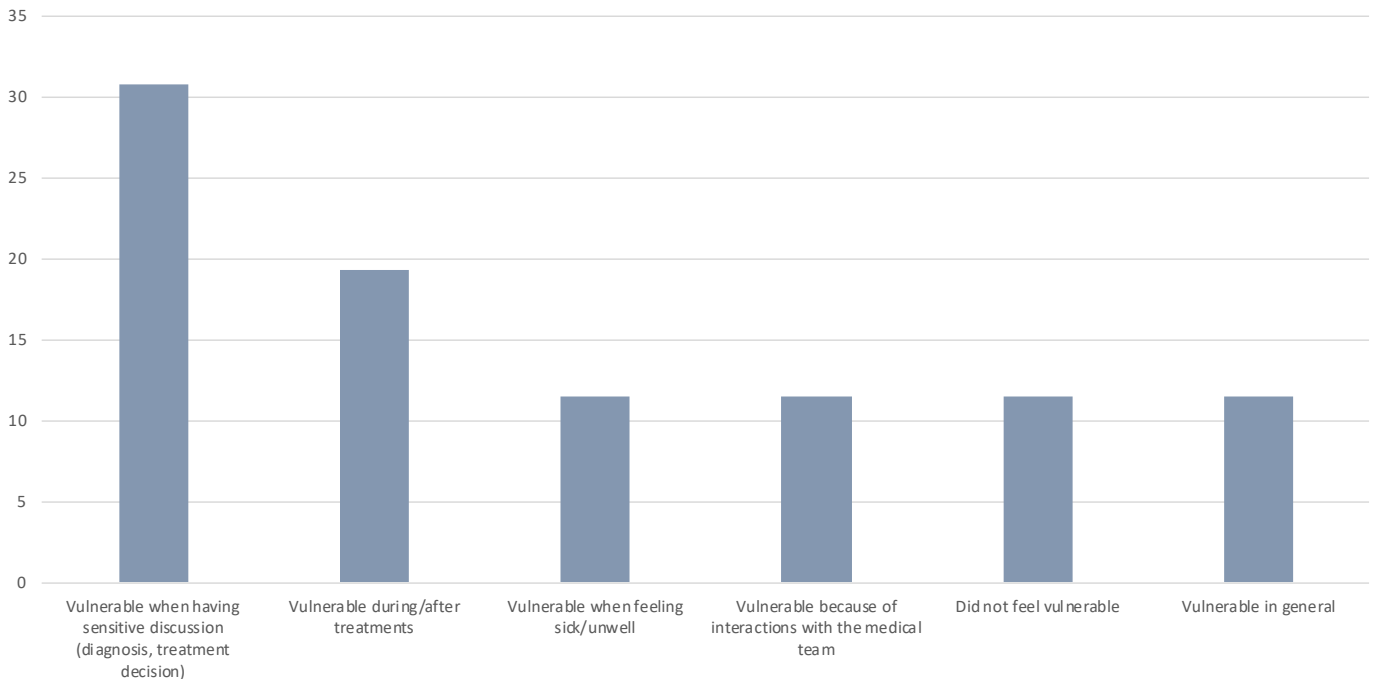
*Participant 019\_2023AULUC*

**Table 8.11: Experience of vulnerability**

Experience of vulnerability	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes feeling vulnerable when having sensitive discussion, for example at diagnosis or when making treatment decisions	8	30.77	8	32.00	0	0.00	3	30.00	5	31.25	6	37.50	2	20.00
Participant describes feeling vulnerable while having treatments or the period following treatments	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	4	25.00	1	10.00
Participant describes feeling vulnerable when feeling sick or unwell	3	11.54	3	12.00	0	0.00	3	30.00	0	0.00	2	12.50	1	10.00
Participant describes feeling vulnerable because of interactions with the medical team	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00
Participant describes that they did not feel vulnerable	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	3	18.75	0	0.00
Participant describes feeling vulnerable in general without giving a description	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	2	12.50	1	10.00

Experience of vulnerability	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes feeling vulnerable when having sensitive discussion, for example at diagnosis or when making treatment decisions	8	30.77	7	41.18	1	11.11	3	23.08	5	38.46	1	50.00	7	29.17	4	44.44	4	23.53
Participant describes feeling vulnerable while having treatments or the period following treatments	5	19.23	3	17.65	2	22.22	3	23.08	2	15.38	0	0.00	5	20.83	0	0.00	5	29.41
Participant describes feeling vulnerable when feeling sick or unwell	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	0	0.00	3	12.50	0	0.00	3	17.65
Participant describes feeling vulnerable because of interactions with the medical team	3	11.54	3	17.65	0	0.00	1	7.69	2	15.38	0	0.00	3	12.50	1	11.11	2	11.76
Participant describes that they did not feel vulnerable	3	11.54	1	5.88	2	22.22	2	15.38	1	7.69	1	50.00	2	8.33	2	22.22	1	5.88
Participant describes feeling vulnerable in general without giving a description	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	0	0.00	3	12.50	2	22.22	1	5.88



**Figure 8.6: Experience of vulnerability**

**Table 8.12: Experience of vulnerability – subgroup variations**

Theme	Less frequently	More frequently
Participant describes feeling vulnerable when having sensitive discussion, for example at diagnosis or when making treatment decisions	Male Aged 65 or older	Aged 35 to 64 Mid to low status
Participant describes feeling vulnerable while having treatments or the period following treatments	Mid to low status	Higher status
Participant describes feeling vulnerable when feeling sick or unwell	Metastatic Mid to low status	Non-metastatic
Participant describes feeling vulnerable because of interactions with the medical team	Male Aged 65 or older	
Participant describes that they did not feel vulnerable	Male	Aged 65 or older Mid to low status
Participant describes feeling vulnerable in general without giving a description		Mid to low status

## Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common response was self-help (resilience, acceptance, staying positive) to manage the feeling of vulnerability (30.77%). This was followed by support from family and friends to manage the feeling of vulnerability (7.69%), and being supported by nurse or treatment team (7.69%).

**Participant describes that self help, for example resilience, acceptance, and staying positive, helped them manage feeling vulnerable**

*I've got to just try and think positive. I don't know what else I can do. I don't want to focus on this cancer all the time because that is such a downer.*  
Participant 001\_2023AULUC

*I just get through it. I get through it. I get out the other side. Luckily for me, I've had good scans every time and the doctors told me, "Yes, everything's fine," and I've relaxed again for a while but yes, there's nothing you can really do*  
Participant 002\_2023AULUC

*Really just a lot of stuff that I tend to do in any case, which is to do with my mindset and just focus on the positives and appreciating everything around you and appreciate the people where you live, natural beauty, all those sorts of things, to just put your mind in a better place where you start looking for the positives and not the negatives*  
Participant 021\_2023AULUC

**Participant describes that support from family and friends helped them manage feeling vulnerable**

*PARTICIPANT: When I was first diagnosed, I said to my husband, "I'm never going to see my son walk, crawl, or talk. I'm never going to see my daughter start her first day at school." I was grieving all the things that I*

*never thought I would see. He told me I would. He reminded me of a time that he said was like climbing Mount Everest. He said, "You just have to remember when you look down from the top, it's easy to remember how you got there." He said, if I can do it, then I could do it again now. Then I worked with a neuro-linguistic programming guy. He helped to reset my values and my beliefs, he challenged my thoughts. We did a lot of visualization every week, twice a week. Just on empowering my mind to get stronger and to improve what I was going to dream of in the future. There's been another time when it spread to my brain. I thought, "Okay, this is it. Things are only going to get worse," so we went on our trip to Disney World. Just, I think, focusing on making as many memories as we can with each other. That's been the main focus. My husband had to refocus me and remind me that that's what our goal is, that's all we want to do. That has helped. Look, there's been lots of other times, but let's just stick to that.*

Participant 015\_2023AULUC

*Honestly, I don't know. I think there is a point where you're in just shock. I think at that point, we probably need emotional support, and I've got that through home. Yes, there's probably a point where if someone doesn't have that they need to have someone they can talk to who isn't a specialist, but can just talk a little bit about the emotional side and a bit of reassurance that you'll get there, you'll get it under your belt. More of counseling sort of thing*

Participant 020\_2023AULUC

Participant describes that support from nurses or their treatment team helped them manage feeling vulnerable

*I go to my GP and I get him to reassure me, but that's about the only way.*

Participant 014\_2023AULUC

*This time I ended up in hospital. My biggest concern, these days they're trying to get you out of hospital as fast as possible, which some ways it's good. In my experience, I don't mind being in hospitals. I'm in no*

*rush to go home. I live alone. My son lives virtually next door to me, so I'm alone but not alone. I've always asked to stay a bit longer. If I could, I've always tried to get an extra day or two in hospital. This time around because of the complications with my lung draining or whatever, not draining properly, they kept me there. Instead of five days I ended up being there for nine days. That was good.*

Participant 028\_2023AULUC

Table 8.13: Methods to manage vulnerability

Methods to manage vulnerability	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes that self help, for example resilience, acceptance, and staying positive, helped them manage feeling vulnerable	8	30.77	8	32.00	0	0.00	3	30.00	5	31.25	6	37.50	2	20.00
Participant describes that they did not feel vulnerable	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	3	18.75	0	0.00
Participant describes that support from family and friends helped them manage feeling vulnerable	2	7.69	2	8.00	0	0.00	0	0.00	2	12.50	2	12.50	0	0.00
Participant describes that support from nurses or their treatment team helped them manage feeling vulnerable	2	7.69	2	8.00	0	0.00	2	20.00	0	0.00	1	6.25	1	10.00

Methods to manage vulnerability	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes that self help, for example resilience, acceptance, and staying positive, helped them manage feeling vulnerable	8	30.77	7	41.18	1	11.11	2	15.38	6	46.15	0	0.00	8	33.33	2	22.22	6	35.29
Participant describes that they did not feel vulnerable	3	11.54	1	5.88	2	22.22	2	15.38	1	7.69	1	50.00	2	8.33	2	22.22	1	5.88
Participant describes that support from family and friends helped them manage feeling vulnerable	2	7.69	2	11.76	0	0.00	1	7.69	1	7.69	0	0.00	2	8.33	0	0.00	2	11.76
Participant describes that support from nurses or their treatment team helped them manage feeling vulnerable	2	7.69	1	5.88	1	11.11	1	7.69	1	7.69	0	0.00	2	8.33	1	11.11	1	5.88

