Section 4

Decision-making

Section 4 Summary: Decision-making

Discussions about treatment

- Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common response from participants was that it was difficult to remember/other response (n=14, 38.89%) which was closely followed by multiple treatment options were discussed which was described by 13 participants (36.11%). Six participants described discussing one treatment option (16.67%) and three participants described no treatment options being discussed (8.33%).

- Among participant who discussed multiple treatment options, five described participating in decision-making (13.89%), four described not participating in the decision-making process (11.11%) and four described being told what to do without discussion (11.11%). Three participants described being presented with no options because no therapies were available (8.33%). Out of those who were presented with one option three participants described being told what to do without discussion (8.33%) and two participants described some but very little discussion (5.56%).

- Some participants described discussions of specific treatments. Six participants described discussing the option of a stem cell transplant (16.67%), while four participants described discussing the option of a liver transplant (11.11%). Other participants described being presented with the option of chemotherapy (n=3, 8.33%), Green tea extract (n=3, 8.33%), Velcade or dexamethasone (n=3, 8.33%) and Bone marrow transplant (n=2, 5.56%).

Decision-making

- Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported consideration was quality of life as part of multiple aspects that they consider when making decisions about treatment and this was described by 13 participants (36.11%). This was followed by efficacy as part of multiple aspects they consider (n=9, 25.00%); side effects as part of multiple aspects they consider (n=9, 25.00%); the long term impact and side effects of treatment as part of multiple aspects they consider (n=7, 19.44%), taking the advice of their clinician as part of multiple aspects they consider (n=6, 16.67%), considering the potential impact on their family or dependents as part of multiple aspects they consider (n=5, 13.89%), survival benefit as part of multiple aspects they consider (n=5, 13.89%) and taking the advice of their clinician as the only aspect they consider (n=5, 13.89%).

Changes in decision-making

- Participants were asked if the way they made decisions had changed over time. There were 15 participants (41.67%) that felt the way they made decisions about treatment had not changed over time, and 12 participants (33.33%) that described decision-making changing. Nine participants (25.00%) were unsure/other or gave no response.

- Where participants had changed the way they make decisions, this was primarily in relation to becoming more informed and/or assertive (n=7, 19.44%). Three participants described their decision-making changing over time as they are more aware of their health, responsibilities and/or limitations (8.33%) Other participants described changing over time as they are more accepting of their condition and choices available (n=1, 2.78%), they are more focused on how treatment impacts their family and dependents (n=1, 2.78%), they are more cautious and considered (n=1, 2.78%) and they are more focused on quality of life or the impact of side effects (n=1, 2.78%).

- Among participants who described no change in the way they make decisions the most common response was that this was because they had always been informed/assertive (n=7, 19.44%) followed by those who did not mention any reason (n=4, 11.11%). Other responses were that there had been no change because they always took the advice of clinicians (n=2, 5.56%) and because they have had no treatment options to choose from (n=1, 2.78%).

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common response from participants was that it was difficult to remember/other response (n=14, 38.89%) which was closely followed by multiple treatment options were discussed which was described by 13 participants (36.11%). Six participants described discussing one treatment option (16.67%) and three participants described no treatment options being discussed (8.33%).

Among participant who discussed multiple treatment options, five described participating in decision-making (13.89%), four described not participating in the decision-making process (11.11%) and four described being told what to do without discussion (11.11%). Three participants described being presented with no options because no therapies were available (8.33%). Out of those who were presented with one option three participants described being told what to do without discussion (8.33%) and two participants described some but very little discussion (5.56%).

Some participants described discussions of specific treatments. Six participants described discussing the option of a stem cell transplant (16.67%), while four participants described discussing the option of a liver transplant (11.11%). Other participants described being presented with the option of chemotherapy (n=3, 8.33%), Green tea extract (n=3, 8.33%), Velcade or dexamethasone (n=3, 8.33%) and Bone marrow transplant (n=2, 5.56%).

In relation to subgroup variations, participants in the subgroups *ATTR-cardiac* (22.22%), *All cardiac* (20.00%), *AL amyloidosis* (20.00%), *Male* (13.64%), *Aged 75 or older* (12.50%), *Trade or high school* (21.43%) and *University* (21.43%) described it being difficult to remember/other response less frequently than the general population (38.89%) while those in the subgroups *Carer* (100.00%), *Female* (78.57%) and *Aged 55 to 64* (62.50%) described this more frequently.

Participants in the subgroups *AL amyloidosis* (50.00%), *Male* (50.00%) and *Trade or high school* (50.00%) described discussing multiple options more frequently than the general population (36.11%) while those in the subgroups *Carer* (0.00%), *Female* (14.29%), *Aged 55 to 64* (25.00%) and *Mid to low SEIFA* (18.18%) described this less frequently.

Participants in the subgroups *AL amyloidosis* (30.00%), *Male* (27.27%) and *Mid to low SEIFA* (27.27%) described discussion one treatment option more frequently than the general population (16.67%) whereas no participants in *Female* (0.00%), and *Carer* (0.00%) described this.

Participants in the subgroup *Aged 75 or older* described no treatment option being presented more frequently (37.50%) than the general population (8.33%).

No participants in the *Carer* (0.00%), or *Female* (0.00%) subgroups described being presented with multiple treatment options and participating in the decision-making process compared to the general population (13.89%).

Participants in the *ATTR-cardiac* subgroup (22.22%), and *Trade or high school* subgroup (28.57%) described being presented with multiple treatment options but not participating in the decision-making process more frequently than the general population (11.11%) while those in the *AL amyloidosis* subgroup (0.00%), *University* (0.00%), *Regional or remote* (0.00%), and *Carer* subgroup (0.00%) did not describe this at all.

Participants in the *AL amyloidosis* (30.00%) subgroup described being presented with multiple options and told what to do without discussion more frequently than the general population (11.11%), while those in the *Carer* (0.00%), *Aged 55 to 64* (0.00%) and *Mid to low SEIFA* (0.00%) subgroups did not describe this at all.

Participants in the *Aged 75 or older* subgroup described being presented with no options/approach as no therapies are available more frequently (37.50%) than the general population (8.33%).

Participants in the *AL amyloidosis* (20.00%) and *Trade or high school* (21.43%) subgroups described being presented with on option/approach and being told what to do without discussion more frequently than the general population (8.33%).

Participants in the *AL amyloidosis* subgroup (20.00%) and *Aged 75 or older* (25.00%) described being presented with one option/approach and having some but very little discussion more frequently than the general population (5.56%).

Participants in the *AL amyloidosis* subgroup (30.00%), *Aged 75 or older* subgroup (37.50%) and *University* subgroup (28.57%) described being presented with the option of a stem cell transplant more frequently than the general population (16.67%), while those in the *Carer* (0.00%), and *Aged 55 to 64* (0.00%) did not describe this at all.

No participants in the *AL amyloidosis* (0.00%), *Aged 75 or older* (0.00%), *Female* (0.00%), and *Carer* (0.00%) subgroups described being presented with the option of a liver transplant, while those in the *ATTR-cardiac* subgroup (22.22%), *Regional or remote* (22.22%), *Aged 55 to 64* (25.00%), and *University* (21.43%) subgroups described this more frequently than the general population (11.11%).

Participants int the subgroups *AL amyloidosis* (20.00%) and *Aged 75 or older* (25.00%) described being presented with the option of chemotherapy more frequently than the general population (8.33%).

Participants in the subgroup *AL amyloidosis* described being presented with the option of Velcade or dexamethasone more frequently (30.00%) than the general population (8.33%).

Participants in the subgroup *AL amyloidosis* described being presented with the option of a bone marrow transplant more frequently (20.00%) than the general population (5.56%).

