

Section 10 Advice to other patients and families

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- Participants were asked what advice they would give to other people who are newly diagnosed with mitochondrial disease and their families. The most common advice is to ask questions and learn as much as you can (n=14, 28.00%). This was followed by the advice to talk to AMDF for information and support and to be part of the community (n=8, 16.00%), seek help (general) (n=8, 16.00%) and to find the right specialist as it is a rare disease and be comfortable with your healthcare team (n=8, 16.00%). There were seven participants (14.00%) whose advice is to seek help through psychological support, six participants (12.00%) whose advice is to share your story to help others and six participants (12.00%) whose advice is to be hopeful.

Advice to others diagnosed with mitochondrial disease

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Participant's advice is to ask questions and learn as much as you can

I think when you're in with the doctor ask lots of questions and keep asking questions till you get answers. Whether the answers can't give any you more information, this is it, this is all we've got, that's okay to be told that. It's annoying, they told us asks questions. I think a lot of people don't ask enough questions. I know when I was working in with pathologies like that, I had a lot of patient asking me what they have been diagnosed for. I said I'm not a person to be asking this. You've got to talk to your doctor. They said, "They're not telling me anything." I said, "You've got to just keep asking questions. Don't leave until you feel satisfied." If you're not- I think my answer would be telling people ask, just keep asking. Definitely it would help. Participant 1

General advice, take your time and it's okay, and it sucks. I think other advice that I would give is like be your own advocate. Don't let the medical professional just because they've got lots of degrees and experience doesn't mean you still can't advocate for yourself and ask lots of questions and take a proactive approach. Participant 5

Go and get your information, go and see a psychologist who is probably very familiar with family therapy and with illness and disease. Participant 7

Participant's advice is to talk to AMDF for information and support and to be part of the community

There are services out there like the AMDF. You don't have to suffer in silence, you can ring them. There's some really great people that work there, they would have a chat to you on the phone if you're stressing out about stuff. Participant 10

Link into organisations like the AMDF. Participant 30

I would highly recommend they join, register with The Mitochondrial Disease Foundation. That's probably the best source of information. They have support groups and information days, and conference phone calls. If I met someone who had just been diagnosed, that's what I would suggest they do. Participant 43

Participant's advice is to seek help (General)

Unfortunately, all I can describe is my condition. It has developed into a...Get as much potential help. That will be to accepting help. Participant 17

Just let them know that they're not alone and there are people out there that are suffering the same as them, and that, if they need guidance or help, that we're always here for them. Participant 25

I could remember ringing up NAME, somebody or another, NAME I think it was. I rang up just because I don't know where to turn, I don't know what to do, I don't know who to see. Someone tried suggesting ultraviolet light. Somebody else is suggesting this at me. I said, "Things, they cost the earth, I can't afford that." There needs to be someone that you can actually talk to who understands what you're saying. Participant 38

Participant's advice is to seek help - find the right specialist as it is a rare disease and be comfortable with your healthcare team

Information is powerful and to learn everything that you can and if you're not happy with the medical care getting or the doctor that you're seeing, if you don't have a relationship, find someone else. You don't have to say, "Oh, we didn't like him, or he is useless. We just didn't get on, could I have a referral to someone else?" I think sometimes people persist with relationships that are not working. If it's not working and they're not on the same page or they're not seeing the person or yourself how that you think they should be. Just get a referral to someone else. Participant 4

If they're not getting anywhere in finding someone who's listening to what's going on with their body and the tests they've had done, persisting to find someone. Whether that's by asking other people who have got it. Participant 27

Find the best medical team for you they may not be Mito specialists, but people willing to work with you. Participant 30

Participant's advice is to seek help (Psychological support)

Go and get your information, go and see a psychologist who is probably very familiar with family therapy and with illness and disease. Participant 6

I think also considering the support of...from a psychological perspective, not just the physical

symptoms and how that affects people and being able to access supports for that too. Participant 26