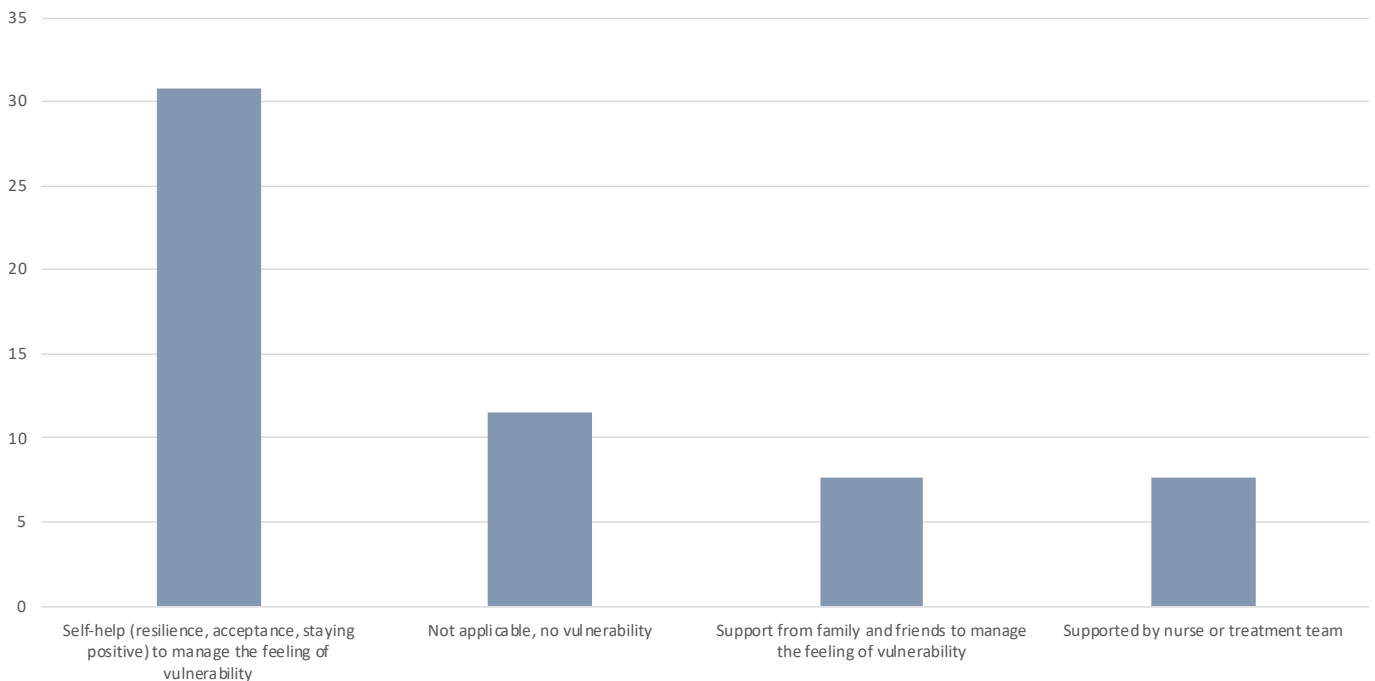


Figure 8.7: Methods to manage vulnerability

Table 8.14: Methods to manage vulnerability– subgroup variations

Theme	Less frequently	More frequently
Participant describes that self help, for example resilience, acceptance, and staying positive, helped them manage feeling vulnerable	Male Aged 65 or older Trade or high school	Aged 35 to 64 University
Participant describes that they did not feel vulnerable	Male	Aged 65 or older Mid to low status
Participant describes that support from nurses or their treatment team helped them manage feeling vulnerable	-	Non-metastatic

## Impact on relationships

Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (30.77%). Other participants descriptions suggested that overall, there was an impact on relationships that was both positive and negative (23.08%), there was a positive impact on relationships (19.23 %), there no impact on relationships (15.38%), and that, there was an impact on relationships that was neither positive nor negative (7.69%).

The most common themes in relation to having a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships (34.62%), and that the dynamics of relationships changed due to anxiety, exacerbations and/or physical limitations of condition (23.08 %).

The most common themes in relation to having a positive impact on relationships from family relationships being strengthened(30.77%), and from people being well-meaning and supportive) (19.23%).

### **Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships**

*Well, I think my friends, I think they're all waiting for me to die. I think it's changed it that way and I don't want people feeling sorry for me. I just want to be the same person. You know what I mean?*

**INTERVIEWER:** Yes.

**PARTICIPANT:** *I think people look at you differently. You know what I mean?*

**Participant 001\_2023AULUC**

*Yes definitely. Definitely. You realize who is actually supportive and who's gutless and runs away. You end up with a very small bubble around you of people that actually care about you, but after a year you realize that that's all you need. You don't need these other people that are cowards, that can't say the right thing. You learn that you just don't need them, and everything's better with just a small group of people that support you.*

**INTERVIEWER:** *That must have been a hard time though, going through that realization.*

**PARTICIPANT:** *Yes, it was a hard time for a year, but then where I am now, I think I'm a lot happier because I only have people that are just loving, kind, supportive. Anyone else who tries to tell me to eat more vegetables or crap like that, that, "You can heal,*

*just eat more veggies," I don't speak to them anymore and I'm a lot happier, and it's good*  
**Participant 004\_2023AULUC**

*I think in some ways yes, mainly because I have a-- I think some people became strange or standoffish because I've got in some. Do you know what I mean? There's a whole range of other things associated with that.*

**Participant 026\_2023AULUC**

### **Participant describes relationships with family being strengthened**

*It's made them better. A lot more honest, because I've got limited time now. I tell people I love them a lot more. I hang out a lot more with them.*

**Participant 006\_2023AULUC**

*I think it's probably made us a lot closer because I feel, perhaps, my life's been compromised, and I won't live for as long as I, perhaps, should. I'm not through my first five years, so, therefore, I don't know-- Only what, 18% make it through the first five years? I have every intention of doing that. I think I try to be as positive as I can with my personal relationships, and, yes, I think it has made a difference in that regard.*

**Participant 018\_2023AULUC**

*It sorts out who's very close to you, who can handle it, and who you can talk frankly about what's coming up and how you feel. You really work at who's very close to you, and who's a step removed. It hasn't impacted negatively on any of those. I feel in a lot of ways it's made my husband and I who has a great relationship actually go, "Okay, we're in this together." It's brought us closer. I've got great relationship with my two kids. I've done my best not to let it be in forefront of their mind that I have this disease so all of that it's been about managing it positively. The more with it mentally, physically the people see me, the better they see me the less everyone else is worried, and unless I worry. I don't think it's had a huge impact. I think if anything, it's made some relationships closer.*

**Participant 020\_2023AULUC**

**Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition**

*Yes, it has. It has because I'm limited to where I can go and what I can do on the time limit to be out of the house given that is a false risk.  
Participant 030\_2023AULUC*

*Yes, it has. Definitely. I'm no longer as sociable as I was before. I don't cope too well with large groups of people, so it had an impact on my social skills as well as my ability to want to do things. I hold back  
Participant 007\_2023AULUC*

*Well, I have a son and a daughter. They're just as stressed as what I am, as I've said about my son. It's caused him a great deal of anxiety, a great deal of stress. My daughter's in Brisbane, so we talk on the phone, and we text, but I haven't seen her for since September last year. They're just as worried as what I am and I try very hard not to complicate the matter and not to be down or let them know exactly how I'm feeling, so basically I'm lying to them. I have two friends that I can talk to and they're there for me if I need them. That's it.  
Participant 003\_2023AULUC*

**Participant describes a positive impact on relationships as people were well meaning and supportive**

*It has, but also in a positive way. When I first ended up in hospital with a seizure, it was just before COVID,*

*so visiting was not an issue. I was in a hospital for 10 days, I had so many people come and see me and there were people that I hadn't seen for a long time that we just had lost connection with. Not a falling out, just a connection with and we rediscover those friendships and relationships. That was a real positive experience. Something really positive to come out of that negative situation and we have maintained those friendships. Yes, it does affect my relationship with my husband, especially at the moment because he's become the carer as well. Affects your relationships like that, but I can also see how I've experienced seeing other cancer patients a [unintelligible] actually. Someone, she passed away, but her marriage fell apart during her cancer treatment. The husband left her and I can understand that now why that would have happened because it can put a strain on your relationship. That's why I said to my husband from the start, he needs the counseling as well as me. He's been to one of the recent psychology sessions with me just to talk about things. Even I suppose with my kids, especially with this last diagnosis, I said to my son we have to embrace every moment we have together, we have to cherish every moment we have together. Keep creating memories because we just don't know.*

*Participant 005\_2023AULUC*

*If anything, it slightly improved it. Particularly with friends, I send out a report after every scan that I have, I'm going to say, report-- It's a brief email just saying how things are going. My friends enjoy getting that information and I enjoy writing it. I'm not sure what more I can say on that.*

