Section 10

Advice to others in the future

Section 10 Summary: Advice to others in the future

Advice to other patients and families in the future

- In the structured interview, participants were asked what advice they would give to other patients and their families. Six themes emerged as a result, the most frequent of which was that newly diagnosed patients should seek peer support or join support groups (n=9, 25.00%), followed by advice to seek and accept support in general (n=8, 22.22%). Other themes that emerged were to do research and ask questions (n=6, 16.67%), to find the best medical support for you (n=5, 13.89%), try to stay positive (n=4, 11.11%) and finally, to be aware of your own body and trust your instincts (n=4, 11.11%).

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Seek peer support/join support groups

Talk to others who are in the same boat. Get support from them because those of us who do it find it very helpful realising you're not alone because it is such a rare disease. There aren't that many people around, so get in touch with people attending a group if possible or online or whatever but try. Participant 001ALX

Other patients or other people with amyloidosis to ring up and chat to each other about that is helpful. Just knowing that you're not alone in these sorts of things. There is someone out there you can reach out to, very important, very balancing. Participant 003ALX

It's good to hear that or someone'd say, 'I've got that too. What do you do? What helps you?' That makes so much of a difference. I think support groups are the most important things in the world. Participant 004CA

Seek and accept support

First of all, they are not alone. Ask. Constantly ask questions. If you are not happy, get a second opinion. If you need help, you just have to reach out and ask for it. Help for either the carers who go through a lot. Participant 002ATR

Find somebody to talk to about it so that you don't feel so alone. Just make sure you've got really good, strong networks around you, that it is okay to feel sad. It's okay to feel devastated, but it's equally okay to look for things that are joyous as well. Participant 003CA

I think through that whatever it takes, and it will be different for everybody, but take advantage of the information centres and networks the carers and your support, family support, community support. Participant 004AL

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I think through that whatever it takes, and it will be different for everybody, but take advantage of the information centres and networks the carers and your support, family support, community support. Get out there, find out everything you can. Be informed, and not just about the treatment, but about your body. Understand what's going on how you can manage that to give the treatment the optimum chance of working. Positive attitude, being informed and acting on that information. I guess getting on with life and keeping at it. Just don't give in. Participant 004AL

Self-advocate. Don't just sit back and listen and take copious notes. Self-advocate and educate yourself. That's the best advice that I could give. You don't know what questions to ask, but the more you read about it the more questions you can ask. Obviously, educate yourself so that you can understand what's being said. Get that family and friends support. They probably go hand in hand. Participant 005CA

Find the best medical support for you

Make sure you see an expert. Don't rely on your GP or some other person. It has to be someone who is specialised in the area. If you have to travel, you've got to do that because that's where the main advice comes from. Participant 001ALX

I think the biggest advice, I would say, is find the team that is going to really go in to bat for you, even if that means searching around a bit, because I'm sure a lot of people just get sent to a doctor, and they're not even aware that they're specialist people around or anything like that. I think that's really important, and having an amazing haematologist is really important. Participant 012ATR

I think accessing appropriate specialist, whether it's your haematologist and heart specialist is important. They're the two people or the two professions that it's most important to have good access to the appropriate people. That's number one. Participant 016ATR

Stay positive

I think the biggest thing in most aspects of life is attitude. Your mental approach, if you like, you've got to get it and maintain it in a positive state. I'm not sure how individuals do that, every individual does it, but that's the key, is to be positive and informed. If you throw the towel and become negative and, 'Oh woe is me,' that's not a great mindset to progress from. You've already failed in a way. Participant 004AL

Well, encouragement. We need encouragement. If I'm having a bad patch with treatments, it's not something I want to lay a burden on somebody that's only recently found out that they have amyloidosis because if they can cope with amyloidosis then it doesn't progress to the point where other people are…Goes back to meeting a guy before I went into the clinic. He mentioned that we were, in fact, going into the same place. He was younger, he still has his active lifestyle. Why should I say, 'Oh, you're going to feel like shit,.' So, encouragement. That's the bottom line. Participant 006AL

The general advice really is to relax with it. I think if you panic-- I've seen people writing in Facebook where they're panicking from day to day to day about what's happening or might not happen. You can hear, from my voice, I went past that probably 20-odd years ago. I don't panic about it. It's going to happen, let's move with it, let's do the things that need to be done. Participant 015ATR

Be aware/trust your instincts

For me, personally, I think you have to be proactive in your own health regardless of what you're diagnosed with and when you're diagnosed, and you just have to-I'd hate to be a GP. I mean, there's so many people coming in and dealing with all sorts of things that it is hard for them to pinpoint whatever. You've just got to take responsibility for your own health, and don't get pushed aside because it's in the 'too hard' basket for the medical professionals. Participant 001ATR