Multiple treatment options presented

Well, I was in his hands. He told me what he went through which was generally, oral chemo, et cetera. That was it. Then suddenly, well, that didn't work. On one particular visit, 'We got to do plan B,' and then he explained to me all about the stem cell transplants. ***Participant 001ALX***

He did suggest that a bone marrow transplant could probably fix the problem, but the pre-treatment would probably kill me. We decided not to go with that. Apart from that, he didn't really talk much about it. He put me on to oral chemo and dexamethasone on the grounds that my system at that stage was so bad that he didn't think I could've taken intravenous chemo. ***Participant 2ALX***

Well, they were essentially a two-track conversation. The first element was, 'we've got to get these rogue protein levels under control'. The recommended treatment for that or the first port of call sort of treatment was Velcade plus dexamethasone plus the cyclophosphamide. The overall objective was to contemplate a stem cell transplant once the levels had been reduced and had become stable on the assumption that all of the normal body functions would have recovered slightly as well. Remember my kidney function's a bit impaired and my heart function a bit impaired. Because I was fit and because I was otherwise very healthy, I'd no other condition and I was … it was still seen as I was a candidate for stem cell transplant albeit with an elevated risk, but not to the level that would preclude a bone marrow transplant—sorry, a stem cell transplant. Those were the two tracks of conversation. ***Participant 004AL***

One treatment option presented

I spoke to them about a liver transplant and then they took into account my age and my condition with the amyloid, how bad it was. I said it was no good doing one it was too far gone… They said to me then that there's no other treatments. All we can do is the best we can with what we've got and they were doing nothing at this stage for us. Participant 009ATR

Well, he said, 'There's really only experimental drugs.' So, I was still ongoing. He recommended that I go into Doctors now for one called, temyphibus I think it's called. Participant 011ATR

Well, the conversation went that it was very hard to treat, especially my type, and that the doctor said that we've got to start this trial. Velcade had been used for a long time, I think, before I started this trial. The trial was different. As far as I can make out, that it was always been given intravenously. I was probably one of the first to have it injected into the fatty part of the stomach. Participant 005AL

Multiple options presented: Participated in decision-making

When I was first diagnosed the first thing, they wanted to do was get me onto the transplant list for a liver transplant, that was through the neurologist and the cardiologist. Essentially that was the first thing then they found NAME SPECIALIST, who's more of a specialist in amyloidosis specifically, the haematologist. He immediately put me on to medical drugs, a combination of drugs to try to stabilize me which I'm still on today. Then he laid out basically every option there was for me, and he does with every patient. We talked through getting assessed for the liver transplant and making sure to make sure-when it's transplants you got to test people to make sure whether I'm going, what severity it was, how it progressed and those kinds of things. Then talked through all the different other options on the horizon or overseas in Italy just around a lot of others, I can't remember more off the top of my head. Participant 6ATR

Well, that sort of thing we spoke about was this trial that might be coming up with this new drug that has been. I think it is called Paprizine or something like that. Apparently, it's available in other countries already…Probably if I have enough money and well, I asked the doctor the other day and said, 'What's going on over in LOCATION, where this is the Bible over there?' and he said, 'Well, yes it is, but to get treatment over there you got to be a resident and you need to have a lot of money.' Well, that puts us out of the case. We're only normal sort of people. He did say that there was some other option, but we have to talk about it. NAME DOCTOR in LOCATION METROPOLITAN, she's my kidney specialist. Apparently, her pile of drugs that might help but they can make you bleed internally, and I'll have to go off some of my blood thinners that I'm on now. We're going to have a discussion about that and I'm going back up on the eighteenth of this coming month so probably now a bit more then. Participant 014ATR

When I was first diagnosed, we talked about the possibility of including a liver transplant because this was about three years ago now, and he said I would be a good candidate for it but we both agreed that it wasn't really viable at that stage even though that biologically is the wrong thing to do. It was also at that stage there was medications and regimes coming along, but there's nothing that had been fully released here in Australia, so it was pretty much wait and see and monitor, not only because I had got in there, because I knew my history, I had got in before hardly anything had had a chance to show. Participant 015ATR

Multiple options presented: Did not participate in decision-making

All we've discussed is I'm currently taking the green tea extract twice a day and was told that it's probably found that people—If they took it at the time that they often suffered the side effect of it. Which was insomnia, so they suggested I take even in the afternoon, morning and mid-afternoon. Which I do, on an empty stomach. Any other, other than, and also the possibility of getting on to these two drug trials coming up. They're kind of hoping that I might be able but there's a lot of people now. They're living in hope as well. To get onto the two drugs, one is Tafamidis, something like that, which I think stops the protein from attaching to the amyloid fibrils. The other one is Patisiran or something like that, which stops the liver from producing the amyloid or the protein. Any other treatments, it's not been discussed. I have no idea. I really, I don't know what I'm in for, to be honest. Participant 001ATR

They were going to try and get me onto the-- trial in Australia, which one of the drugs is? I think, one of the options for the trial is-- because it's cardio involvement I've had a recorder, I had to recorder implanted in my chest in LOCATION METROPOLITAN. When they investigated the recorder here on a Wednesday, that Friday, I was in having a defibrillator pacemaker fitted. Then, as a result of having that fitted, I had a fluid buildup, which, because of me being admitted to the hospital, it made me ineligible for the trial. Other than the trial or the current treatment I'm on, that's pretty much all they've discussed. Participant 004ATR

When I was first diagnosed, the oncologist, haematologist, he said that we would do stem cell, but he was going away. He'd booked something, and he couldn't stop it for two or three weeks. He said as soon as he got back, they'd start stem cell on me. That was probably one of the worst weeks of my life, because I did a lot of reading, and I was at that stage 70-years-old, not very well, very low kidney function. In my own research, it showed that I was in a very high bracket of people who don't get through stem cell treatment. When he came back and he was about to start it, he had a meeting with, I think, NAME SPECIALIST at NAME HOSPITAL, who, as you know, runs the amyloidosis stuff there, and they decided that stem cell was going to be too severe for me. They put me on dex and thalidomide. I did six months on that. Participant 017ATR

Multiple options presented: Told what to do without discussion

That was with the renal specialist. He really just was talking about cyclophosphamide. I don't recall it being in combination with any other drugs although now I know that it's traditionally given in combination with dexamethasone and thalidomide as one combination. He just talked about cyclophosphamide. Once I contacted the haematologist, he said that he would like to try the combination of cyclophosphamide, thalidomide, and dexamethasone, but really only to check that the cells in the bone marrow were responsive to that treatment. If they're responsive to that, then there would be responsive, hopefully, to stem cell transplants. He put me on that combination just for a couple of months just to check that they were affecting the free light chains, and they did, and then we just scheduled the stem cell transplant. There wasn't really an option to go on a clinical trial at that point. The trial that was going on then was for relapsed amyloidosis. I wasn't a candidate for the clinical trial that he was on. It was before Velcade came on the scene, I think. He just offered me what was probably the best option at the time. Participant 002AL

I was told about the Velcade treatment, and that it had been shown to work against reducing the imbalances of the kappa lambda chains, the light chains and I was told that what possible side effects there might be. Then we started basically, and I've got comments that I've written down after each treatment and right though this and then I took my blood pressure and everything else. I had very few side effects apart from, I think, the dexameth which gave me a few hassles about sleeping and things like that. I was given dexameth either by IV at the hospital, they ran out once and they gave me

tablets then as well. Then I took 20-milligram tablets, 5 of them the day after, say, on the treatment day and the day after I was given dexameth… Really, that was all we discussed. He said the results was good. I was just on a monitoring regime until just recently. Participant 003AL

Of course, you put your faith in your cardiologist or with the doctors, of course, and he just said, 'Well, look, you're going to have to start up straight away on this chemo.' I had no idea what was involved, so we started on the chemo and then about halfway through the chemo system, another cardiologist specialist came in and gave me a good talk because they were talking about giving me a stem cell transplant. There were grave concerns because my age put me right on the limit and they said, 'You may not even—Two things, you may not even survive the stem cell transplant, or it'll have no effect.' I think I was only about two weeks away from having that when they decided to put the hold on that because it just seemed a little bit too risky. Participant 013ATR

Specific treatment discussed: Stem cell transplant

Because I was fit and because I was otherwise very healthy, I'd no other condition and I was… it was still seen as I was a candidate for stem cell transplant albeit with an elevated risk, but not to the level that would preclude a bone marrow transplant—sorry, a stem cell transplant. Those were the two tracks of conversation. Participant 004AL

When I was first diagnosed, the oncologist, haematologist, he said that we would do stem cell, but he was going away. He'd booked something, and he couldn't stop it for two or three weeks. He said as soon as he got back, they'd start stem cell on me. That was probably one of the worst weeks of my life, because I did a lot of reading, and I was at that stage 70-years-old, not very well, very low kidney function. In my own research, it showed that I was in a very high bracket of people who don't get through stem cell treatment. Participant 017ATR