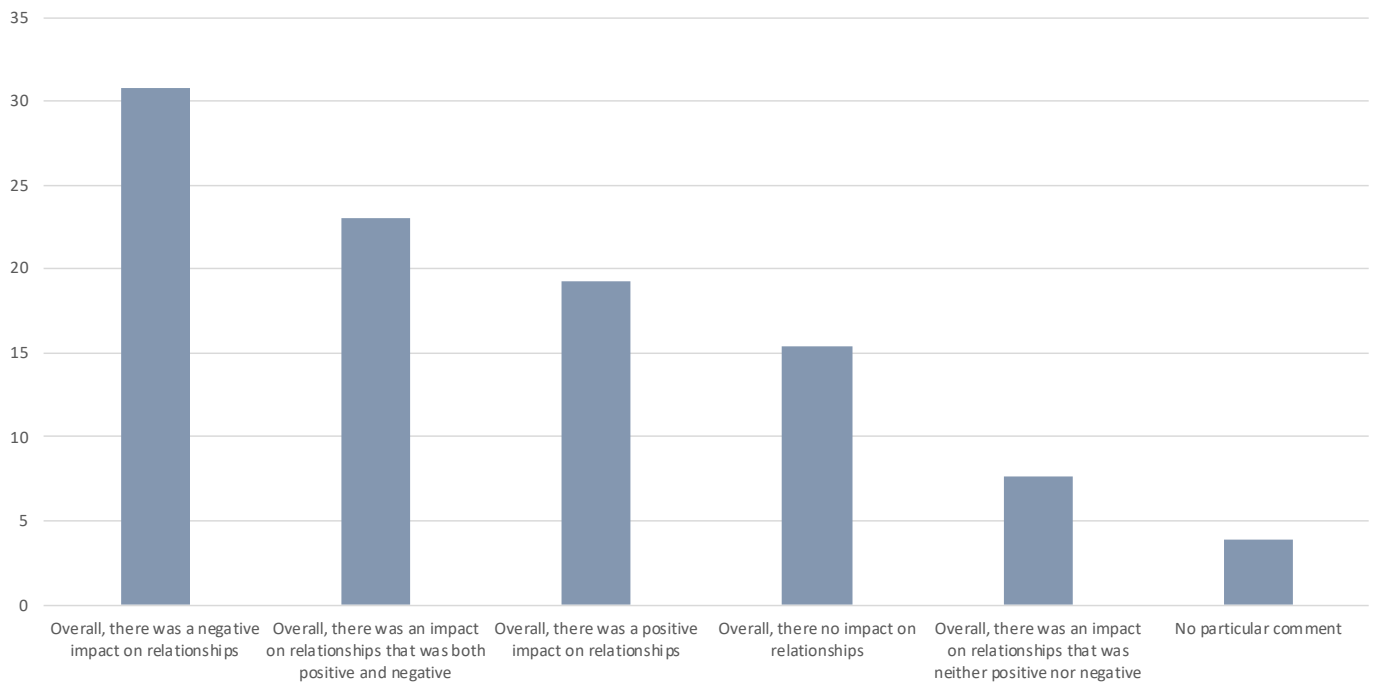
*Participant 022\_2023AULUC*

**Table 8.15: Impact on relationships**

Impact on relationships	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Overall, there was a negative impact on relationships	8	30.77	7	28.00	1	100.00	3	30.00	5	31.25	7	43.75	1	10.00
Overall, there was an impact on relationships that was both positive and negative	6	23.08	6	24.00	0	0.00	2	20.00	4	25.00	5	31.25	1	10.00
Overall, there was a positive impact on relationships	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	3	18.75	2	20.00
Overall, there no impact on relationships	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	2	12.50	2	20.00
Overall, there was an impact on relationships that was neither positive nor negative	2	7.69	2	8.00	0	0.00	1	10.00	1	6.25	2	12.50	0	0.00
No particular comment	1	3.85	1	4.00	0	0.00	0	0.00	1	6.25	0	0.00	1	10.00

Impact on relationships	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Overall, there was a negative impact on relationships	8	30.77	5	29.41	3	33.33	4	30.77	4	30.77	1	50.00	7	29.17	4	44.44	4	23.53
Overall, there was an impact on relationships that was both positive and negative	6	23.08	6	35.29	0	0.00	3	23.08	3	23.08	0	0.00	6	25.00	2	22.22	4	23.53
Overall, there was a positive impact on relationships	5	19.23	3	17.65	2	22.22	1	7.69	4	30.77	1	50.00	4	16.67	1	11.11	4	23.53
Overall, there no impact on relationships	4	15.38	1	5.88	3	33.33	3	23.08	1	7.69	0	0.00	4	16.67	0	0.00	4	23.53
Overall, there was an impact on relationships that was neither positive nor negative	2	7.69	1	5.88	1	11.11	1	7.69	1	7.69	0	0.00	2	8.33	2	22.22	0	0.00
No particular comment	1	3.85	0	0.00	1	11.11	1	7.69	0	0.00	0	0.00	1	4.17	0	0.00	1	5.88



**Figure 8.8: Impact on relationships**

**Table 8.16: Impact on relationships – subgroup variations**

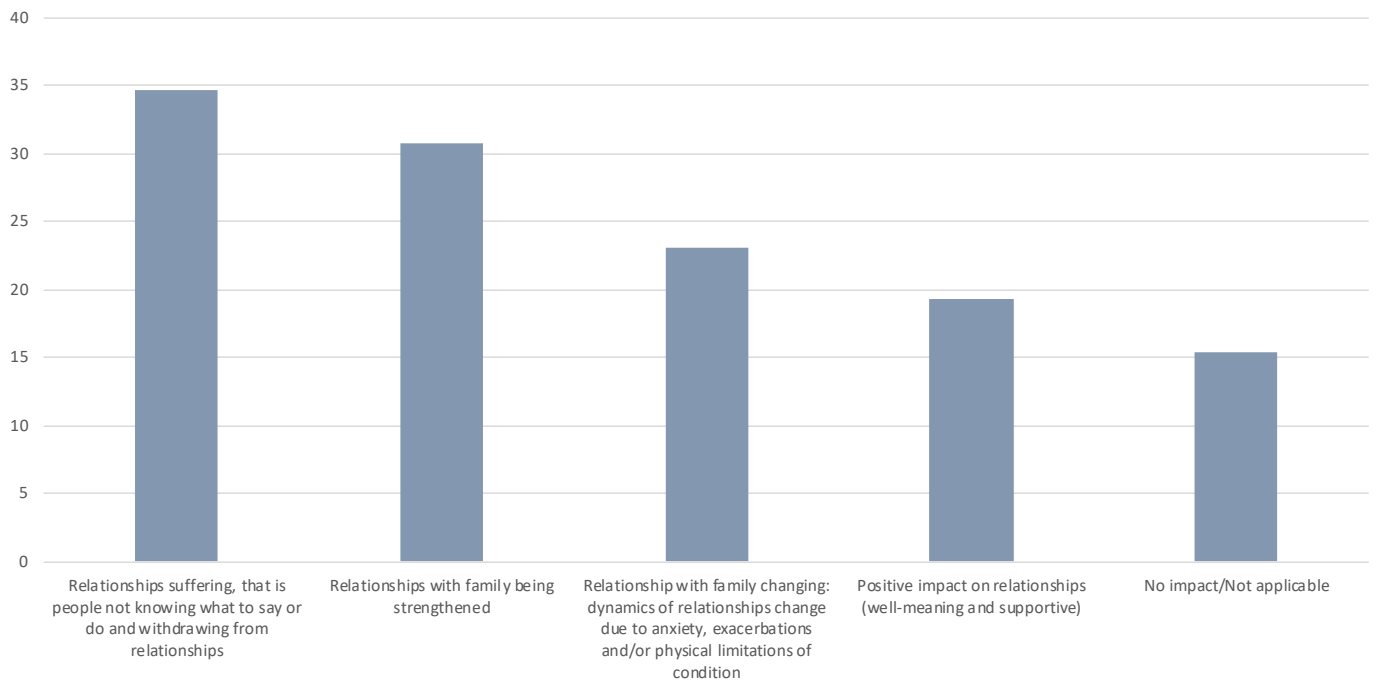
Theme	Less frequently	More frequently
Overall, there was a negative impact on relationships	Male	Female
Overall, there was an impact on relationships that was both positive and negative	Male Aged 65 or older	Mid to low status Aged 35 to 64
Overall, there was a positive impact on relationships	Trade or high school	University
Overall, there no impact on relationships	Mid to low status	Aged 65 or older
Overall, there was an impact on relationships that was neither positive nor negative	-	Mid to low status

**Table 8.17: Impact on relationships (Reason for impact)**

Impact on relationships (reasons)	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	9	34.62	9	36.00	0	0.00	3	30.00	6	37.50	8	50.00	1	10.00
Participant describes relationships with family being strengthened	8	30.77	8	32.00	0	0.00	4	40.00	4	25.00	6	37.50	2	20.00
Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition	6	23.08	5	20.00	1	100.00	2	20.00	4	25.00	5	31.25	1	10.00
Participant describes a positive impact on relationships as people were well meaning and supportive	5	19.23	5	20.00	0	0.00	1	10.00	4	25.00	3	18.75	2	20.00
Participant describes no impact on relationships	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	2	12.50	2	20.00

Impact on relationships (reasons)	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	9	34.62	8	47.06	1	11.11	3	23.08	6	46.15	0	0.00	9	37.50	3	33.33	6	35.29
Participant describes relationships with family being strengthened	8	30.77	6	35.29	2	22.22	3	23.08	5	38.46	1	50.00	7	29.17	1	11.11	7	41.18
Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition	6	23.08	4	23.53	2	22.22	4	30.77	2	15.38	1	50.00	5	20.83	3	33.33	3	17.65
Participant describes a positive impact on relationships as people were well meaning and supportive	5	19.23	4	23.53	1	11.11	1	7.69	4	30.77	0	0.00	5	20.83	2	22.22	3	17.65
Participant describes no impact on relationships	4	15.38	1	5.88	3	33.33	3	23.08	1	7.69	0	0.00	4	16.67	0	0.00	4	23.53



**Figure 8.9: Impact on relationships**

**Table 8.18: Impact on relationships: Reason for impact – subgroup variations**

Theme	Less frequently	More frequently
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	Male Aged 65 or older Trade or high school	Female Aged 35 to 64 University
Participant describes relationships with family being strengthened	Male Mid to low status	Higher status
Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition	Male	Mid to low status
Participant describes a positive impact on relationships as people were well meaning and supportive	Trade or high school	University
Participant describes no impact on relationships	Mid to low status	Aged 65 or older

## Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Most commonly, the descriptions suggested that overall, there was a burden on their family (76.92%). Other participants descriptions suggested that overall, there was not a burden on their family (15.38%).

The main reason that participant described their condition being a burden was from the mental and emotional strain placed on their family (38.46%).