I feel younger people would need...I know my daughter had a lot of trouble coming to terms with it. I think having me to bounce things off helped with her. I do feel that especially people who are from the country like we're, they would need some health-someone to talk to, someone to unload to mainly and I know I don't know whether that's what it is. This is, of course, by the mitochondrial whatever they've got. Apart from social workers, really...on that at all. For their mental health, I know, it hit my daughter very hard when she had to give up work because she's just so unpredictable. She'll have two or three days where she feels quite good and then she'll spend the next few days on the bed on and off and she says no employer would put up with her. Participant 31

Table 10.1: Advice from patients

Advice to patients in the future	All participants		Metropolitan		Rural		SEIFA (High)		SEIFA (Low)	
	n=50	%	n=30	%	n=20	%	n=27	%	n=23	%
Participant's advice is to ask questions and learn as much as you can	14	28.00	9	30.00	6	30.00	7	25.93	8	34.78
Participant's advice is to talk to AMDF for information and support and to be part of the community	8	16.00	6	20.00	3	15.00	3	11.11	6	26.09
Participant's advice is to seek help (General)	8	16.00	6	20.00	2	10.00	4	14.81	4	17.39
Participant's advice is to seek help - find the right specialist as it is a rare disease and be comfortable with your healthcare team	8	16.00	7	23.33	1	5.00	4	14.81	4	17.39
Participant's advice is to seek help (Psychological support)	7	14.00	4	13.33	3	15.00	3	11.11	4	17.39
Participant's advice is to share your story to help others and help you find your path	6	12.00	4	13.33	3	15.00	2	7.41	5	21.74
Participant's advice is to be hopeful	6	12.00	5	16.67	2	10.00	5	18.52	2	8.70
Participant's advice is to take one day at a time and appreciate each day	5	10.00	3	10.00	2	10.00	4	14.81	1	4.35
Participant's advice is to be a strong advocate for your or your child's health and wellbeing	5	10.00	3	10.00	2	10.00	1	3.70	4	17.39

Advice to patients in the future	All participants		High school or trade		University		Hearing impairment		Eye or visual impairment	
	n=50	%	n=26	%	n=24	%	n=24	%	n=34	%
Participant's advice is to ask questions and learn as much as you can	14	28.00	9	34.62	6	25.00	6	25.00	12	35.29
Participant's advice is to talk to AMDF for information and support and to be part of the community	8	16.00	6	23.08	3	12.50	3	12.50	7	20.59
Participant's advice is to seek help (General)	8	16.00	4	15.38	4	16.67	6	25.00	6	17.65
Participant's advice is to seek help - find the right specialist as it is a rare disease and be comfortable with your healthcare team	8	16.00	4	15.38	4	16.67	3	12.50	7	20.59
Participant's advice is to seek help (Psychological support)	7	14.00	2	7.69	5	20.83	3	12.50	3	8.82
Participant's advice is to share your story to help others and help you find your path	6	12.00	6	23.08	1	4.17	3	12.50	4	11.76
Participant's advice is to be hopeful	6	12.00	2	7.69	5	20.83	5	20.83	3	8.82
Participant's advice is to take one day at a time and appreciate each day	5	10.00	2	7.69	3	12.50	3	12.50	3	8.82
Participant's advice is to be a strong advocate for your or your child's health and wellbeing	5	10.00	0	0.00	5	20.83	4	16.67	4	11.76