He put me on that combination just for a couple of months just to check that they were affecting the free light chains, and they did, and then we just scheduled the stem cell transplant. Participant 002AL

Specific treatment discussed: Liver transplant

I spoke to them about a liver transplant and then they took into account my age and my condition with the amyloid, how bad it was. I said it was no good doing one it was too far gone…They said to me then that there's no other treatments. All we can do is the best we can with what we've got and they were doing nothing at this stage for us. Participant 009ATR

Essentially it was medical treatment versus the liver transplant which he then at that point said, 'You don't need.' Based off my specific thing and generally what he was actually recommending in my case. Participant 006ATR

The second time, as I was put on that treatment, I was assessed for a liver and a heart transplant because this protein is produced by the liver. It produces trans-direction and it converts it into this amyloid. One treatment or intervention was to—And the heart, I should say, is the key organ. Participant 016ATR

Table 4.1: Discussions about treatment

Discussions about treatment	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes it being difficult to remember/other response	14	38.89	4	22.22	5	20.00	2	20.00	8	100.00	3	13.64	11	78.57	3	33.33	11	40.74
Participant describes discussing multiple options	13	36.11	8	44.44	11	44.00	5	50.00	0	0.00	11	50.00	2	14.29	3	33.33	10	37.04
Participant describes discussing one treatment option	6	16.67	3	16.67	6	24.00	3	30.00	0	0.00	6	27.27	0	0.00	2	22.22	4	14.81
Participant describes no treatment options being discussed	3	8.33	3	16.67	3	12.00	0	0.00	0	0.00	2	9.09	1	7.14	1	11.11	2	7.41

Discussions about treatment	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes it being difficult to remember/other response	14	38.89	5	62.50	8	42.11	1	12.50	3	21.43	3	21.43	5	45.45	9	36.00
Participant describes discussing multiple options	13	36.11	2	25.00	7	36.84	3	37.50	7	50.00	6	42.86	2	18.18	11	44.00
Participant describes discussing one treatment option	6	16.67	1	12.50	4	21.05	1	12.50	3	21.43	3	21.43	3	27.27	3	12.00
Participant describes no treatment options being discussed	3	8.33	0	0.00	0	0.00	3	37.50	1	7.14	2	14.29	1	9.09	2	8.00

Table 4.2: Discussions about treatment, options discussed

Discussions about treatment: Options discussed	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes being presented with multiple options: Participated in the decision-making process	5	13.89	3	16.67	4	16.00	2	20.00	0	0.00	5	22.73	0	0.00	2	22.22	3	11.11
Participant describes being presented with multiple options: Did not participate in the decision-making process	4	11.11	4	22.22	4	16.00	0	0.00	0	0.00	3	13.64	1	7.14	0	0.00	4	14.81
Participant describes being presented with multiple options: They were told what to do without discussion	4	11.11	1	5.56	3	12.00	3	30.00	0	0.00	3	13.64	1	7.14	1	11.11	3	11.11
Participant describes being presented with no options/approach: No therapies are available	3	8.33	3	16.67	3	12.00	0	0.00	0	0.00	2	9.09	1	7.14	1	11.11	2	7.41
Participant describes being presented with one option/approach: They were told what to do without discussion	3	8.33	1	5.56	3	12.00	2	20.00	0	0.00	3	13.64	0	0.00	1	11.11	2	7.41
Participant describes being presented with one option/approach: Some but very little discussion	2	5.56	0	0.00	1	4.00	2	20.00	0	0.00	1	4.55	1	7.14	0	0.00	2	7.41

Discussions about treatment: Options discussed	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes being presented with multiple options: Participated in the decision-making process	5	13.89	1	12.50	2	10.53	1	12.50	2	14.29	3	21.43	1	9.09	4	16.00
Participant describes being presented with multiple options: Did not participate in the decision-making process	4	11.11	1	12.50	2	10.53	1	12.50	4	28.57	0	0.00	1	9.09	3	12.00
Participant describes being presented with multiple options: They were told what to do without discussion	4	11.11	0	0.00	3	15.79	1	12.50	1	7.14	3	21.43	0	0.00	4	16.00
Participant describes being presented with no options/approach: No therapies are available	3	8.33	0	0.00	0	0.00	3	37.50	1	7.14	2	14.29	1	9.09	2	8.00
Participant describes being presented with one option/approach: They were told what to do without discussion	3	8.33	0	0.00	3	15.79	0	0.00	3	21.43	0	0.00	2	18.18	1	4.00
Participant describes being presented with one option/approach: Some but very little discussion	2	5.56	0	0.00	0	0.00	2	25.00	1	7.14	1	7.14	0	0.00	2	8.00

