

Section 10

Advice to others in the future: The benefit of hindsight

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Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common things that participants had wished they'd known earlier were to be assertive, an advocate, informed, and ask questions (12.77%), and to know the early signs and symptoms of their condition (12.77%), to understand the trajectory of the disease (10.64%), that they had known the risk factors and causes (8.51%), and they had been diagnosed sooner or had access to treatment sooner (8.51%). There were 10 participants (21.28%) that had no particular comment and were satisfied with experience (21.28%).

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would not change any aspect of their care or treatment and were satisfied with care and treatment received (25.53%), and would not change any aspect of their care or treatment, with no reason given (14.89%). Other themes included would have liked to have had a better understanding of their condition (6.38%), and were not sure if they would change anything (6.38%).

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Participant had no particular comment and were satisfied with experience

*No. No. I've had all I need.
Participant 026_2023AUHBV*

No, no, no. I want to tell you like what was the thing already everything was so good or the fabulous like everyone was a good. Like there was a doing such a cooperation and doctors was doing so good like they was doing the test and all that things. So it was a OK that was a fab.

Participant 027_2023AUHBV

Participant wishes they had known to be assertive, an advocate, informed, and ask questions

I probably the only thing I probably would have liked from myself more than professionals was that you know from professionals as well that they had it, that they had explained a little bit more to me the chance, the lack of or how the how the stent probably would definitely almost not have worked in my case. Then, you know, they just found a Doctor Who was willing to do it. And I think in hindsight, I probably should have had a little bit more time in discussion with somebody who said, well, you know, it'll it probably worked for a short time and then I might have just bit the bullet and said, OK, let's do this.

Participant 005_2023AUHBV

I think like I say given more information at the beginning and not just left, to find it all out for myself would have been helpful because it would have made I would have got up to the lifestyle changes quicker than I did, we could make a significant difference. As I say, just just those two to increase what I received rather than any changes to what I did receive, just more, more of the same really.

Participant 017_2023AUHBV

Participant wishes they had known the early signs and symptoms of their condition

I wish to be honest. I wish I was more aware of any warning signs. You know that even the slightest discomfort, and you know on your you know over that side of your chest. You know that you should, you know, at least get it checked out and not shrug it off. Yeah, so it doesn't. The big thing for me was it doesn't have to be a great big stabbing pain. It can just be mild discomfort. That could be the warnings of like, I had no idea.

Participant 028_2023AUHBV

I just wish I knew that my headaches were a precursor for stroke. I wish I knew that my double vision was a sign that I could have been in the front line for a stroke. The fact that I was given a misdiagnosis of I was just seeking attention that-- Look, I honestly don't think that would have changed the course of treatment back then, but it might've been able to prepare my parents better. There's also a part of me that goes, "Well, you can't look back and wish on something that's already been and gone." It is what it is.

Participant 050_2023AUHBV

Participant wishes they had understood the trajectory of the disease

I wish I had have known that if this is definitely genetic, that it doesn't matter what I eat, My numbers will still be high. The risk is higher that despite what you eat.

Participant 003_2023AUHBV

At diagnosis, sorry. Yeah, yeah. I think knowing, I think knowing the day-to-day impacts of it, not so much the clinical stuff. It would be great to know you've had an arrest. You don't get to drive for the next six months. When you get, when you get, when six months is up, this is what we have to do to get Vicroads to give you license back. It would be great to know this. You know these things are short term treatments, they're short term things we need to do to keep you safe and avoid recurrence and all those things in six, you know, a six month goal. This is what happens in six months. This is so is that you're not surprised when you find out that that's for everything. Oh, that's going in three months. I think knowing what the path ahead looks like, just a bit of a timeline would be really helpful.

Participant 009_2023AUHBV

Participant wishes they had known the risk factors and causes

If I'd taken those conditions seriously, I probably wouldn't have had my stroke. Educating people about the effects of alcohol and smoking and stress and the right food. If I'd have known that prior to my stroke, I probably wouldn't have had one.

Participant 045_2023AUHBV

Yes, plaque breaking off in my arteries caused by cholesterol. if I'd known how important that was, I would-- When I got cancer, I said to the doctor, I can't take Lipitor anymore. It makes me go too much and I'm in agony. I said I'm not taking it anymore. If I'd known then a build-up of Lipitor could cause a stroke, I would not have done that.

Participant 048_2023AUHBV

Participant wishes they had been diagnosed sooner and had access to treatment sooner

I think if I had of known about lipoprotein A earlier. I think I would have asked to have been tested earlier.