### Overall, there was a burden on their family

*Oh, absolutely. My mother would cry nearly every day when she found out. She's elderly, she's in her 90s, and she was in the late 80s when I was diagnosed, and that's a terrible thing for a mother to have to deal with, to know that her daughter is so sick, and for me to know that she was so upset was terrible. I felt awful. I felt guilty making her feel that way. It's been a burden to my husband, work-wise, and his emotion,*

*not knowing when he was going to see me come out of surgery. There's lots of different impacts that happen that no one realizes.*

*Participant 018\_2023AULUC*

*Oh, God, yes. Yes, definitely. Although I'm no physical burden to them it's an emotional one and it's that psychological thing that you try and protect the people you love from but I know it had an impact on them. I do feel I'm concerned about the future impact as the disease progresses and need becomes more physical issue. I think it has had an emotional burden on them, of course. At the moment, there's no physical burden because I totally [unintelligible] gosh I'm just like I was pre-diagnosis, I don't feel any different. I'm not doing anything particularly different.*

*Participant 020\_2023AULUC*

*Well, yes, I do. I feel sorry because my daughter is living with us till she got a unit fixed up. I think she feels that she can't move out now because of me, but I want her to have a life. You know what I mean?*



**INTERVIEWER:** Yes.

**PARTICIPANT:** I think it's affected her and I think she worries a lot. My youngest son, he was so devastated when he found out. I wouldn't like to tell him anything bad now, you know what I mean? Everything's good. I worry about my kids and I worry about my grandkids. Anyway.

**INTERVIEWER:** Sounds really difficult.

**PARTICIPANT:** Can be sometimes. Yes. I do worry about them. That's what upsets me more than anything but them

**Participant 001\_2023AULUC**

**Overall, there was not a burden on their family**

*No, not really. One thing I'm aware of as I hear patients talk about the stigma and shame of the diagnosis and I've not felt a shred of that. I know that if I had been a long-term smoker, I would feel it, but I don't feel that at all about my condition. It was just*

*the short straw, in my view. It's been no problem at all.*

**Participant 022\_2023AULUC**

**PARTICIPANT:** Actually, I live next door to my son and I've got two granddaughters. Actually, I do more for them than they do for me. I do all my cleaning, I do my gardening, I do my washing. I do all my cooking. I bake. I baked nearly 800 different cakes. I don't get much sympathy from people because I look fairly...I also use a moisturizer. Actually, my granddaughter, a few years ago, she showed a photo of me with her and the person said, "You've got a very lovely grandfather. Looks he's really young," and my granddaughter says, "Yes, papa uses a moisturizer." Over the years, I'm slim fairly in good condition, so I have trouble getting sympathy from people because they look at me and say, "Oh, you must be okay. You are looking so good."

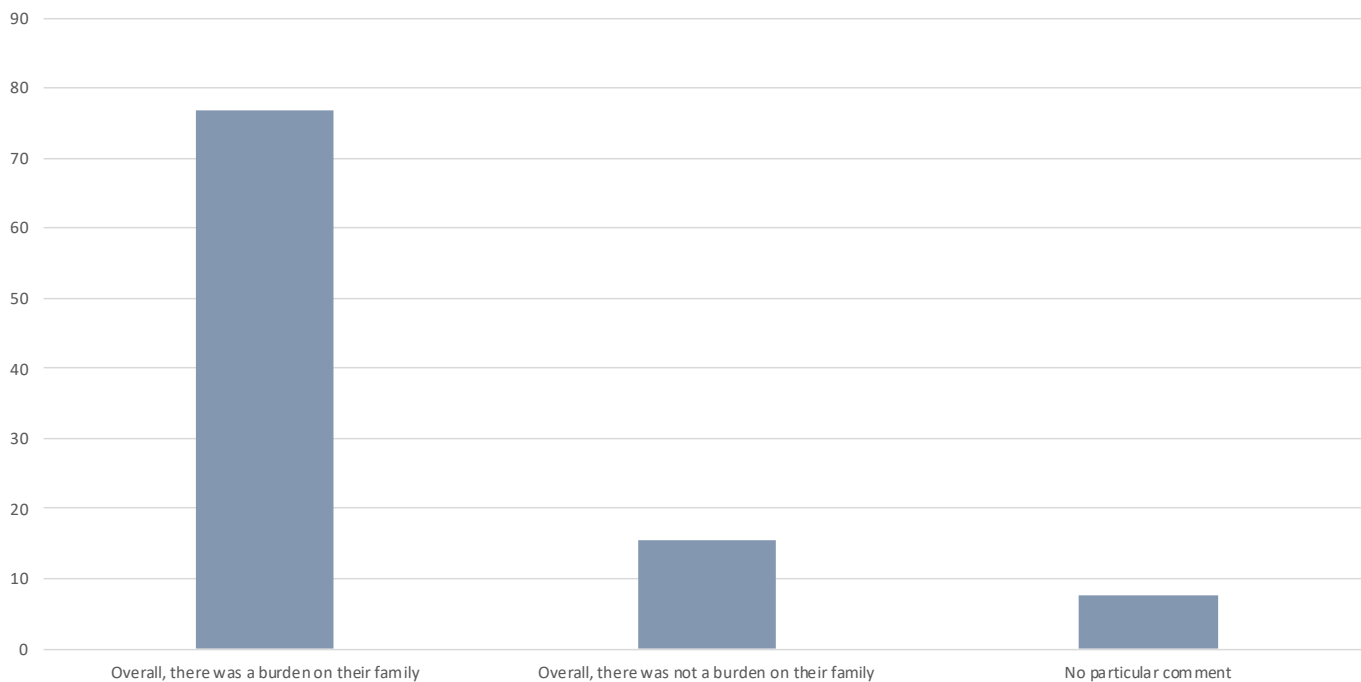
**Participant 028\_2023AULUC**

**Table 8.19: Burden on family**

Burden on family	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Overall, there was a burden on their family	20	76.92	19	76.00	1	100.00	6	60.00	14	87.50	17	106.25	3	30.00
Overall, there was not a burden on their family	4	15.38	4	16.00	0	0.00	3	30.00	1	6.25	1	6.25	3	30.00
No particular comment	2	7.69	2	8.00	0	0.00	1	10.00	1	6.25	1	6.25	1	10.00

Burden on family	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Overall, there was a burden on their family	20	76.92	14	82.35	6	66.67	9	69.23	11	84.62	2	100.00	18	75.00	8	88.89	12	70.59
Overall, there was not a burden on their family	4	15.38	1	5.88	3	33.33	3	23.08	1	7.69	0	0.00	4	16.67	1	11.11	3	17.65
No particular comment	2	7.69	1	5.88	1	11.11	1	7.69	1	7.69	0	0.00	2	8.33	0	0.00	2	11.76



**Figure 8.10: Burden on family**

**Table 8.20: Burden on family – subgroup variations**

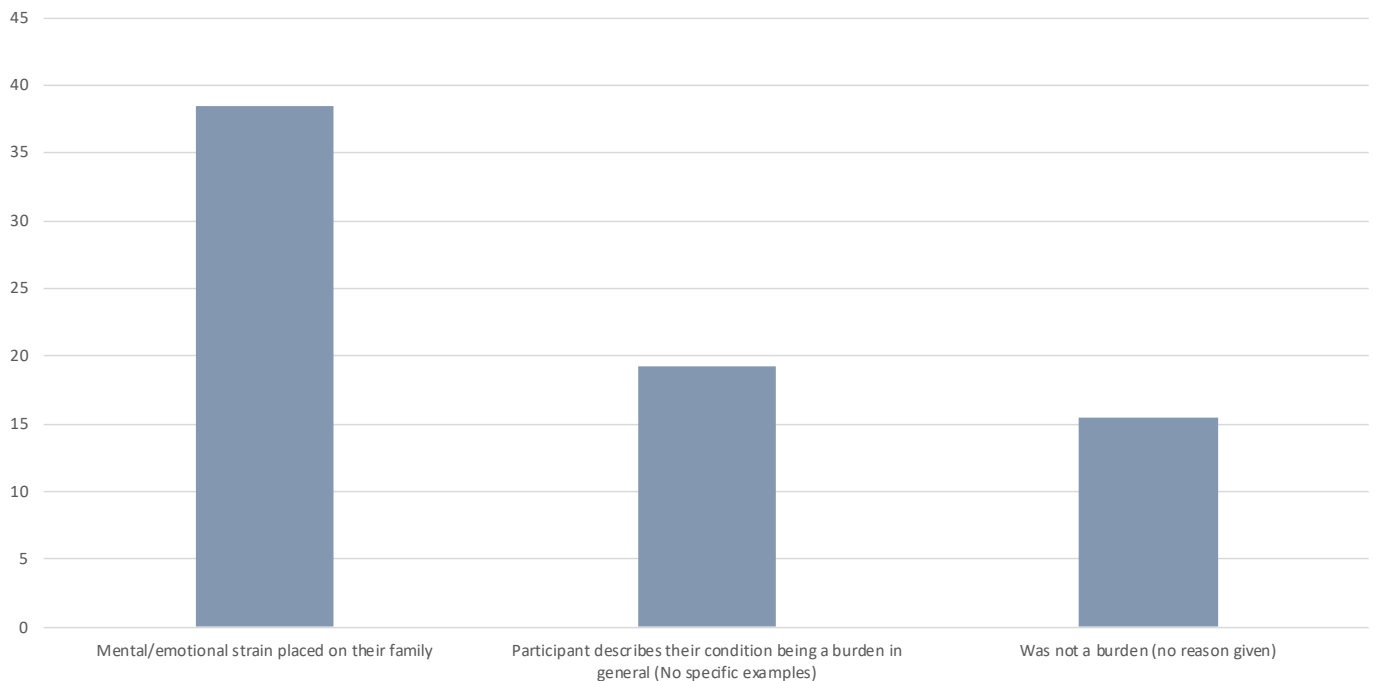
Theme	Less frequently	More frequently
Overall, there was a burden on their family	Non-metastatic Male Aged 65 or older	Metastatic Female Mid to low status
Overall, there was not a burden on their family	-	Non-metastatic Male Aged 65 or older