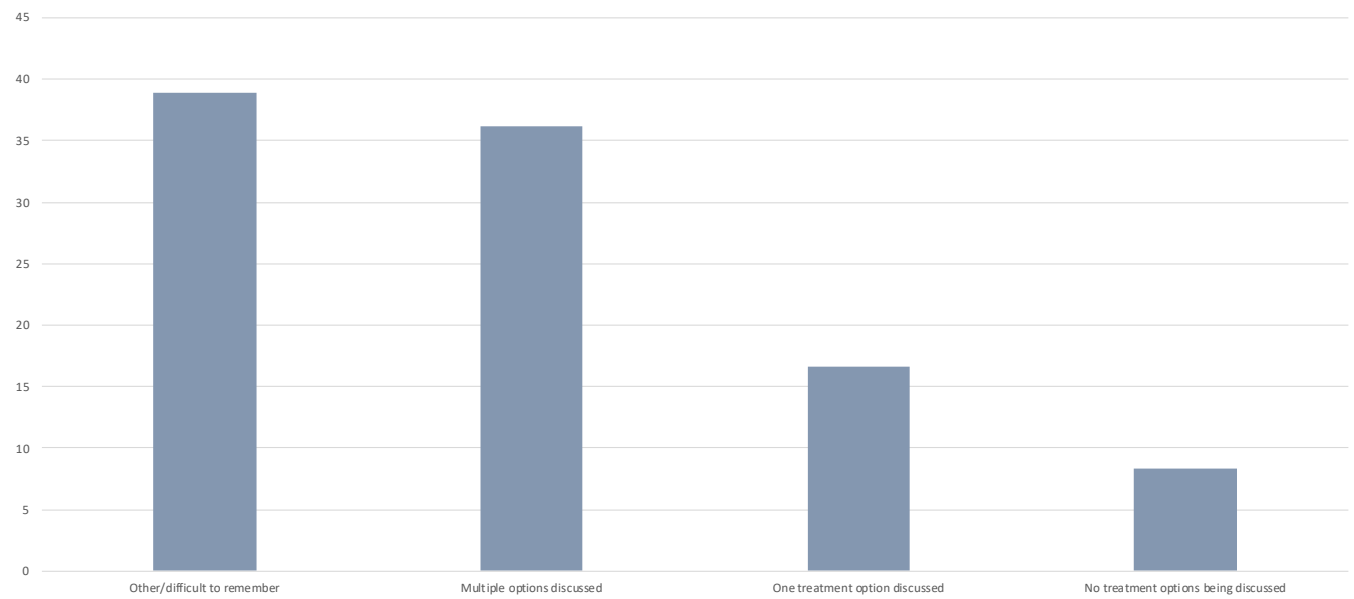

Figure 4.1: Discussions about treatment

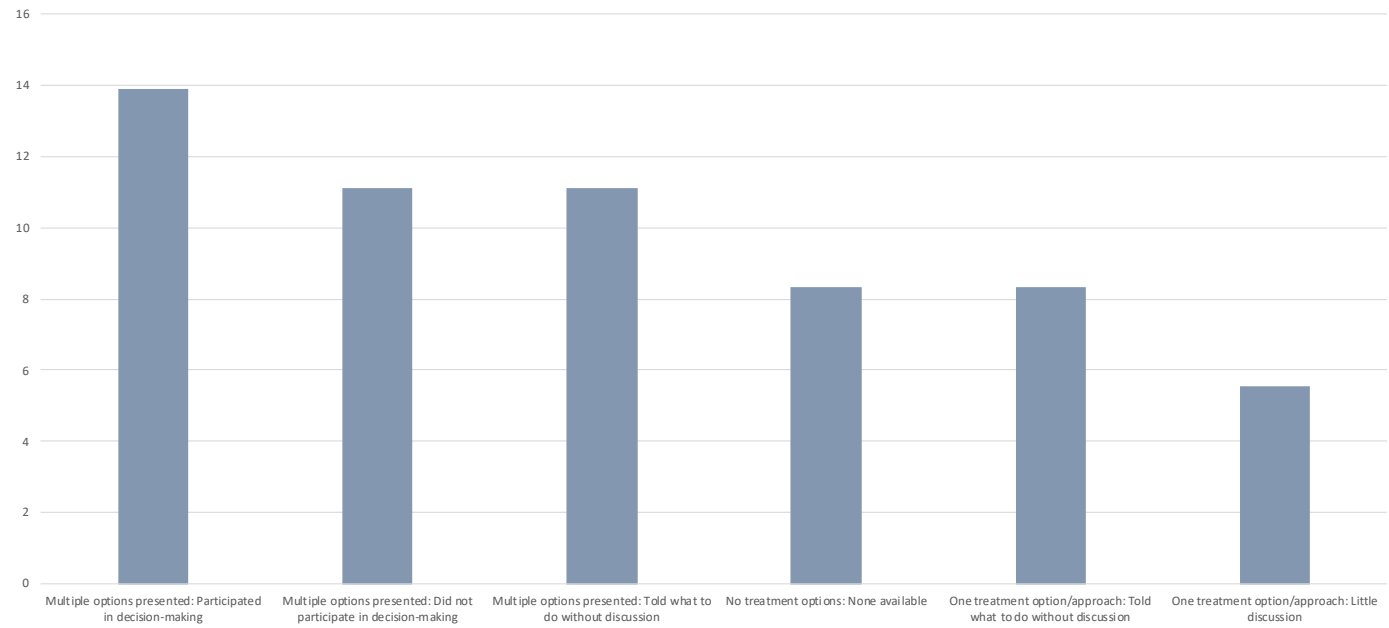

Figure 4.2: Discussions about treatment, options discussed

Table 4.3: Specific treatment discussed

Discussions about treatment: Options discussed	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes being presented with the option of stem cell transplant	6	16.67	3	16.67	5	20.00	3	30.00	0	0.00	5	22.73	1	7.14	1	11.11	5	18.52
Participant describes being presented with the option of liver transplant	4	11.11	4	22.22	4	16.00	0	0.00	0	0.00	4	18.18	0	0.00	2	22.22	2	7.41
Participant describes being presented with the option of chemotherapy	3	8.33	1	5.56	1	4.00	2	20.00	0	0.00	3	13.64	0	0.00	0	0.00	3	11.11
Participant describes being presented with the option of Green tea extract	3	8.33	3	16.67	3	12.00	0	0.00	0	0.00	2	9.09	1	7.14	1	11.11	2	7.41
Participant describes being presented with the option of Velcade or dexamethasone	3	8.33	0	0.00	2	8.00	3	30.00	0	0.00	3	13.64	0	0.00	1	11.11	2	7.41
Participant describes being presented with the option of Bone marrow transplant	2	5.56	0	0.00	1	4.00	2	20.00	0	0.00	2	9.09	0	0.00	1	11.11	1	3.70

Discussions about treatment: Options discussed	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes being presented with the option of stem cell transplant	6	16.67	0	0.00	3	15.79	3	37.50	2	14.29	4	28.57	1	9.09	5	20.00
Participant describes being presented with the option of liver transplant	4	11.11	2	25.00	1	5.26	0	0.00	1	7.14	3	21.43	2	18.18	2	8.00
Participant describes being presented with the option of chemotherapy	3	8.33	0	0.00	1	5.26	2	25.00	2	14.29	1	7.14	0	0.00	3	12.00
Participant describes being presented with the option of Green tea extract	3	8.33	1	12.50	1	5.26	1	12.50	1	7.14	2	14.29	1	9.09	2	8.00
Participant describes being presented with the option of Velcade or dexamethasone	3	8.33	0	0.00	2	10.53	1	12.50	2	14.29	1	7.14	1	9.09	2	8.00
Participant describes being presented with the option of Bone marrow transplant	2	5.56	0	0.00	1	5.26	1	12.50	1	7.14	1	7.14	0	0.00	2	8.00

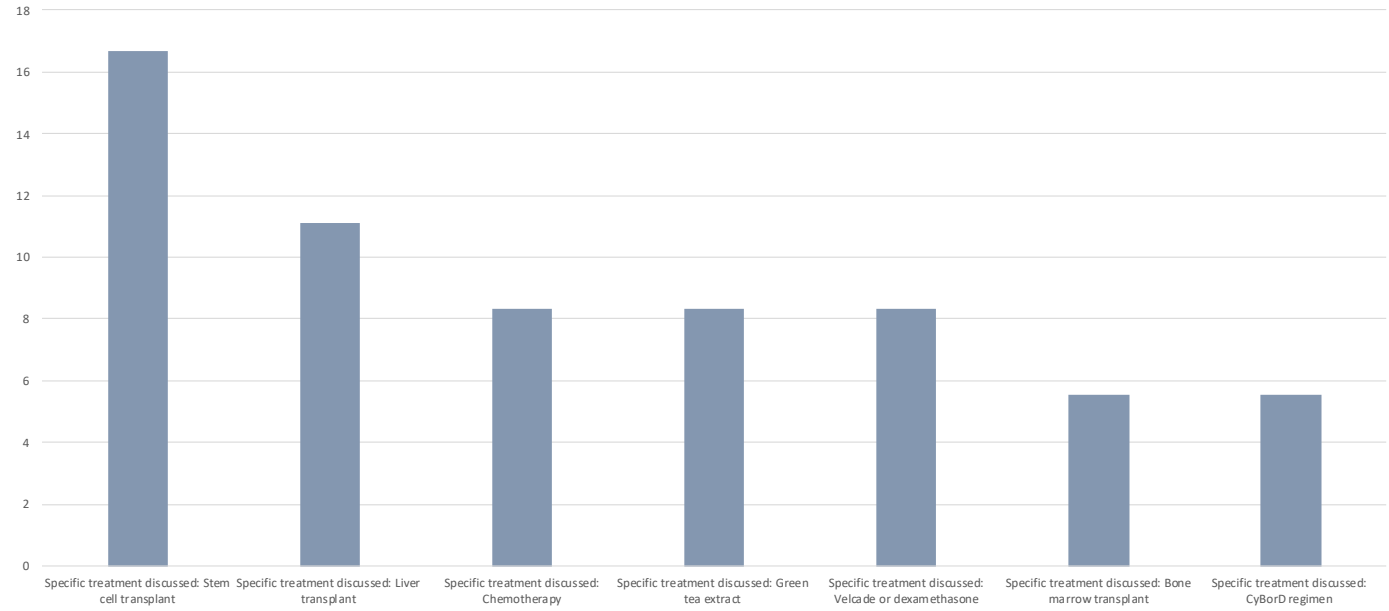

Figure 4.3: Specific treatment discussed

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported consideration was quality of life as part of multiple aspects that they consider when making decisions about treatment and this was described by 13 participants (36.11%). This was followed by efficacy as part of multiple aspects they consider (n=9, 25.00%); side effects as part of multiple aspects they consider (n=9, 25.00%); the long term impact and side effects of treatment as part of multiple aspects they consider (n=7, 19.44%), taking the advice of their clinician as part of multiple aspects they consider (n=6, 16.67%), considering the potential impact on their family or dependents as part of multiple aspects they consider (n=5, 13.89%), survival benefit as part of multiple aspects they consider (n=5, 13.89%) and taking the advice of their clinician as the only aspect they consider (n=5, 13.89%).

In relation to subgroup variations, participants in the *Regional or remote* (22.22%), and *Mid to low SEIFA* (18.18%) subgroups described taking quality of life as part of multiple aspects they consider less frequently than the general population (36.11%), while those in the *Aged 75 or older* (50.00%) subgroup described this more frequently.

Participants in the subgroups *AL amyloidosis* (50.00%), *Aged 75 or older* (50.00%), *Male* (40.91%), *University* (42.86%), and *Regional or remote* (44.44%) described taking efficacy taking efficacy into account as part of multiple aspects that they consider more frequently than the general population (25.00%) while those in subgroups *Carer* (0.00%), *Aged 55 to 64* (0.00%), and *Female* (0.00%) did not describe this at all.