I wasn't asked. I wasn't. I didn't ask to be tested this time. But I do remember a couple of years ago seeing the cardiologist and he and I wasn't and I told him I said can I please be tested for lipoprotein A and he said no there's no need to test for that. But I didn't kind of go into it with him. And then it was two years later that he decided to to perform the lipoprotein a test. So. Not sure what changed his mind there. Maybe it was his own research and he was looking into it himself, but I think maybe if I had a known back then, I could have been much more of an advocate for myself instead of letting it sort of go on.

Participant 011_2023AUHBV

I wish that I hadn't just fobbed it off as asthma, but that's just me, because I'd be six months further into my journey.

Participant 014_2023AUHBV

Table 10.1: Anything participants wish they had known earlier

Anything participants wish they had known earlier	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant had no particular comment and were satisfied with experience	10	21.28	3	16.67	7	24.14	4	44.44	2	11.76	4	19.05	4	14.81	6	30.00
Participant wishes they had known to be assertive, an advocate, informed, and ask questions	6	12.77	3	16.67	3	10.34	2	22.22	3	17.65	1	4.76	4	14.81	2	10.00
Participant wishes they had known the early signs and symptoms of their condition	6	12.77	3	16.67	3	10.34	1	11.11	3	17.65	2	9.52	2	7.41	4	20.00
Participant wishes they had understood the trajectory of the disease	5	10.64	0	0.00	5	17.24	1	11.11	3	17.65	1	4.76	3	11.11	2	10.00
Participant wishes they had known the risk factors and causes	4	8.51	2	11.11	2	6.90	2	22.22	2	11.76	0	0.00	3	11.11	1	5.00
Participant wishes they had been diagnosed sooner and had access to treatment sooner	4	8.51	3	16.67	1	3.45	1	11.11	1	5.88	2	9.52	3	11.11	1	5.00

Anything participants wish they had known earlier	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant had no particular comment and were satisfied with experience	10	21.28	6	23.08	4	19.05	7	29.17	3	13.04	1	6.67	9	28.13	6	24.00	4	18.18
Participant wishes they had known to be assertive, an advocate, informed, and ask questions	6	12.77	4	15.38	2	9.52	3	12.50	3	13.04	1	6.67	5	15.63	3	12.00	3	13.64
Participant wishes they had known the early signs and symptoms of their condition	6	12.77	4	15.38	2	9.52	2	8.33	4	17.39	2	13.33	4	12.50	4	16.00	2	9.09
Participant wishes they had understood the trajectory of the disease	5	10.64	2	7.69	3	14.29	2	8.33	3	13.04	2	13.33	3	9.38	2	8.00	3	13.64
Participant wishes they had known the risk factors and causes	4	8.51	2	7.69	2	9.52	2	8.33	2	8.70	2	13.33	2	6.25	2	8.00	2	9.09
Participant wishes they had been diagnosed sooner and had access to treatment sooner	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	2	13.33	2	6.25	3	12.00	1	4.55

