

Section 10 Advice to other patients and families

Section 10: Advice to other patients and families**Summary**

- Participants were asked what advice they would give to other people who are newly diagnosed with AD and their families. There were two key themes including to find what works best for you and this was noted by 26 participants (26.00%). The next most common theme was in a similar vein where participants spoke about various individual products that had worked for them, demonstrating the individual nature of the condition (n=24, 24.00%). Other themes included to pay attention to your diet, as many people found this to be helpful (n=18, 18.00%), do as much of your own research as possible (n=11, 11.00%) and to use gentle body washes and moisturizers - be diligent with moisturizing (n=11, 11.00%).

Advice to others diagnosed with AD

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Participant's advice is to find what works for you

*Never stop looking for the right treatment for you, because treatments work for some people and don't work for other people. I've been recommended things that-- a miracle cure for some people, but have no effect on me. I feel the best thing somebody could do is just to continue looking for an answer. **Participant 38***

*Just see a doctor and get on to it if things are getting bad. And keep trying moisturisers and those kinds of things and find out what works for you, but what works for someone is not going to work for someone else. You kind of ... It's a bit of a trial and error sometimes. But yeah just kind of make sure you get on to it before it gets too bad. **Participant 56***

My general advice would be do what works for you. Sometimes they're going to tell you not to have a hot shower, but sometimes that's what you want. Your skin's a mess, you just want to dry it out. You want a hot shower that's steaming hot. I know it's the worst thing you can do for it, and you regret it the next day probably, when you have a scratch, but in the moment, the temporary relief is everything. I don't know, it's just, I think, do what works for you as well. Some things, it's generalized to do this, and sometimes that just doesn't work for someone. There's no point doing a general plan for someone that's not going to work for. I think, as well, talk about it. Actually, say how much it's having a problem, an impact on you, because I've gotten very complacent with it, and have just been-- I've gotten very complacent with it and been like, "It's fine, it's all right." When actually, it's quite bad. I think the more people that let people know how horrible it is, the

*more people are going to be able to understand. **Participant 83***

Participant's advice is to concentrate on their diet

*The other thing I would tell them, too, would be to sort their diet out. Yeah. I would say to them to minimise your sugar ... I'm not saying avoid it, I'm just saying minimise it, and eat well. Yes, just get good nutrition. But if you actually minimise your flour and sugar intake, you actually minimise a lot of rubbishy foods, processed foods. And then that all gets worked out. But yes, if you eat rubbish, your skin will be a lot worse. **Participant 32***

*I would definitely say, just that three-pronged approach, almost like a stool. Like stool legs. I'd say, good quality, nourishing, simple whole foods. Eating less from packets, and more just preparing food from scratch. Then, I would say, gut health, gut support, and then, stress levels and sleep. I think those three things are really imperative to just good health, and good, happy skin, and happy energy levels. Then, if possible, and if someone's in a position to afford it, like, just seeking help of a professional, like a naturopath or a herbalist. Just to help them make those lifestyle tweaks, because I think it can be quite overwhelming. You look at our general lifestyle, and our general diet, which is from packets. To make that change over to cooking your own food, I think, can be a bit of a jump for a lot of people, but I think just simplifying diet and lifestyle, that's the main thing. **Participant 46***

*Number one, I would say look internally. Look for good, healthy fruits and vegetables. Find any food allergies that may trigger the eczema and yeah, just look internally. I think that's the best advice I can suggest. **Participant 67***

Participant's advice is to do your research and find as much information as possible - ask for help

*Well, seek out as much information as you can about it. Talk about it to your GP and just take the advice that you're given. **Participant 7***

For an eczema sufferer I'd tell them what I wish I could tell them, that it's okay, it's all good and that what you're going through is actually going to make you a better person, but from a family perspective I suppose I would tell them to really try connect with the right sources to ensure they were up to date with everything that was happening within any eczema discussions etc, etc. I try to think if it, if I had a kid

right now I would be actively searching for a reputable source that could give me advice on what I could do to ensure the quality of life that my kid or whatever. Definitely, as I said there needs to be a forum for that, and I'm not sure if there is one, or if I have missed that. **Participant 54**

Do your research. Especially if you feel like you're not getting anywhere with the medical system, definitely. Do a lot of reading. Educate yourself, rather than finding out knowledge, things from other people. But also, taking things from other people on board, but definitely do your own research. **Participant 58**

Participant's advice is to use gentle body washes and moisturizers - be diligent with moisturizing.

Look, I have to say, that I think for me, probably, making sure that I'm moisturise regularly. I tend to have dry skin at the best of times and I think that weighs as a precursor to eczema, sort of, increasing or becoming more of a problem. So, I do think keeping moisturising up all over probably has actually helped with some of the outbreaks. For me, anyway. And I think that's probably why my back is the worst because that's probably the area that is the hardest to put moisturiser and stuff on. Because it's the area you

often forget. The area you often, probably you don't attend to as much and then you get a little flare up and you go, "Oh, bugger." And then you start paying attention to it for a while, it settles down, and it goes away and then you sort of get back into that habit and forget about it again, and then, bang. It comes up again. **Participant 8**

I think the thing that has really helped me was committing to regular moisturising, and that's something that the dermatologist really drummed into me. And I probably was a bit slack on that for quite a while, it doesn't necessary help but it does help a bit. **Participant 44**

Okay, I think the advice that I would give them, is keep tabs on how long you've used the steroid cream for, if the doctor gives you steroid cream. And if you've used it for more than two weeks and it's not working or each time you try and get off it, the eczema comes back even worse than it's time to go to the GP and actually tell them that and say and actually ask where to from here because this is actually not working. Don't give me more of this because it's not working. **Participant 65**