Participants in the *Aged 75 or older* subgroup (12.50%) described taking side effects into account as part of multiple aspects they consider less frequently than the general population (25.00%).

Participants in the subgroups *Aged 75 or older* (37.50%) and *University* (35.71%) described taking the long-term impact and side effects of treatment into account as part of multiple aspects that they consider more frequently than the general population (19.44%), whereas those in the subgroups *Mid to low SEIFA* (9.09%), *Aged 65 to 74* (5.26%) and *Carer* (0.00%) described this less frequently.

Participants in the subgroups *AL amyloidosis* (40.00%) and *University* (28.57%) described taking the advice of their clinician into account as part of multiple aspects that they consider more frequently than the general population (16.67%) while those in the *Carer* subgroup did not describe this at all (0.00%).

Participants in the *Aged 75 or older* subgroup described taking into account the potential impact on their family or dependents more frequently (25.00%) than the general population (13.89%).

Participants in the subgroups *Aged 55 to 64* (25.00%) and *University* (28.57%) described taking the survival

benefit into account as part of multiple aspects they consider more frequently than the general population (13.89%) while those in the *Carer* (0.00%), *Aged 75 or older* (0.00%), *Regional or remote* (0.00%), and *Mid to low SEIFA* (0.00%) subgroups did not describe this at all.

Participants in the *Mid to low SEIFA* (27.27%) subgroup described taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment more frequently than the general population (13.89%), while participants in the *Aged 55 to 64* (0.00%) subgroup did not describe this at all.

Quality of life (as part of multiple considerations)

My decisions about treatment are pretty much based on the quality of life and the effect of the treatment. That's probably the same thing, isn't it? I mean, quality of life and the treatment and what the actual amyloidosis does. Participant 001AL

Quality of life, as we get further along in the journey, the quality of life balance I think is really important. A few times, he's been losing track now because we've just gone back on chemo again as of last Friday. Participant 002CA

I list the benefits and the risks and what the outcome. The outcome is to live longer. The outcome is to live with the quality of life and not be restricted to our bed or our medication and the ongoing care. Participant 002ATR

Efficacy (as part of multiple considerations)

Obviously, efficacy is the principal one. Does the damn thing work, and will it have long-term effects, will it result with the AL being under control or diminished to the point where it's not an issue? Those to me were the principal issues. Participant 004AL

The first thing is asking how realistic it is in terms of a way for me to get better. That's the first step that I go through with NAME and/or whoever the specialist who is discussing it. Then second stage is really about the risks involved. Participant 006ATR

The thing that I ask with them is what it's going to do for me, and is it going to help me, or what are the side effects? That's you're but outside that, no, we haven't been asked to look into much the treatments as yet. Participant 009ATR

Side effects (as part of multiple considerations)

An experienced doctor would be able to fill you in with what options there are, what side effects you will have, will affect the lifestyle, et cetera. I don't think that any of the other doctors really have that experience. An experienced doctor would have far better knowledge and far better to be able to impart that knowledge to the patient and outline what some of the effects would be. Participant 006AL

The secondary one was side effects. The tertiary one would have been effects on lifestyle, diet changes, exercise changes, the ability to live a normal life type of thing. Those would be the hierarchy for me. Participant 004AL

The thing that I ask with them is what it's going to do for me, and is it going to help me, or what are the side effects? That's you're but outside that, no, we haven't been asked to look into much the treatments as yet.
Participant 009ATR

Long term impact/side effects (as part of multiple considerations)

How it would affect me and how long it would be, the length of time. Participant 003ALX

As long as it doesn't affect my other organs, my kidney and my liver were the main things, I just keep taking that tablet. Participant 003ATR

I am looking for not a short-term gain, but I look to see what the benefits are, what the side effects could be, the timescales for them to actually be noticeable, and then long-term prognosis down the line, is that long-term, how we would go. Those are the sort of things I'm looking for. Participant 015ATR

Taking the advice of their clinician (as part of multiple considerations)

Anyway, recommendations by him. He's my haematologist, and I would think a haematologist should have a pretty good idea of the effects of a particular drug on your blood system. Participant 016ATR

Well, when you're making decisions about a treatment, you just do what your oncologist or haematologist recommends. There wasn't really much alternative for me. I couldn't do stem cell, and here, just thinking about my overall health hell coming out of it and the side effects of it, and that was about it, yes. Participant 017ATR

An experienced doctor would be able to fill you in with what options there are, what side effects you will have, will affect the lifestyle, et cetera. I don't think that any of the other doctors really have that experience. An experienced doctor would have far better knowledge and far better to be able to impart that knowledge to the patient and outline what some of the effects would be. Participant 006AL

Impact on family and dependents (as part of multiple considerations)

I would consider my family, my husband and I, we were to involve and see if I had to go away somewhere or could have the treatments here in LOCATION METROPOLITAN, usual concerns that me as a potential patient would have with relation to treatment. Participant 003ALX

I was keeping my peace, at least somewhat even a normal life. That became it's now like how actually, how my little life at this stage, and then, I guess costs and probably the family and friends. Participant 006ATR

Well, I make those decisions in conjunction with my wife. The things that we focus on are, if there's a treatment available, would we just rush in and say-- just anything to get another year of life-- and we're not inclined to that way. The way things are going it's restricting my wife's life, and it's restricting mine, not being able to go on bush walks and not being able to-- Well, I can't even go and pick up a carton of beer from the bottle shop without someone putting it in the car because of the symptoms. Participant 013ATR

Survival benefit (as part of multiple considerations)

The outcome is to live longer. The outcome is to live with the quality of life and not be restricted to our bed or our medication and the ongoing care. So, in question aligned to you to make the decision of how successful it is. If you take the liver transplant for example—what is the length of time that somebody needs afterwards, what are the complications of the liver transplant, what is that like, what medications are we on, what are the side effects of the medication, what is the ongoing care that is involved, would there be treatment after the transplant, and so forth. Participant 002ATR

The first thing is asking how realistic it is in terms of a way for me to get better. That's the first step that I go through with NAME and/or whoever the specialist who is discussing it. Then second stage is really about the risks involved. The other thing is because of my character which has been affected today to a certain extent. It's do I have to go off somewhere is there a chance I get nothing for six months, eight months, a year or whatever that I've then regressed and become much worse. Personally, for me, one of the biggest reasons I really wasn't particularly fond of the idea of a liver transplant, is that I could still go to work every day at this stage. I can still go and drink with my friends. I'm still quite young. Participant 006ATR

Yes, I mean if it got side effects, we deal with those and maybe change or then modify something about the length of the treatment. How long am I? How sick am I going to be? How long it's going to be? What's going to be the outcome? I'd be prepared to do it. Participant 001ATR

Advice of clinician (only consideration)

Look, we were lost. We went to see NAME CLINICIAN hoping that what he knew about amyloidosis, he would be able to give him some treatment. NAME CLINICIAN basically told us that the only thing that they give him was a drug called diflunisal, which we basically said, 'Yes, okay. We'll go on that.' Participant 004CA

Well, I just take what the doctors—I've got full trust in my doctors. I know I'm very, very lucky to be in LOCATION METROPOLITAN here because the NAME HOSPITAL and the Amyloid Centre and the NAME HOSPITAL is one of the top three in the world, they're in constant communication with the Mayo Clinic in America, and the London Amyloidosis Clinic updated on trials, working and failed. The head haematologist I had, he's one of the top guys. Well, he would be the top guy in Australia I would say, if not one of the top guys in the world. Like I said, I have complete faith or whatever they say or recommend. Participant 005AL

Well, mainly the recommendation of the haematologist, NAME SPECIALIST because you can go online and read about this and it's so complex.