**Table 8.21: Burden on family (description)**

Burden on family (reasons)	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes the mental/emotional strain placed on their family	10	38.46	10	40.00	0	0.00	3	30.00	7	43.75	8	50.00	2	20.00
Participant describes their condition being a burden in general (No specific examples)	5	19.23	4	16.00	1	100.00	2	20.00	3	18.75	4	25.00	1	10.00
Participant described not being a burden without giving a description	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	2	12.50	2	20.00

Burden on family (reasons)	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes the mental/emotional strain placed on their family	10	38.46	8	47.06	2	22.22	3	23.08	7	53.85	1	50.00	9	37.50	2	22.22	8	47.06
Participant describes their condition being a burden in general (No specific examples)	5	19.23	4	23.53	1	11.11	2	15.38	3	23.08	1	50.00	4	16.67	4	44.44	1	5.88
Participant described not being a burden without giving a description	4	15.38	1	5.88	3	33.33	3	23.08	1	7.69	0	0.00	4	16.67	1	11.11	3	17.65



**Figure 8.11: Burden on family (description)**

**Table 8.22: Burden on family (description)– subgroup variations**

Theme	Less frequently	More frequently
Participant describes the mental/emotional strain placed on their family	Male Aged 65 or older Trade or high school Mid to low status	Female University
Participant describes their condition being a burden in general (No specific examples)	Higher status	Mid to low status

**Cost considerations**

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (61.54%), and that overall, there was no cost burden (34.62%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to needing to take time off work (38.46%), and the cost of treatments (26.92%). Other costs included diagnostic tests and scans (15.38%), cost of parking and travel to attend appointments (including accommodation) (15.38%), the cost of specialist

appointments (15.38%), and public or private gap payments (11.54%). Where participants described no cost burden associated with their condition, this was because nearly everything was paid for through the health system (26.92%)

**Participant describes a cost burden in relation to needing to take time off work**

*The cost of financial loss? I haven't been able to work in the same capacity as I did before. I've not been able to work full-time. I had to stop my career and do a job that was less demanding and challenging. The impact of financial income has been massive. I have to pay a few \$100, probably \$1,500 a year on scans. Car parking alone, every time you to [unintelligible] get a car parking. The biggest impact is the job loss.*  
Participant 007\_2023AULUC

*Yes, I had to quit my job, obviously. It's cost us fortunes. We couldn't go into the public system because they were taking too long. We went into the private system. It's just constantly-- I went to the cardiologist a few weeks ago. It cost me \$800.*  
Participant 002\_2023AULUC

**Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)**

*No, I wouldn't say compared to other people, we haven't been affected as heavily as what others have. Definitely, they're all little added costs. Every time you need an additional medication to support the side effects. Then with COVID having problems, the addition of-- The amount I've spent on masks and sanitizer. All additional things that you need as a result of your condition, but not necessarily specifically relating to the treatment itself, as in the side effects and the drug. Whether it's a cream for your face, or whether it's a tablet to reduce your cholesterol, or because of the side effects.*  
Participant 015\_2023AULUC

*The first op cost me. I mucked up my private insurance and I didn't have cardiac surgery, thoracic surgery. I can't believe it. I had to pay for that one.*  
Participant 024\_2023AULUC

**Participant describes a cost burden in relation to diagnostic tests and scans**

*I was very lucky because I was on the public trial, everything was free, but the \$6,000 mutation test was not free, which is pretty disappointing. I had to have*

*another one and I had to pay another \$6,000, but that one they didn't get any information from. They repaid us, but it's \$12,000 just to get access to a tablet. The thing is, they're doing tests in Australia, but they're not as good as that one. I've done collected surveys on that because they do some things in Australia, but they're obviously not as good. The waiting period can be eight weeks or three months. That is too long to wait when you've been diagnosed with cancer. You really just need everything done as quickly as possible.*  
Participant 019\_2023AULUC

*It's incredible, everything. Like I said, I'm in this private system, and everything, even my scans-- Luckily my blood tests don't cost me every month. I've got to have a CAT scan. At the moment I'm having-- Everything I have to pay for, call it CAT scan, the CT scan, the MRI, I have to pay for all of this.*  
Participant 027\_2023AULUC

**Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)**

*Treatment, minimal, because I was on a clinical trial, so there's the benefits there. Then just PBS-listed drugs since. I'm in a public system. Then car parking, that's a huge one.*  
Participant 015\_2023AULUC

*I probably would have been affected if I was still in the workforce. I'm having to work but not like I used to work. I wouldn't have been able to do that. I would have had to cut right back. Perhaps the income might have been affected. In my case, that wasn't the case because I'm only working voluntarily. Other than the driving in and out, which is about an hour in and then an hour back during busy times, and it always seems to be busy times when you go. With the fuel costs and the parking was probably the killer. The parking was costing up to \$30 to \$45 a day. That's ridiculous. You can get a discount on that, but you've got to actually go for two whole weeks, but you're still spending about \$500 on parking before you start getting your discount. It does cut it down to probably about half of that. The Cancer Council, as I said, sent me a check for \$200 for fuel, so that's helped that. Other than that, I did have to go out and buy a lot of creams and tablets and stuff like that, but I wouldn't say that was major.*  
Participant 017\_2023AULUC

*Extremely expensive for me. I was taken by accident by ambulance to a private emergency department of a private hospital and I needed to be put in ICU sooner.*

*It was \$12,000 a night and I didn't know because I was unconscious. I think I spent two nights in ICU which was 24,000 just for two nights. That was a bit of a surprise. Then when I had chemotherapy and radiation, I'm between two hospitals, I did everything in taxi. I spent \$6,000 in taxi to be driven there, and then be driven between hospitals. Then I had to pay \$45 an hour for the children to be looked after at my place.*

*Participant 023\_2023AULUC*

#### **Participant describes a cost burden in relation to the cost specialist appointments**

*Well, at the moment, I've got private insurance, and then I have to pay the first \$500, which I got diagnosed, say 10th for December and then 1st of January, I have to pay another \$500. It's a lot of costs involved, but I'm not paying at all for my actual treatment, which is great, but I'm spending a lot of money on seeing specialists and doctors and that cost me a lot because they might charge you \$180 and you get about \$40 back if you're lucky, for Medicare.*

*Participant 001\_2023AULUC*

*Other than it's gotten very expensive. That's the only. Considering what's my insurance company paid and the government subsidizes, the huge amount of money that I still had out of pocket extra to paying the surgeon and things like this. Every time you go to a doctor, you out of pocket, \$90 whatever, \$100 whatever. I can afford it. It's not an issue but considering how much, years ago you were never out of pocket.*

*Participant 028\_2023AULUC*

#### **Participant describes a cost burden in relation to public or private health gap payments**

*I went down the private path, so there was always an out-of-pocket somewhere in amongst the mix. Most of my bronchoscopies were covered. Thankfully, because I did change surgeons, my surgery was covered. I just had to pay my excess, but my radiation wasn't. I had to go on a payment plan, and, yes, you get something back from Medicare, but they have this convoluted bloody system that sounded dodgy that won't get out. Anyway, you're still out of pocket, \$3,000 or \$4,000. I'm a commission-only salesperson, so if I don't work, I don't have any money coming in. That makes things a bit tight. Then, of course, in the background, you are having people on hideous conversations with your insurance people, for your income protection, and*

*what have you, to try and get that all sorted as well. [chuckles] It's been an interesting journey.*

*Participant 018\_2023AULUC*

*I'm going to say just like with my breast cancer, it's damn expensive to be in the private system. Yes, you get that beautiful follow-up with the ones that are specialists, et cetera, but your surgery hospital that did all these costs involved. The diagnosis meant that I decided to early retirement, resigned from work, and I am blessed that I am financially able to because I just felt I did not have any longer the headspace for the sort of work I was doing. I don't think I've got the stamina to do the hours I used to do. It was the best thing. I took two months off, and I came to that conclusion that no, I wouldn't go back but it's incredibly costly. That means 100,000 plus a year income lost. It means I spent about 10,000 or so out of pocket with the surgery and everything and, of course, it's all ongoing with all the scans. I am so fortunate that I can afford it.*

*Participant 020\_2023AULUC*

*Other than it's gotten very expensive. That's the only. Considering what's my insurance company paid and the government subsidizes, the huge amount of money that I still had out of pocket extra to paying the surgeon and things like this. Every time you go to a doctor, you out of pocket, \$90 whatever, \$100 whatever. I can afford it. It's not an issue but considering how much, years ago you were never out of pocket.*

*Participant 028\_2023AULUC*

#### **Participant describes no cost burden and that nearly everything was paid for through the health system**

*I didn't keep a good track, but I did have to quit work. I went from working full-time to not working. I think it was for a year and a half, after that I didn't work. That was a fair drop. I had lots of sick pay and stuff like that which was good. The hospital I worked for was very good with monies and out-of-pocket tests, there's only been a couple. I can't really remember. I think originally to do the cytology, a \$300 visit to a respiratory specialist, a couple of medical reports to get on the disability pension that I had to pay for out of pocket. Otherwise, most things have been covered by Medicare.*

*Participant 006\_2023AULUC*

The only costs were some of the medications that were prescribed for me. Some I got for nothing in the hospital and through the system. Some I had to purchase myself. In most cases it was small. It's small costs. I'm retired and my wife is retired so I was, what do you call it, on the public system, public health system. I had private, but then I have DVA as well, Gold cards. There was no cost to me as such except for a few ancillary bits and pieces of medications and stuff like that.