Advice to patients in the future	All participants		Physical function (High)		Physical function (Low)		Emotional well-being (High)		Emotional well-being (Low)	
	n=50	%	n=22	%	n=28	%	n=26	%	n=24	%
Participant's advice is to ask questions and learn as much as you can	14	28.00	8	36.36	7	25.00	6	23.08	9	37.50
Participant's advice is to talk to AMDF for information and support and to be part of the community	8	16.00	4	18.18	5	17.86	5	19.23	4	16.67
Participant's advice is to seek help (General)	8	16.00	4	18.18	4	14.29	4	15.38	4	16.67
Participant's advice is to seek help - find the right specialist as it is a rare disease and be comfortable with your healthcare team	8	16.00	5	22.73	3	10.71	3	11.54	5	20.83
Participant's advice is to seek help (Psychological support)	7	14.00	1	4.55	6	21.43	5	19.23	2	8.33
Participant's advice is to share your story to help others and help you find your path	6	12.00	3	13.64	4	14.29	2	7.69	5	20.83
Participant's advice is to be hopeful	6	12.00	2	9.09	5	17.86	4	15.38	3	12.50
Participant's advice is to take one day at a time and appreciate each day	5	10.00	0	0.00	5	17.86	4	15.38	1	4.17
Participant's advice is to be a strong advocate for your or your child's health and wellbeing	5	10.00	4	18.18	1	3.57	3	11.54	2	8.33

Advice to patients in the future	All participants		Social functioning (High)		Social functioning (Low)		General health (High)		General health (Low)	
	n=50	%	n=20	%	n=30	%	n=22	%	n=28	%
Participant's advice is to ask questions and learn as much as you can	14	28.00	7	35.00	8	26.67	6	27.27	9	32.14
Participant's advice is to talk to AMDF for information and support and to be part of the community	8	16.00	6	30.00	3	10.00	5	22.73	4	14.29
Participant's advice is to seek help (General)	8	16.00	5	25.00	3	10.00	2	9.09	6	21.43
Participant's advice is to seek help - find the right specialist as it is a rare disease and be comfortable with your healthcare team	8	16.00	4	20.00	4	13.33	2	9.09	6	21.43
Participant's advice is to seek help (Psychological support)	7	14.00	5	25.00	2	6.67	2	9.09	5	17.86
Participant's advice is to share your story to help others and help you find your path	6	12.00	2	10.00	5	16.67	2	9.09	5	17.86
Participant's advice is to be hopeful	6	12.00	3	15.00	4	13.33	2	9.09	5	17.86
Participant's advice is to take one day at a time and appreciate each day	5	10.00	0	0.00	5	16.67	1	4.55	4	14.29
Participant's advice is to be a strong advocate for your or your child's health and wellbeing	5	10.00	2	10.00	3	10.00	3	13.64	2	7.14

Advice to patients in the future	All participants		Under 18		24-44		45-54		55-64		65-74+	
	n=50	%	n=6	%	n=14	%	n=9	%	n=11	%	n=10	%
Participant's advice is to ask questions and learn as much as you can	14	28.00	2	33.33	6	42.86	2	22.22	3	27.27	2	20.00
Participant's advice is to talk to AMDF for information and support and to be part of the community	8	16.00	1	16.67	3	21.43	3	33.33	2	18.18	0	0.00
Participant's advice is to seek help (General)	8	16.00	0	0.00	4	28.57	2	22.22	1	9.09	1	10.00
Participant's advice is to seek help - find the right specialist as it is a rare disease and be comfortable with your healthcare team	8	16.00	0	0.00	4	28.57	3	33.33	1	9.09	0	0.00
Participant's advice is to seek help (Psychological support)	7	14.00	1	16.67	4	28.57	0	0.00	1	9.09	1	10.00
Participant's advice is to share your story to help others and help you find your path	6	12.00	1	16.67	3	21.43	1	11.11	1	9.09	1	10.00
Participant's advice is to be hopeful	6	12.00	2	33.33	1	7.14	3	33.33	1	9.09	0	0.00
Participant's advice is to take one day at a time and appreciate each day	5	10.00	1	16.67	1	7.14	1	11.11	1	9.09	1	10.00
Participant's advice is to be a strong advocate for your or your child's health and wellbeing	5	10.00	0	0.00	3	21.43	0	0.00	2	18.18	0	0.00