You have to be guided by the professionals that you are being treated by. Participant 14ATR

Table 4.4: Considerations when making decisions

Considerations when making decisions about treatment	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	13	36.11	7	38.89	10	40.00	3	30.00	3	37.50	8	36.36	5	35.71	2	22.22	11	40.74
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	9	25.00	4	22.22	7	28.00	5	50.00	0	0.00	9	40.91	0	0.00	4	44.44	5	18.52
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	9	25.00	4	22.22	7	28.00	3	30.00	2	25.00	5	22.73	4	28.57	3	33.33	6	22.22
Participant describes taking the long term impact and side effects of treatment into account as part of multiple aspects that they consider when making decisions about treatment	7	19.44	5	27.78	6	24.00	2	20.00	0	0.00	5	22.73	2	14.29	2	22.22	5	18.52
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	6	16.67	2	11.11	5	20.00	4	40.00	0	0.00	5	22.73	1	7.14	1	11.11	5	18.52
Participant describes taking the potential impact on their family or dependents into account as part of multiple aspects that they consider when making decisions about treatment	5	13.89	3	16.67	3	12.00	1	10.00	1	12.50	2	9.09	3	21.43	1	11.11	4	14.81
Participant describes taking the survival benefit into account as part of multiple aspects that they consider when making decisions about treatment	5	13.89	4	22.22	5	20.00	1	10.00	0	0.00	2	9.09	3	21.43	0	0.00	5	18.52
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	5	13.89	3	16.67	4	16.00	1	10.00	1	12.50	3	13.64	2	14.29	1	11.11	4	14.81

Considerations when making decisions about treatment	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	13	36.11	3	37.50	5	26.32	4	50.00	5	35.71	5	35.71	2	18.18	11	44.00
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	9	25.00	0	0.00	4	21.05	4	50.00	3	21.43	6	42.86	2	18.18	7	28.00
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	9	25.00	2	25.00	6	31.58	1	12.50	4	28.57	3	21.43	2	18.18	7	28.00
Participant describes taking the long term impact and side effects of treatment into account as part of multiple aspects that they consider when making decisions about treatment	7	19.44	2	25.00	1	5.26	3	37.50	2	14.29	5	35.71	1	9.09	6	24.00
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	6	16.67	1	12.50	3	15.79	2	25.00	2	14.29	4	28.57	2	18.18	4	16.00
Participant describes taking the potential impact on their family or dependents into account as part of multiple aspects that they consider when making decisions about treatment	5	13.89	1	12.50	1	5.26	2	25.00	2	14.29	2	14.29	1	9.09	4	16.00
Participant describes taking the survival benefit into account as part of multiple aspects that they consider when making decisions about treatment	5	13.89	2	25.00	2	10.53	0	0.00	1	7.14	4	28.57	0	0.00	5	20.00
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	5	13.89	0	0.00	4	21.05	1	12.50	3	21.43	1	7.14	3	27.27	2	8.00

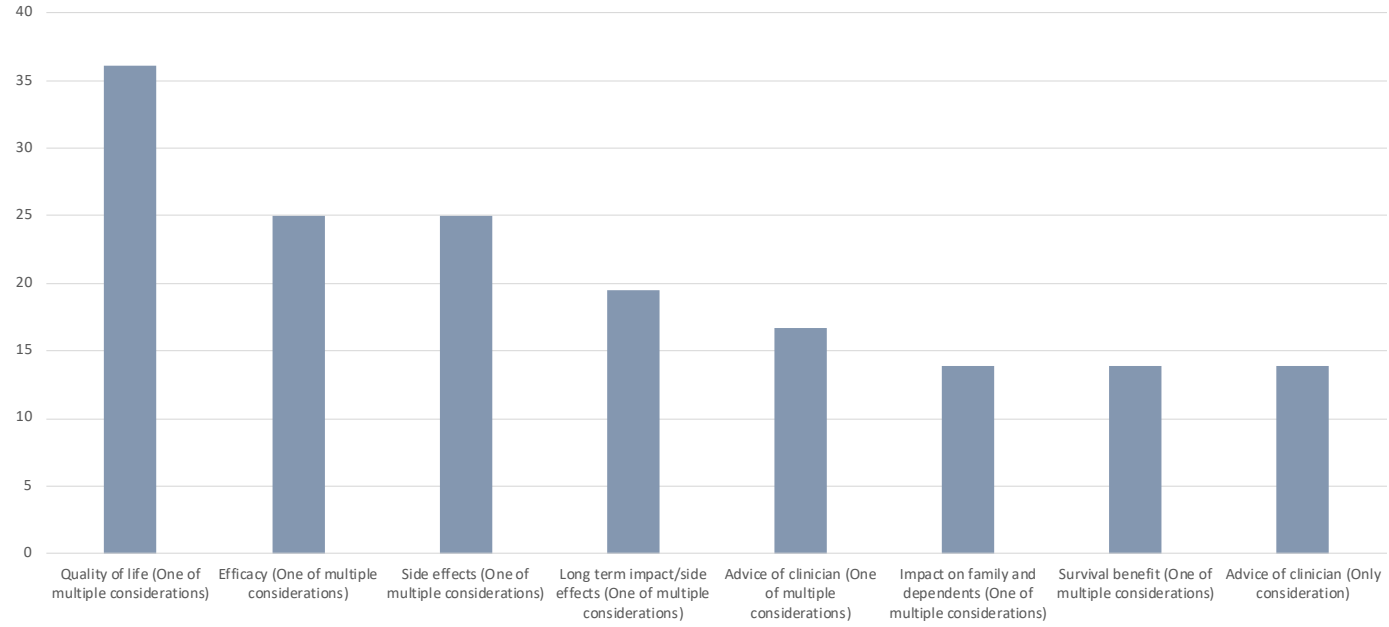

Figure 4.4 Considerations when making decisions

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 15 participants (41.67%) that felt the way they made decisions about treatment had not changed over time, and 12 participants (33.33%) that described decision-making changing. Nine participants (25.00%) were unsure/other or gave no response.

Where participants had changed the way they make decisions, this was primarily in relation to becoming more informed and/or assertive (n=7, 19.44%). Three participants described their decision-making changing over time as they are more aware of their health, responsibilities and/or limitations (8.33%) Other participants described changing over time as they are more accepting of their condition and choices available (n=1, 2.78%), they are more focused on how treatment impacts their family and dependents (n=1, 2.78%), they are more cautious and considered (n=1, 2.78%) and they are more focused on quality of life or the impact of side effects (n=1, 2.78%).

Among participants who described no change in the way they make decisions the most common response was that this was because they had always been informed/assertive (n=7, 19.44%) followed by those who did not mention any reason (n=4, 11.11%). Other responses were that there had been no change because they always took the advice of clinicians (n=2, 5.56%) and because they have had no treatment options to choose from (n=1, 2.78%).

In relation to subgroup variations, participants in the subgroups *AL amyloidosis* (60.00%), *Regional or remote* (55.56%), and *Aged 75 or older* (62.50%) described no change in decisions-making over time more frequently than the general population (41.67%) while those in the subgroups *Carer* (25.00%) and *Aged 55 to 64* (25.00%) described this less frequently.

Participants in the *Aged 55 to 64* subgroup (50.00%) described decision-making changing over time more frequently than the general population (33.33%), while those in the subgroups *Female* (21.43%) and *Mid to low SEIFA* (18.18%) described this less frequently.

Participants in the subgroups *Carer* (50.00%), *Female* (35.71%), and *Mid to low SEIFA* (36.36%) were unsure/other or gave no response more frequently than the general population (25.00%), while those in the subgroups *AL amyloidosis* (10.00%), *Aged 75 or older* (12.50%), and *University* (14.29%) described this less frequently.

Participants in the *Carer* (0.00%), *Female* (7.14%), and the *Trade or high school* (7.14%) subgroups described decision-making changing over time as they are more informed and/or assertive less frequently than the general population (19.44%), while those in the subgroup *University* (42.86%) described this more frequently.

Participants in the *University* (35.7%), *Regional or remote* (44.44%), and *AL Amyloidosis* (30.00%) subgroups described no change in decision-making

as they have always been informed and/or assertive more frequently than the general population (19.44%), while those in the *Trade or high school* subgroup (0.00%) did not describe this at all.

No participants in the subgroups *Carer* (0.00%), *Female* (0.00%) and *Aged 55 to 64* (0.00%) described no change in decision-making and did not mention any reason, whereas those in the subgroups *Aged 75 or older* (25.00%) and *Trade or high school* (21.43%) described this more frequently than the general population (11.11%).

Participants in the *AL amyloidosis* subgroup described no change in decision-making over time as they have always taken the advice of clinicians more frequently (20.00%) than the general population (5.56%).