Participant 012\_2023AULUC

All right, well, very favorable. The cost of my treatment electronic is \$42 a month and if it were not for PBS, it would be \$6,800 a month. That is why I say I could not afford to keep alive if it was going to drain my finances at that rate. A dilemma I currently don't face. The cost, look, it's been incredible. I had the surgery under Medicare from a top surgeon, just incredibly fortunate. No financial cost of any significance

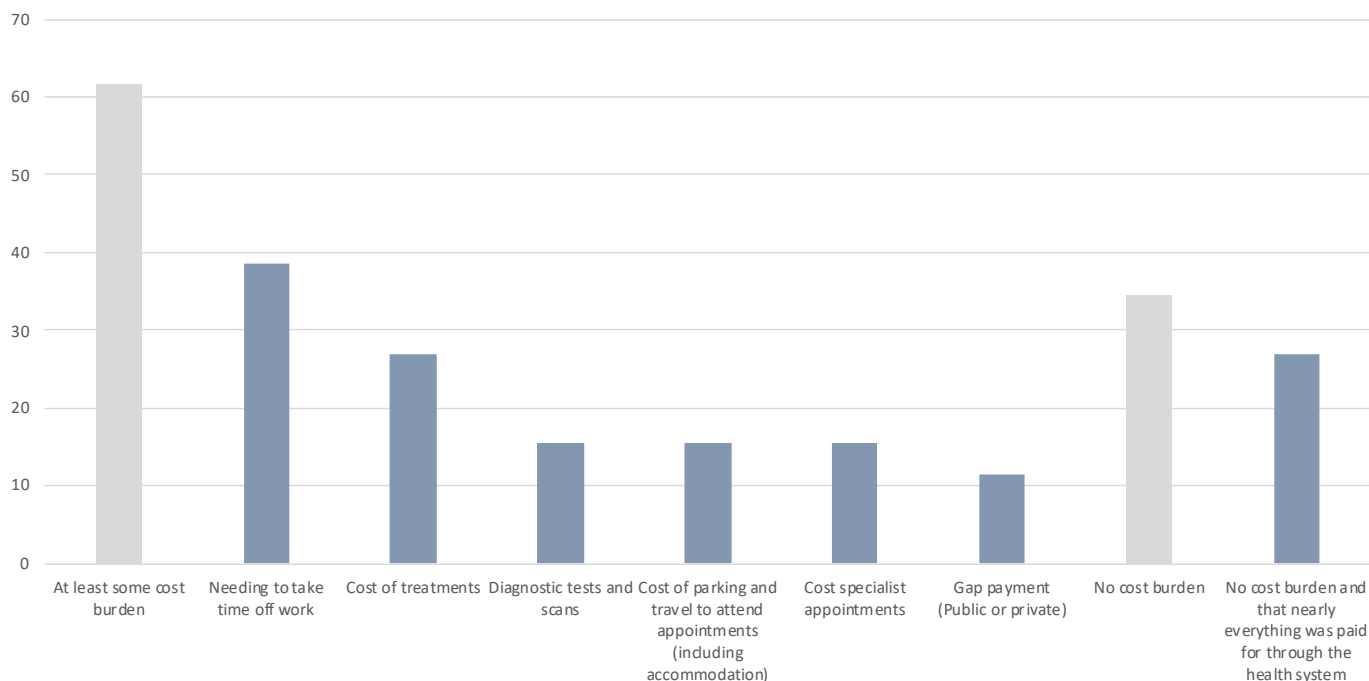
Participant 022\_2023AULUC

Table 8.23: Cost considerations

Cost considerations	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Experience described suggests that overall, there was at least some cost burden	16	61.54	16	64.00	0	0.00	5	50.00	11	68.75	15	93.75	1	10.00
Participant describes a cost burden in relation to needing to take time off work	10	38.46	10	40.00	0	0.00	3	30.00	7	43.75	9	56.25	1	10.00
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	7	26.92	7	28.00	0	0.00	2	20.00	5	31.25	6	37.50	1	10.00
Participant describes a cost burden in relation to diagnostic tests and scans	4	15.38	4	16.00	0	0.00	1	10.00	3	18.75	4	25.00	0	0.00
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	4	15.38	4	16.00	0	0.00	1	10.00	3	18.75	4	25.00	0	0.00
Participant describes a cost burden in relation to the cost of specialist appointments	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	3	18.75	1	10.00
Participant describes a cost burden in relation to public or private health gap payments	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00
Experience described suggests that overall, there was no cost burden	9	34.62	8	32.00	1	100.00	5	50.00	4	25.00	4	25.00	5	50.00
Participant describes no cost burden and that nearly everything was paid for through the health system	7	26.92	7	28.00	0	0.00	2	20.00	5	31.25	4	25.00	3	30.00
Other/No response	1	3.85	1	4.00	0	0.00	0	0.00	1	6.25	0	0.00	1	10.00

Cost considerations	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Experience described suggests that overall, there was at least some cost burden	16	61.54	12	70.59	4	44.44	6	46.15	10	76.92	2	100.00	14	58.33	6	66.67	10	58.82
Participant describes a cost burden in relation to needing to take time off work	10	38.46	9	52.94	1	11.11	3	23.08	7	53.85	2	100.00	8	33.33	4	44.44	6	35.29
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	7	26.92	5	29.41	2	22.22	3	23.08	4	30.77	0	0.00	7	29.17	2	22.22	5	29.41
Participant describes a cost burden in relation to diagnostic tests and scans	4	15.38	4	23.53	0	0.00	2	15.38	2	15.38	0	0.00	4	16.67	1	11.11	3	17.65
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	4	15.38	2	11.76	2	22.22	3	23.08	1	7.69	0	0.00	4	16.67	1	11.11	3	17.65
Participant describes a cost burden in relation to the cost of specialist appointments	4	15.38	2	11.76	2	22.22	1	7.69	3	23.08	0	0.00	4	16.67	0	0.00	4	23.53
Participant describes a cost burden in relation to public or private health gap payments	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	0	0.00	3	12.50	0	0.00	3	17.65
Experience described suggests that overall, there was no cost burden	9	34.62	4	23.53	5	55.56	6	46.15	3	23.08	0	0.00	9	37.50	3	33.33	6	35.29
Participant describes no cost burden and that nearly everything was paid for through the health system	7	26.92	5	29.41	2	22.22	1	7.69	6	46.15	1	50.00	6	25.00	2	22.22	5	29.41
Other/No response	1	3.85	0	0.00	1	11.11	1	7.69	0	0.00	0	0.00	1	4.17	0	0.00	1	5.88



**Figure 8.12: Cost considerations**

**Table 8.24: Cost considerations – subgroup variations**

Theme	Less frequently	More frequently
Experience described suggests that overall, there was at least some cost burden	Non-metastatic Male Aged 65 or older Trade or high school	Female University
Participant describes a cost burden in relation to needing to take time off work	Male Aged 65 or older Trade or high school	Female Aged 35 to 64 University
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	Male	Female
Participant describes a cost burden in relation to diagnostic tests and scans	Male Aged 65 or older	-
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	Male	-
Participant describes a cost burden in relation to the cost specialist appointments	Mid to low status	-
Participant describes a cost burden in relation to public or private health gap payments	Mid to low status	-
Experience described suggests that overall, there was no cost burden	Aged 35 to 64 University	Non-metastatic Male Aged 65 or older Trade or high school
Participant describes no cost burden and that nearly everything was paid for through the health system	Trade or high school	University

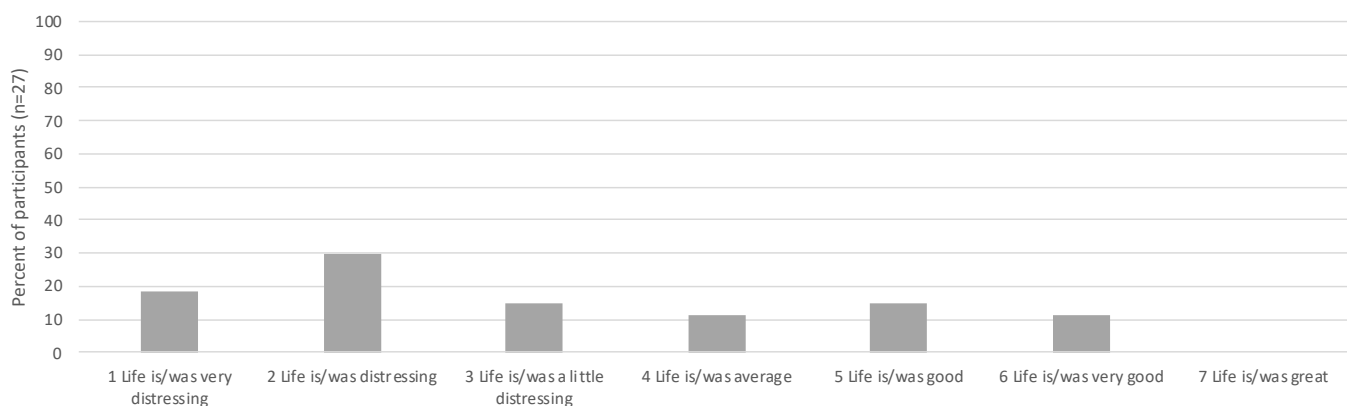
### Overall impact of condition on quality of life

In the online questionnaire, participants were asked to rate the overall impact their condition on quality of life. Quality of life was rated on a Likert scale from one to seven, where one is Life was very distressing and seven is life was great.

The average score was in the Life was a little distressing range (median=3.00, IQR=3.50) (Table 8.29, Figure 8.15).

**Table 8.25: Overall impact of condition on quality of life**

Impact of condition on quality of life	Number (n=27)	Percent
1 Life is/was very distressing	5	18.52
2 Life is/was distressing	8	29.63
3 Life is/was a little distressing	4	14.81
4 Life is/was average	3	11.11
5 Life is/was good	4	14.81
6 Life is/was very good	3	11.11
7 Life is/was great	0	0.00



**Figure 8.13: Overall impact of condition on quality of life**

### Experience of anxiety related to disease progression

#### Fear of progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Summary statistics for the entire cohort are displayed in Table 8.10.

The overall scores for the cohort were in the highest quintile for Fear of progression: Total score

(mean=37.70, SD=11.27) indicating moderate levels of anxiety

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated moderate levels of anxiety.

**Table 8.26: Fear of progression summary statistics**

Fear of progression (n=27)	Mean	SD	Median	IQR	Possible range	Quintile
Total score*	37.70	11.27	39.00	17.50	12 to 60	3

\*Normal distribution use mean and SD as measure of central tendency

#### Fear of progression by participant type

There were 25 participants (92.59%) that had been diagnosed with lung cancer, and 2 participants (7.41%) that were family members or carers to people with lung

cancer. Comparisons were not made because there were too few family members and carers. Summary statistics are displayed in Table 8.x

**Table 8.27: Fear of progression total score by participant type summary statistics**

Fear of progression	Group	Number (n=27)	Percent	Mean	SD	Median	IQR	Quintile
Total score	Person with lung cancer	25	92.59	36.76	11.07	38.00	17.00	3
	Family member or carer	2	7.41	49.50	7.78	49.50	5.50	-

#### Fear of progression by lung cancer stage

Comparisons were made by cancer stage, there were 11 participants (44.00%) with non-metastatic lung cancer and, 14 participants (56.00%) with metastatic lung cancer.