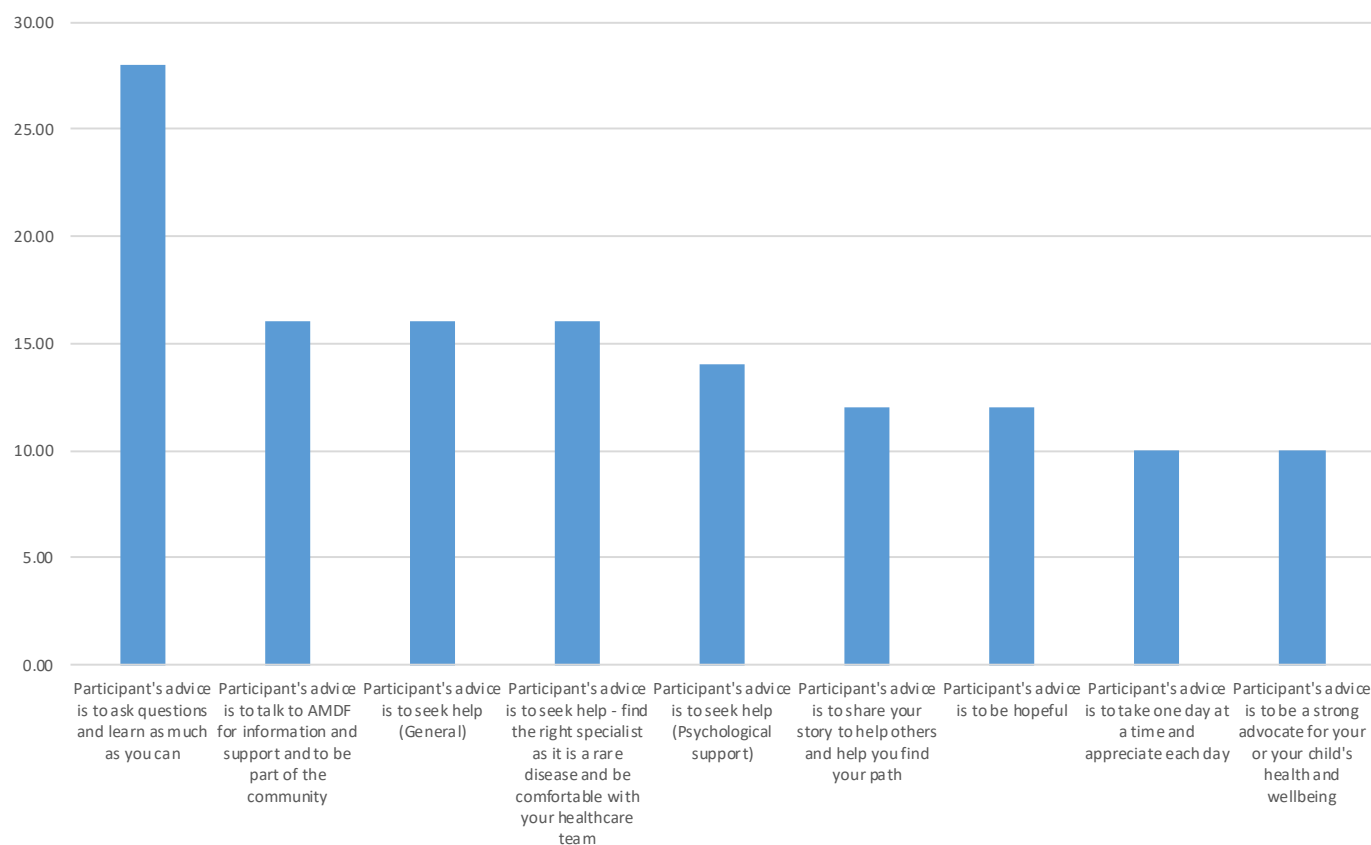


Figure 10.1: Advice from patients (% of all participants)