No change (total)

I think I probably make decisions in the same kind of way because I've always wanted to be informed, I guess. I like to make informed choices and weigh things up. I like to understand what the treatments are doing and how they work, but that's probably just assigned to me really. Participant 002AL

As much as the same way as I've always done. Amyloidosis isn't the first health scare I had. Participant 002ALX

Oh, pretty well the same. NAME HUSBAND has always been a very independent person, was late marrying, late becoming a father. I think one of the biggest impacts of this disease was all of a sudden, he had no control. I don't know whether he would say that. I don't think he would say that, but he'd always been in control of his life. Participant 002CA

Change (total)

No, the decision-making, I think, is helped by knowledge about the disease, understanding about it, talking to other people, talking to various specialists about it. I feel reasonably informed and I think that makes the decisions a lot easier. Participant 001AL

As time has gone on, he has definitely let down his guard and discusses it much more, but in saying this, I did have to say to him that this condition that he has is impacting on the whole family and we are all part of this. I did have to throw that comment out a few times which may have encouraged him to look at things a bit differently. Participant 001CA

I think it's changed. I think for a long time, I've made a lot of decisions, thinking about NAME HUSBAND and what he'd want and all that sort of thing, but often he wasn't in a situation to make a decision. I've ended up being the decision-maker and the driver in a lot of ways, and I guess that's where the carer side of me kicks in and doing the very best I can, for all concerned that at the end of the day I'm making a decision. That's probably one of the biggest changes as a carer that has changed our relationship. Participant 003CA

Changed over time: more informed/assertive

No, the decision-making, I think, is helped by knowledge about the disease, understanding about it, talking to other people, talking to various specialists about it. I feel reasonably informed and I think that makes the decisions a lot easier. Participant 001AL

My decision has changed because I've learned and understood much more things that I didn't know before. Participant 005ATR

No, because I think in the beginning when you're first told you've got it, I'm going to do whatever it takes, this is what we're going to do. We're going to—You think you're invincible and then the reality of everything sets in a bit. Anything now I would research into. I wouldn't make that statement. 'Oh, yes, I'm going to go and, have everything and it will be terrific,' because you realise that's not the case. I guess you do look at it a bit thoroughly is a good way to put it. Participant 012ATR

No change over time: has always been informed/assertive

Oh, pretty well the same. NAME HUSBAND has always been a very independent person, was late marrying, late becoming a father. I think one of the biggest impacts of this disease was all of a sudden, he had no control. I don't know whether he would say that. I don't think he would say that, but he'd always been in control of his life. Participant 002CA

No, I'm pretty consistent and the way I make decisions point at my background IN PROFESSION... I try not to let emotions and other things get in the way too much. A very objective sort of a person, and always seeking outcome, not one to delay or defer decision-making. Participant 004AL

I think I probably make decisions in the same kind of way because I've always wanted to be informed, I guess. I like to make informed choices and weigh things up. I like to understand what the treatments are doing and how they work, but that's probably just assigned to me really. Participant 002AL

No change over time: no reason described or noted

As much as the same way as I've always done. Amyloidosis isn't the first health scare I had. Participant 002ALX

I'll probably do the same way. Participant 014ATR

In the same way, I think, yes. Participant 017ATR

Table 4.5: Decision-making over time

Decision-making over time	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
No change over time	15	41.67	7	38.89	11	44.00	6	60.00	2	25.00	9	40.91	6	42.86	5	55.56	10	37.04
Changed over time	12	33.33	7	38.89	9	36.00	3	30.00	2	25.00	9	40.91	3	21.43	2	22.22	10	37.04
Other/unsure/no response	9	25.00	4	22.22	5	20.00	1	10.00	4	50.00	4	18.18	5	35.71	2	22.22	7	25.93

Decision-making over time	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
No change over time	15	41.67	2	25.00	8	42.11	5	62.50	7	50.00	6	42.86	5	45.45	10	40.00
Changed over time	12	33.33	4	50.00	5	26.32	2	25.00	4	28.57	6	42.86	2	18.18	10	40.00
Other/unsure/no response	9	25.00	2	25.00	6	31.58	1	12.50	3	21.43	2	14.29	4	36.36	5	20.00

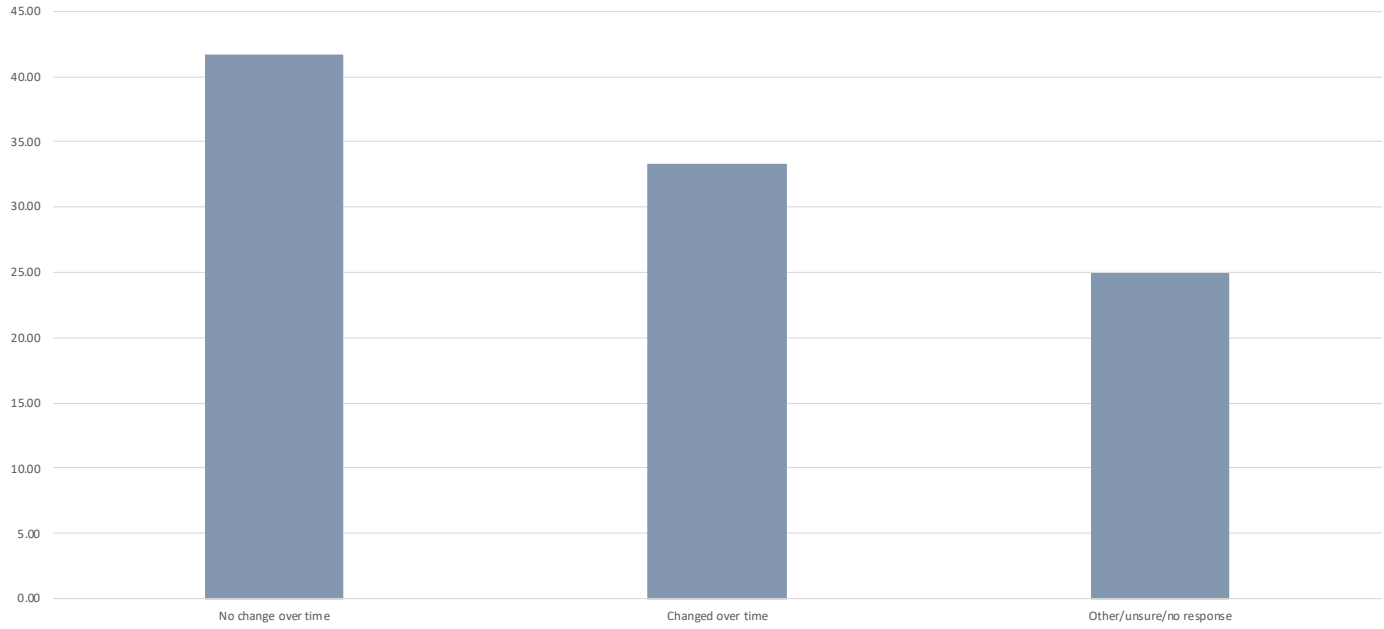

Figure 4.5: Decision-making over time

Table 4.6: Decision-making over time, rationale for change

Decision-making over time: Rationale for change	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes decision-making changing over time as they are more informed and/or more assertive	7	19.44	5	27.78	6	24.00	2	20.00	0	0.00	6	27.27	1	7.14	1	11.11	6	22.22
Participant describes decision-making changing over time as they are more aware of their health, responsibilities and/or limitations	3	8.33	2	11.11	2	8.00	0	0.00	1	12.50	1	4.55	2	14.29	1	11.11	2	7.41
Participant describes decision-making changing over time as they are more accepting of their condition and choices available (however not by choice)	1	2.78	1	5.56	1	4.00	0	0.00	0	0.00	1	4.55	0	0.00	0	0.00	1	3.70
Participant describes decision-making changing over time as they are more focused on how treatment impacts their family and dependents	1	2.78	0	0.00	0	0.00	0	0.00	1	12.50	0	0.00	1	7.14	1	11.11	0	0.00
Participant describes decision-making changing over time as they are more cautious and considered	1	2.78	1	5.56	1	4.00	0	0.00	0	0.00	1	4.55	0	0.00	0	0.00	1	3.70
Participant describes decision-making changing over time as they are more focused on quality of life or impact of side effects	1	2.78	0	0.00	1	4.00	1	10.00	0	0.00	1	4.55	0	0.00	0	0.00	1	3.70