A two sample t-test indicated that the mean score for the Fear of progression Total score scale [t(23) = -2.08, p = 0.0485] was significantly lower for participants in the **Non-metastatic** subgroup (Mean = 32.91, SD = 10.24) compared to participants in the **Metastatic** subgroup (Mean = 41.57, SD = 10.38.)

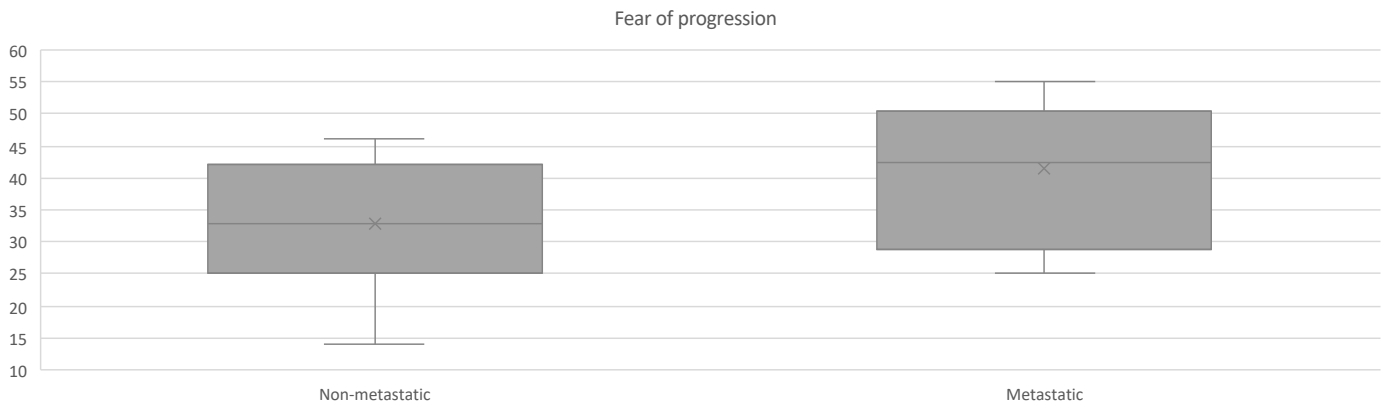
Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.28).

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average, participants in the **metastatic cancer** subgroup scored higher than participants in the **non-metastatic cancer** subgroup. This indicates

that participants in the **metastatic cancer** subgroup had high levels of anxiety, and participants in the **non-metastatic cancer** subgroup had moderate levels of anxiety.

**Table 8.28: Fear of progression total score by lung cancer stage summary statistics and T-test**

Fear of progression	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Total score	Non-metastatic	11	44.00	32.91	10.24	-2.08	23	0.0485*
	Metastatic	14	56.00	41.57	10.38			



**Figure 8.14: Boxplot of Fear of progression total score by lung cancer stage**

### Fear of progression by gender

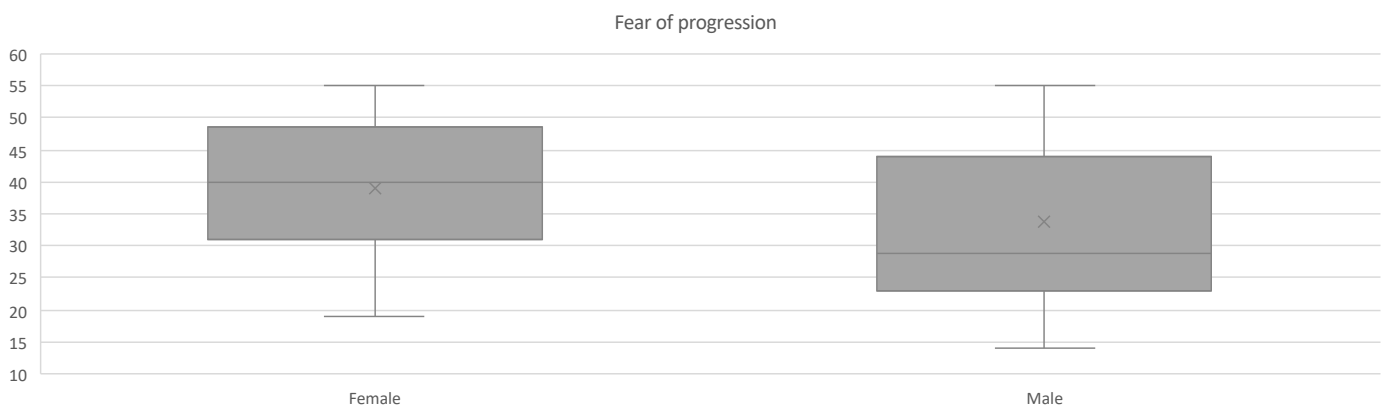
Comparisons were made by gender, there were 20 female participants (74.07%), and 8 male participants (25.93%).

No significant differences were observed between participants by **gender** for any of the Fear of progression scales.

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.29).

**Table 8.29: Fear of progression total score by gender summary statistics and T-test**

Fear of progression	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Total score	Female	20	74.07	39.10	10.20	1.09	25	0.2853
	Male	7	25.93	33.71	14.00			



**Figure 8.15: Boxplot of Fear of progression total score by gender**

### Fear of progression by age

Participants were grouped according to age, with comparisons made between participants aged 35 to 64

(n=15, 55.56%), and participants aged 65 or older (n=12, 44.44%).

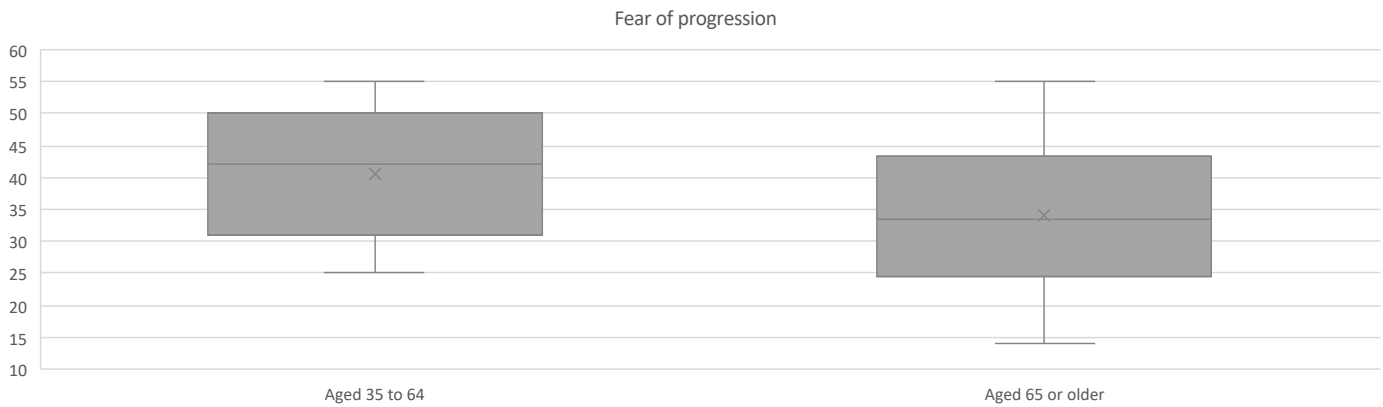


Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.30).

No significant differences were observed between participants by **age** for any of the Fear of progression scales.

**Table 8.30: Fear of progression total score by age summary statistics and T-test**

Fear of progression	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Total score	Aged 35 to 64	15	55.56	40.67	9.95	1.57	25	0.1291
	Aged 65 or older	12	44.44	34.00	12.14			



**Figure 8.16: Boxplot of Fear of progression total score by age**

### Fear of progression by education

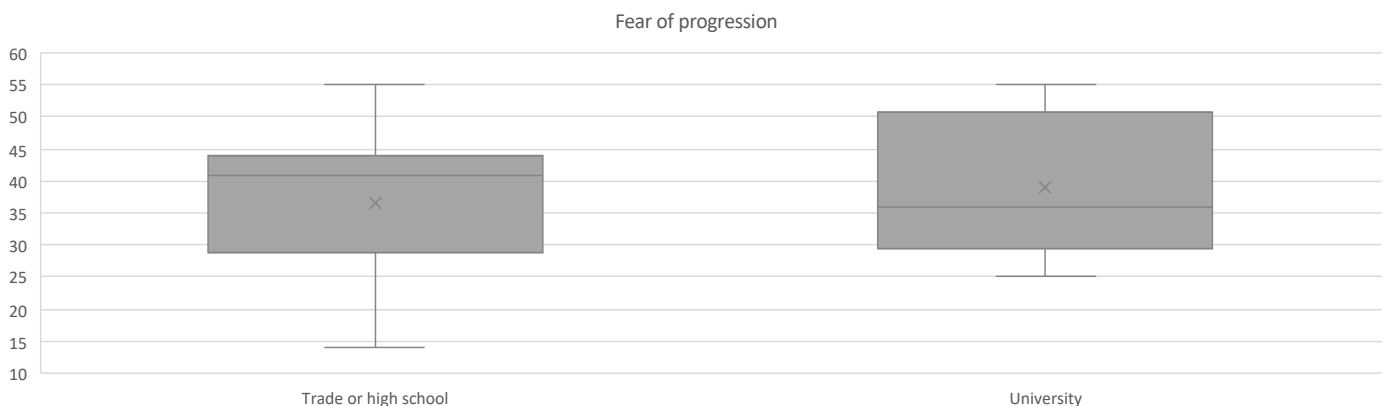
Comparisons were made by education status, between those with trade or high school qualifications (n=15, 55.56%), and those with a university qualification (n=12, 44.44%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.31).

No significant differences were observed between participants by **education** for any of the Fear of progression scales.