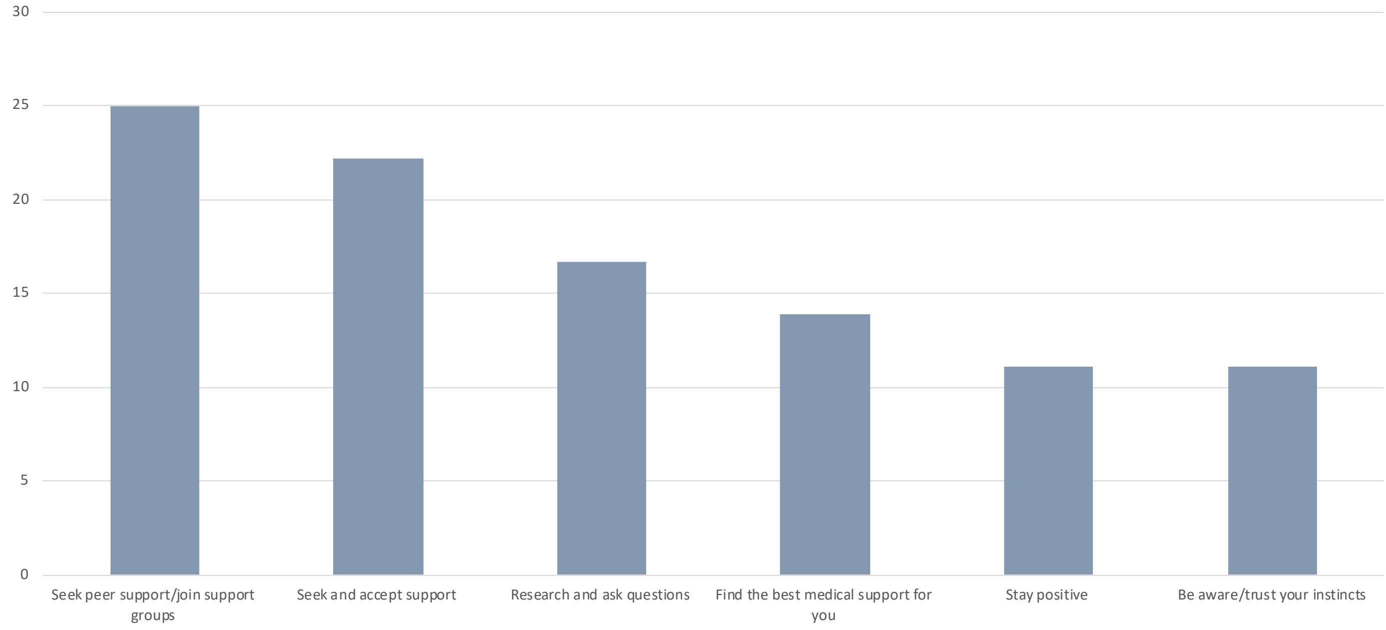
It's probably prior to diagnosis. If you're not comfortable with what your specialist is telling you, don't just accept that what they're telling you is true…The only-- again, it goes back down to education of specialists because my GP, both my GPs were aware of the condition because we moved from LOCATION METROPOLITAN first, both my GPs were aware of the condition when they were told that I had it. But they didn't-- there wasn't anything that clicked in the back of their head that goes, 'I know this is rare, maybe we should test this.' If you're not feeling well and the specialist tells you, you're fine find another specialist. Participant 004ATR

I would tell people, which I'm telling my family, if you find anything strange in your body or anything that's affecting you, go straight away and have a test. Participant 010ATR

Table 10.1: Advice to other patients and families in the future

Advice to others in the future	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's advice is to seek peer support and/or join support groups	9	25.00	2	11.11	4	16.00	4	40.00	3	37.50	4	18.18	5	35.71	3	33.33	6	22.22
Participant's advice is to seek and accept support	8	22.22	4	22.22	6	24.00	2	20.00	2	25.00	3	13.64	5	35.71	3	33.33	5	18.52
Participant's advice is to do research and ask questions	6	16.67	2	11.11	4	16.00	2	20.00	2	25.00	3	13.64	3	21.43	3	33.33	3	11.11
Participant's advice is to find the best medical support for you (including that it is ok to seek a second opinion)	5	13.89	4	22.22	4	16.00	1	10.00	0	0.00	3	13.64	2	14.29	1	11.11	4	14.81
Participant's advice is to try and stay positive	4	11.11	1	5.56	3	12.00	3	30.00	0	0.00	4	18.18	0	0.00	1	11.11	3	11.11
Participant's advice is to be aware of your own body and trust your instincts	4	11.11	4	22.22	4	16.00	0	0.00	0	0.00	2	9.09	2	14.29	0	0.00	4	14.81

Advice to others in the future	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's advice is to seek peer support and/or join support groups	9	25.00	1	12.50	6	31.58	2	25.00	2	14.29	4	28.57	2	18.18	7	28.00
Participant's advice is to seek and accept support	8	22.22	3	37.50	4	21.05	0	0.00	2	14.29	4	28.57	3	27.27	5	20.00
Participant's advice is to do research and ask questions	6	16.67	2	25.00	3	15.79	1	12.50	1	7.14	3	21.43	1	9.09	5	20.00
Participant's advice is to find the best medical support for you (including that it is ok to seek a second opinion)	5	13.89	3	37.50	2	10.53	0	0.00	2	14.29	3	21.43	2	18.18	3	12.00
Participant's advice is to try and stay positive	4	11.11	1	12.50	2	10.53	1	12.50	2	14.29	2	14.29	0	0.00	4	16.00
Participant's advice is to be aware of your own body and trust your instincts	4	11.11	2	25.00	1	5.26	1	12.50	3	21.43	1	7.14	0	0.00	4	16.00



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