Decision-making over time: Rationale for change	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes decision-making changing over time as they are more informed and/or more assertive	7	19.44	2	25.00	3	15.79	1	12.50	1	7.14	6	42.86	2	18.18	5	20.00
Participant describes decision-making changing over time as they are more aware of their health, responsibilities and/or limitations	3	8.33	0	0.00	2	10.53	0	0.00	1	7.14	1	7.14	1	9.09	2	8.00
Participant describes decision-making changing over time as they are more accepting of their condition and choices available (however not by choice)	1	2.78	1	12.50	0	0.00	0	0.00	1	7.14	0	0.00	0	0.00	1	4.00
Participant describes decision-making changing over time as they are more focused on how treatment impacts their family and dependents	1	2.78	0	0.00	1	5.26	0	0.00	0	0.00	0	0.00	0	0.00	1	4.00
Participant describes decision-making changing over time as they are more cautious and considered	1	2.78	0	0.00	0	0.00	1	12.50	1	7.14	0	0.00	0	0.00	1	4.00
Participant describes decision-making changing over time as they are more focused on quality of life or impact of side effects	1	2.78	0	0.00	1	5.26	0	0.00	1	7.14	0	0.00	0	0.00	1	4.00

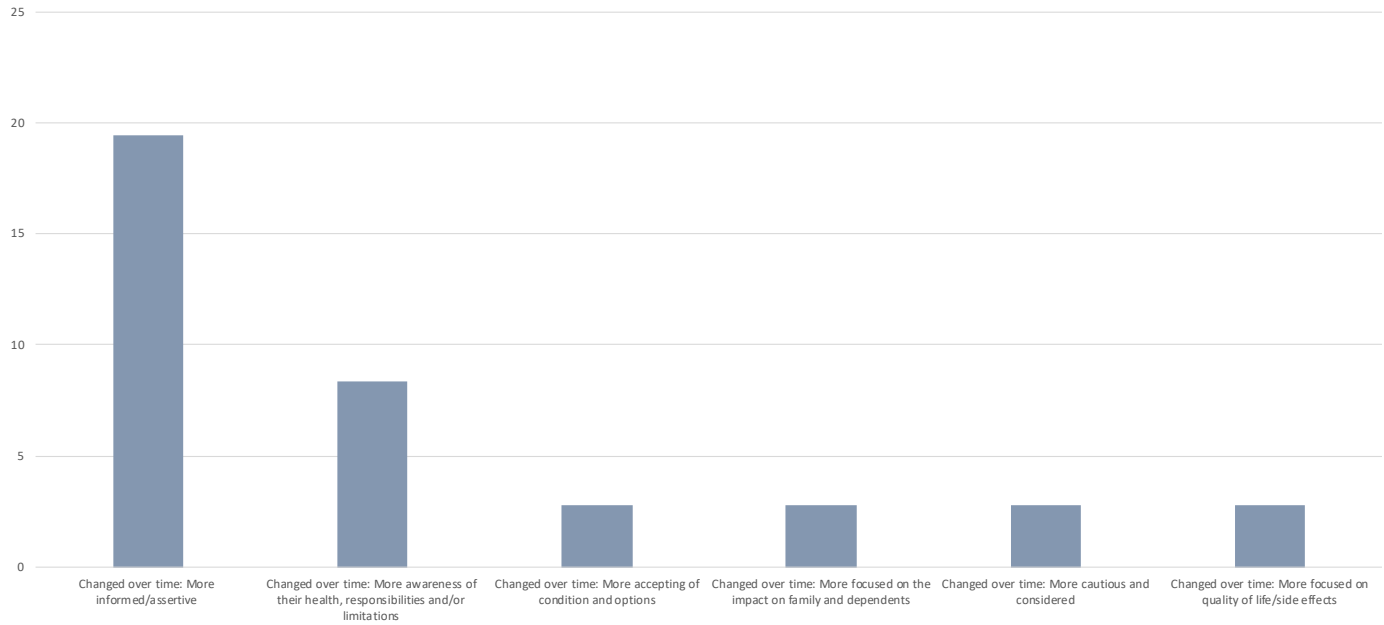

Figure 4.6: Decision-making over time, rationale for change

Table 4.7: Decision-making over time, rationale for no change

Decision-making over time: Rationale for no change	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes no change in decision-making over time as they have always been informed/assertive	7	19.44	2	11.11	5	20.00	3	30.00	2	25.00	3	13.64	4	28.57	4	44.44	3	11.11
Participant describes no change in decision-making but does not mention any reason	4	11.11	3	16.67	3	12.00	1	10.00	0	0.00	4	18.18	0	0.00	1	11.11	3	11.11
Participant describes no change in decision-making over time as they have always taken advice of clinicians	2	5.56	0	0.00	1	4.00	2	20.00	0	0.00	1	4.55	1	7.14	0	0.00	2	7.41
Participant describes no change in decision-making over time as they have not had treatment options to choose from	1	2.78	1	5.56	1	4.00	0	0.00	0	0.00	1	4.55	0	0.00	0	0.00	1	3.70

Decision-making over time: Rationale for no change	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes no change in decision-making over time as they have always been informed/assertive	7	19.44	2	25.00	4	21.05	1	12.50	0	0.00	5	35.71	2	18.18	5	20.00
Participant describes no change in decision-making but does not mention any reason	4	11.11	0	0.00	2	10.53	2	25.00	3	21.43	1	7.14	2	18.18	2	8.00
Participant describes no change in decision-making over time as they have always taken advice of clinicians	2	5.56	0	0.00	1	5.26	1	12.50	2	14.29	0	0.00	1	9.09	1	4.00
Participant describes no change in decision-making over time as they have not had treatment options to choose from	1	2.78	0	0.00	1	5.26	0	0.00	1	7.14	0	0.00	0	0.00	1	4.00

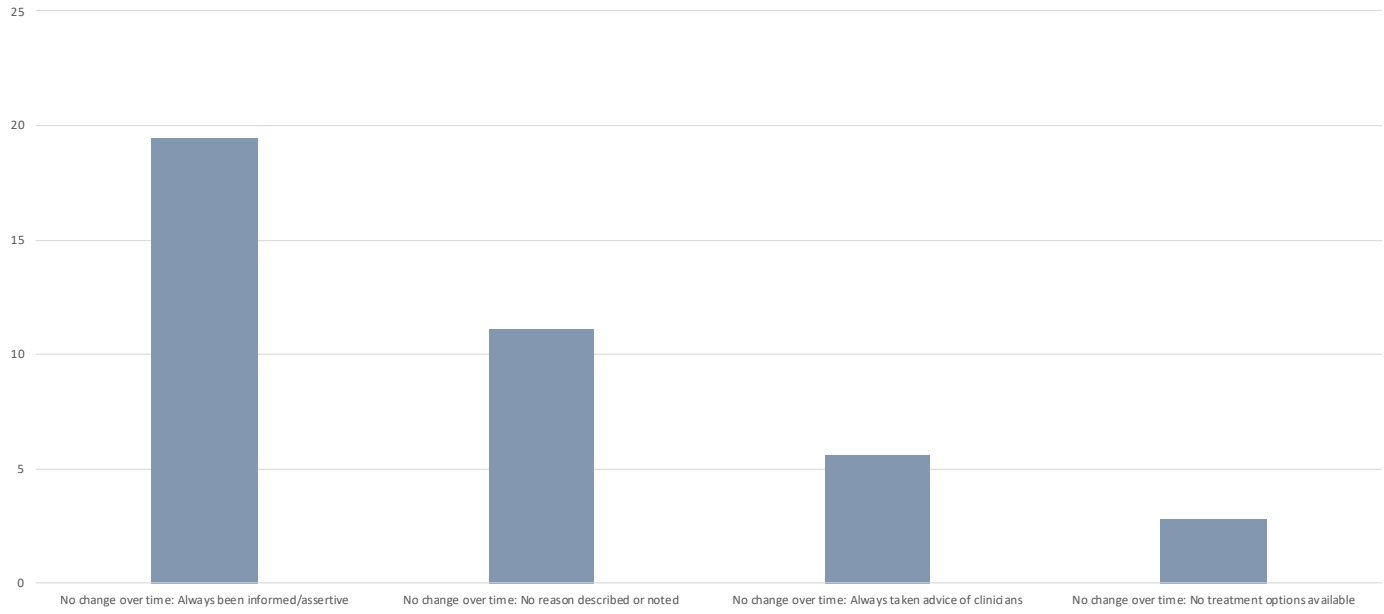

Figure 4.7: Decision-making over time, rationale for no change