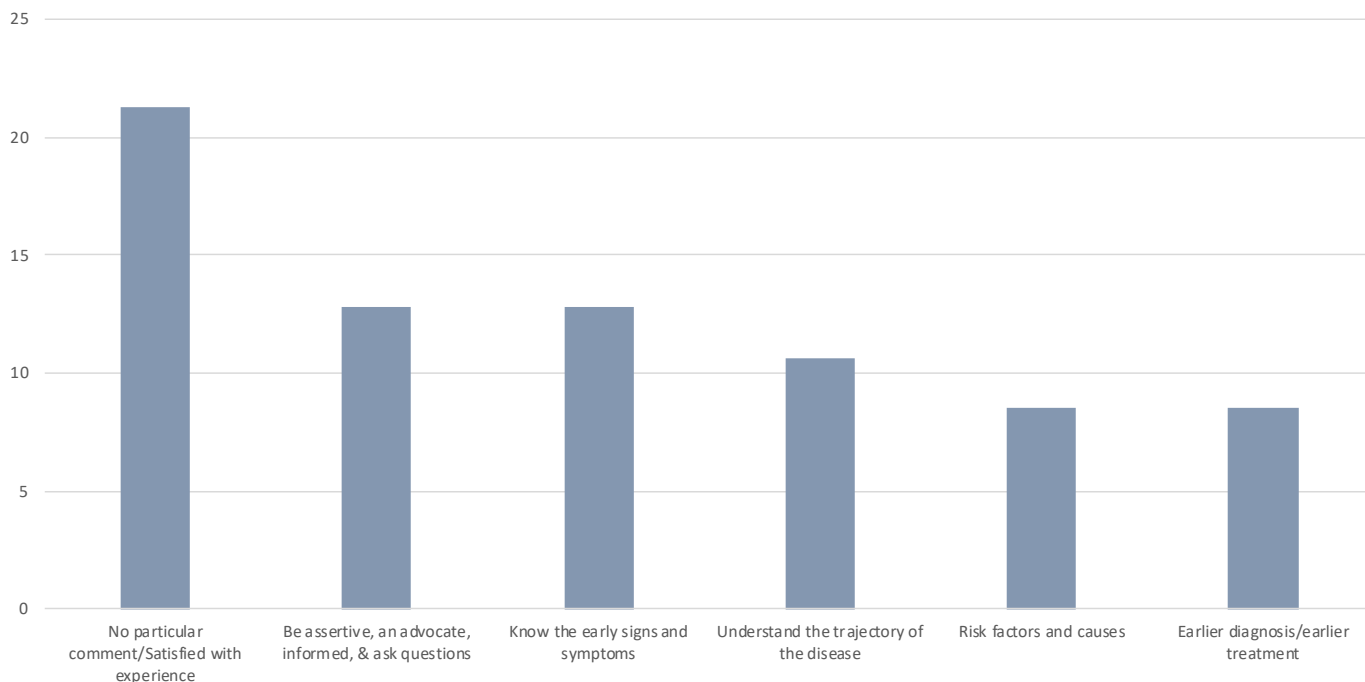


Figure 10.1: Anything participants wish they had known earlier

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

Anything participants wish they had known earlier	Reported less frequently	Reported more frequently
Participant had no particular comment and were satisfied with experience	Regional or remote	High cholesterol under 50 years of age
Participant wishes they had understood the trajectory of the disease	Had LP(a) test	-
Participant wishes they had known the risk factors and causes	-	High cholesterol under 50 years of age 0 0

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would not change any aspect of their care or treatment and were satisfied with care and treatment received (25.53%), and would not change any aspect of their care or treatment, with no reason given (14.89%). Other themes included would have liked to have had a better understanding of their condition (6.38%), and were not sure if they would change anything (6.38%).

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

Yeah, I feel like, yeah, it's I'm getting sort of pretty close to optimal care.

Participant 001_2023AUHBV

I was happy with everything that happened.

Participant 007_2023AUHBV

No, I don't know. About that, to be honest, yeah. I thought I've had pretty good care and treatment. You know, the only bonus for me would be if there was a cardiologist in my area, but you know, that's more about availability.

Participant 009_2023AUHBV

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

INTERVIEWER: Is there any aspect of your care or treatment that you would change?

PARTICIPANT: Yes, better information.

Participant 041_2023AUHBV

Maybe we should have pushed for more information and knowledge earlier on but I think we were both in shock about my diagnosis.

Participant 047_2023AUHBV

Table 10.3: Aspect of care or treatment they would change

Aspect of care or treatment they would change	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant would not change any aspect of their care or treatment and were satisfied with care and treatment received	12	25.53	6	33.33	6	20.69	4	44.44	3	17.65	5	23.81	6	22.22	6	30.00
Participant would not change any aspect of their care or treatment, with no reason given	7	14.89	4	22.22	3	10.34	1	11.11	4	23.53	2	9.52	3	11.11	4	20.00
Participant would have liked to have had a better understanding of their condition	3	6.38	1	5.56	2	6.90	0	0.00	2	11.76	1	4.76	2	7.41	1	5.00

Aspect of care or treatment they would change	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant would not change any aspect of their care or treatment and were satisfied with care and treatment received	12	25.53	7	26.92	5	23.81	7	29.17	5	21.74	5	33.33	7	21.88	8	32.00	4	18.18
Participant would not change any aspect of their care or treatment, with no reason given	7	14.89	3	11.54	4	19.05	3	12.50	4	17.39	1	6.67	6	18.75	4	16.00	3	13.64
Participant would have liked to have had a better understanding of their condition	3	6.38	2	7.69	1	4.76	2	8.33	1	4.35	1	6.67	2	6.25	1	4.00	2	9.09

Figure 10.2: Aspect of care or treatment they would change

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

Aspect of care or treatment they would change	Reported less frequently	Reported more frequently
Participant would not change any aspect of their care or treatment and were satisfied with care and treatment received	-	High cholesterol under 50 years of age