**Table 8.31: Fear of progression total score by education summary statistics and T-test**

Fear of progression	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Total score	Trade or high school	15	55.56	36.53	11.38	-0.60	25	0.5568
	University	12	44.44	39.17	11.46			



**Figure 8.17: Boxplot of Fear of progression total score by education**

### Fear of progression by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian

Bureau of Statistics. There were 2 participants (7.41%) living in regional or remote areas and 25 participants (92.59%) living in metropolitan areas. Comparisons

were not made because there were too few participants lived in regional or remote areas. Summary statistics are displayed in Table 8.32

**Table 8.32: Fear of progression total score by location summary statistics**

Fear of progression	Group	Number (n=27)	Percent	Mean	SD	Median	IQR	Quintile
Total score	Regional or remote	2	7.41	38.00	18.38	38.00	13.00	3
	Metropolitan	25	92.59	37.68	11.12	39.00	17.00	-

### Fear of progression by socioeconomic status

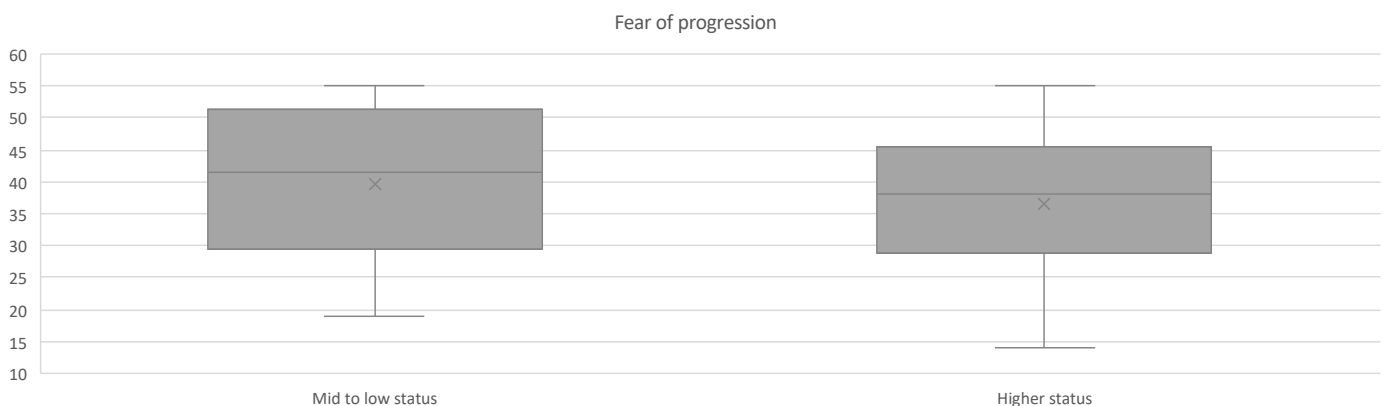
Comparisons were made by socioeconomic status, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6, Mid to low status (n=10, 37.04%) compared to those with a higher SEIFA score of 7-10, Higher status (n=17, 62.96%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.33).

No significant differences were observed between participants by **socioeconomic status** for any of the Fear of progression scales.

**Table 8.33: Fear of progression total score by socioeconomic status summary statistics and T-test**

Fear of progression	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Total score	Mid to low status	10	37.04	39.50	12.13	0.63	25	0.5359
	Higher status	17	62.96	36.65	10.98			



**Figure 8.18: Boxplot of Fear of progression total score by socioeconomic status**

### Anxiety about treatment

An overview of responses to individual fear of progression questions is given in Table 8.34.

#### Fear of progression individual questions

On average, participants scored in the “Seldom” range for the following questions: “Is disturbed that they may have to rely on strangers for activities of daily living” (mean=2.44, SD=1.34), “Anxious if not experiencing any side effects think it doesn’t work” (mean=1.96, SD=1.22).

On average, participants scored in the “Sometimes” range for the following questions: “Afraid of pain” (mean=3.19, SD=1.39), “Has concerns about reaching professional and/or personal goals because of illness:”

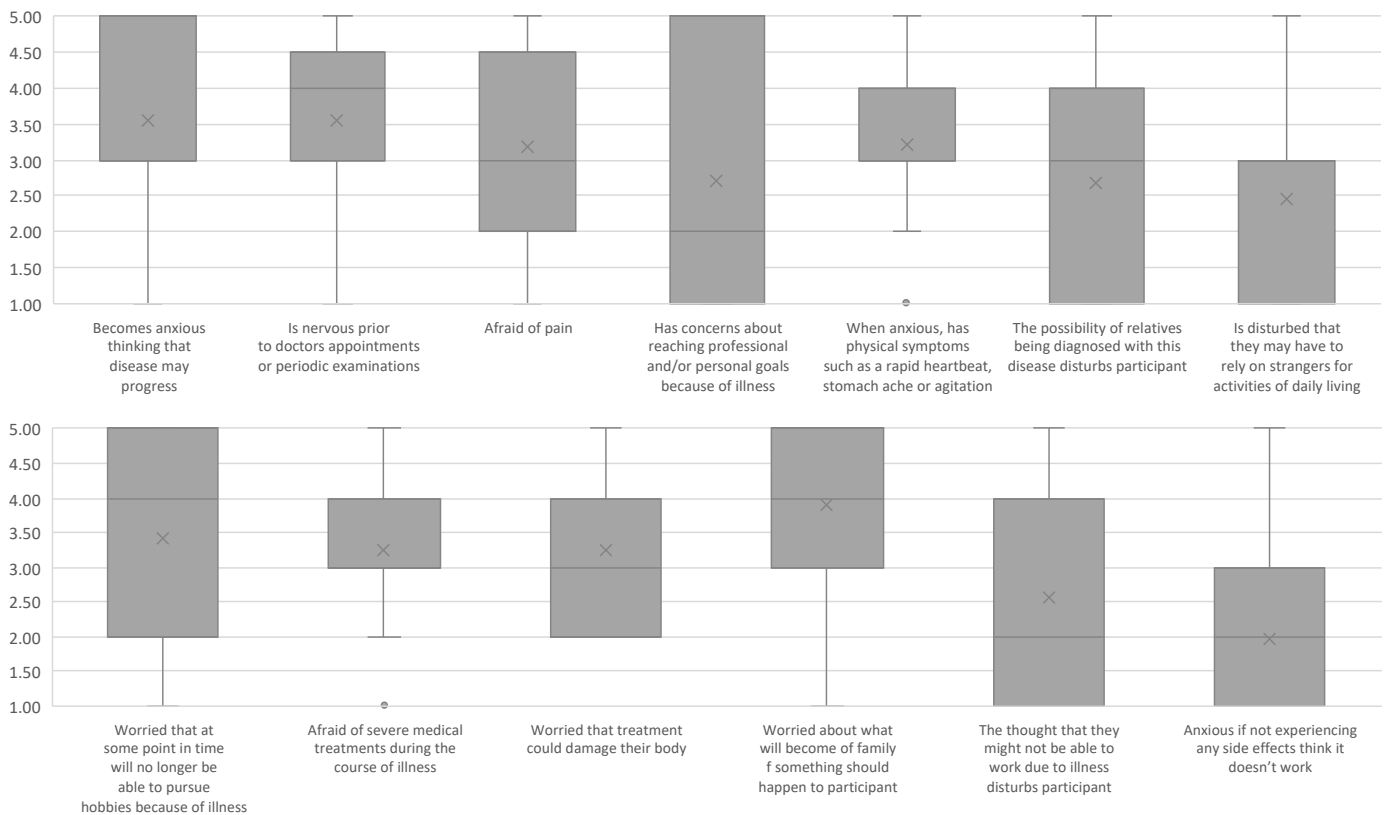
(mean=2.70, SD=1.79), “When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation” (mean=3.22, SD=1.12), “The possibility of relatives being diagnosed with this disease disturbs participant” (mean=2.67, SD=1.59), “Worried that at some point in time will no longer be able to pursue hobbies because of illness” (mean=3.41, SD=1.47), “Afraid of severe medical treatments during the course of illness” (mean=3.26, SD=1.26), “Worried that treatment could damage their body” (mean=3.26, SD=1.02), “The thought that they might not be able to work due to illness disturbs participant” (mean=2.56, SD=1.60).

On average, participants scored in the “Often” range for the following questions: “Becomes anxious thinking that disease may progress” (mean=3.56, SD=1.22), “Is nervous prior to doctors appointments or periodic examinations” (mean=3.56, SD=1.31), “Is nervous prior to doctors appointments or periodic

examinations” (mean=3.56, SD=1.31), “Worried about what will become of family if something should happen to participant” (mean=3.89, SD=1.22).

**Table 8.34: Fear of progression individual questions**

Fear of progression (n=27)	Mean	SD	Median	IQR	Average response
Becomes anxious thinking that disease may progress	3.56	1.22	3.00	2.00	Often
Is nervous prior to doctors appointments or periodic examinations	3.56	1.31	4.00	1.50	Often
Afraid of pain	3.19	1.39	3.00	2.50	Sometimes
Has concerns about reaching professional and/or personal goals because of illness:	2.70	1.79	2.00	4.00	Sometimes
When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation	3.22	1.12	3.00	1.00	Sometimes
The possibility of relatives being diagnosed with this disease disturbs participant	2.67	1.59	3.00	3.00	Sometimes
Is disturbed that they may have to rely on strangers for activities of daily living	2.44	1.34	3.00	2.00	Seldom
Worried that at some point in time will no longer be able to pursue hobbies because of illness	3.41	1.47	4.00	3.00	Sometimes
Afraid of severe medical treatments during the course of illness	3.26	1.26	3.00	1.00	Sometimes
Worried that treatment could damage their body	3.26	1.02	3.00	1.50	Sometimes
Worried about what will become of family if something should happen to participant	3.89	1.22	4.00	2.00	Often
The thought that they might not be able to work due to illness disturbs participant	2.56	1.60	2.00	3.00	Sometimes
Anxious if not experiencing any side effects think it doesn't work	1.96	1.22	2.00	1.50	Seldom



**Figure 8.19: Fear of progression individual questions**