Table 10.1: Advice from patients

Advice from patients	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant's advice is to find what works for you	26	26.00	0	0.00	6	23.08	16	39.02	4	18.18
Participant's advice is varied/Things that have worked for others....use oatmeal baths, cool and hydrated, coconut oil, ointments, bleach baths, don't scratch, go in the sun/don't go in the sun, get lots of sleep, be aware of triggers, wear certain fabrics.	24	24.00	1	9.09	8	30.77	3	7.32	12	54.55
Participant's advice is to concentrate on their diet	18	18.00	3	27.27	3	11.54	9	21.95	3	13.64
Participant's advice is to do your research and find as much information as possible - ask for help	11	11.00	1	9.09	2	7.69	5	12.20	3	13.64
Participant's advice is to use gentle body washes and moisturizers - be diligent with moisturising and careful with steroid cream	11	11.00	3	27.27	4	15.38	4	9.76	0	0.00
Participant's advice is 'don't give up, it will be ok'	8	8.00	1	9.09	2	7.69	2	4.88	3	13.64
Participant's advice is to be aware of stress as a trigger and the importance of mental health	7	7.00	0	0.00	2	7.69	3	7.32	2	9.09
Participant's advice is to seek medical advice and find a GP or dermatologist that you can have a good relationship with	6	6.00	2	18.18	1	3.85	2	4.88	1	4.55

Advice from patients	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/ Trade educated (n=42)	
Participant's advice is to find what works for you	12	30.77	11	26.83	15	25.42	17	29.31	9	21.43
Participant's advice is varied/Things that have worked for others....use oatmeal baths, cool and hydrated, coconut oil, ointments, bleach baths, don't scratch, go in the sun/don't go in the sun, get lots of sleep, be aware of triggers, wear certain fabrics.	11	28.21	12	29.27	12	20.34	12	20.69	12	28.57
Participant's advice is to concentrate on their diet	5	12.82	8	19.51	10	16.95	13	22.41	5	11.90
Participant's advice is to do your research and find as much information as possible - ask for help	5	12.82	4	9.76	7	11.86	2	3.45	9	21.43
Participant's advice is to use gentle body washes and moisturizers - be diligent with moisturising and careful with steroid cream	2	5.13	5	12.20	6	10.17	10	17.24	1	2.38
Participant's advice is 'don't give up, it will be ok'	2	5.13	2	4.88	6	10.17	2	3.45	6	14.29
Participant's advice is to be aware of stress as a trigger and the importance of mental health	2	5.13	3	7.32	4	6.78	5	8.62	2	4.76
Participant's advice is to seek medical advice and find a GP or dermatologist that you can have a good relationship with	3	7.69	3	7.32	3	5.08	5	8.62	1	2.38

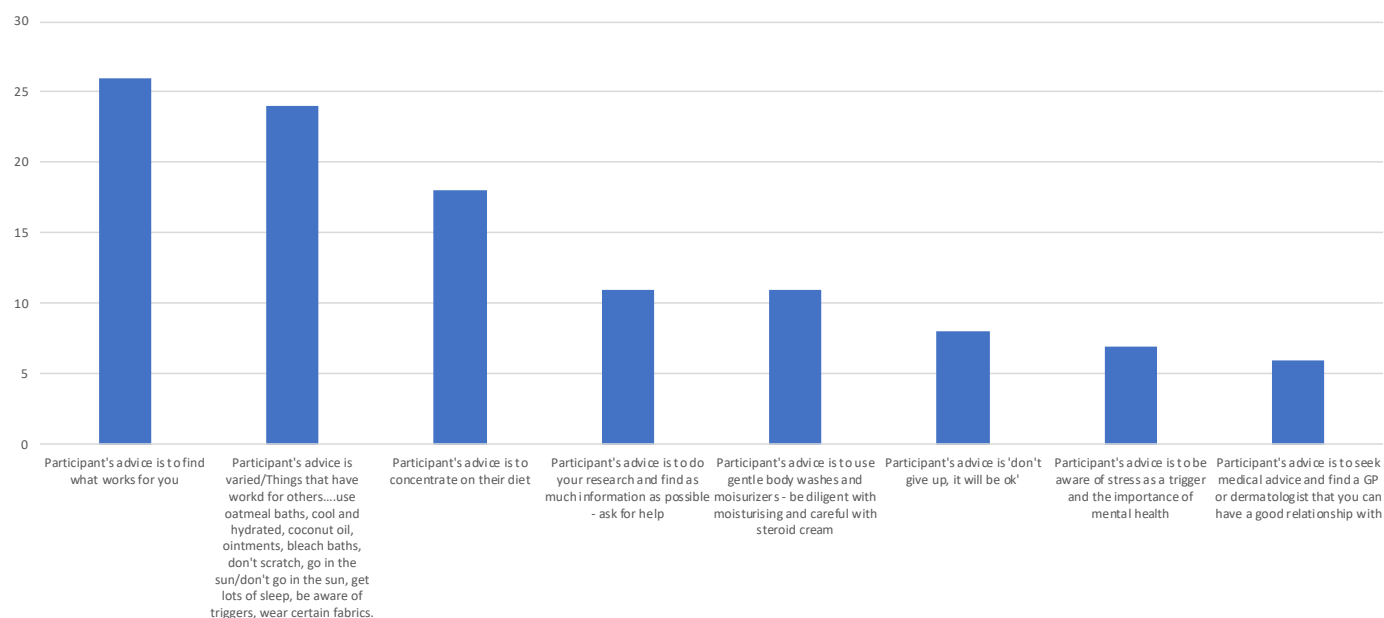


Figure 10.1: Advice from patients (% of all participants)

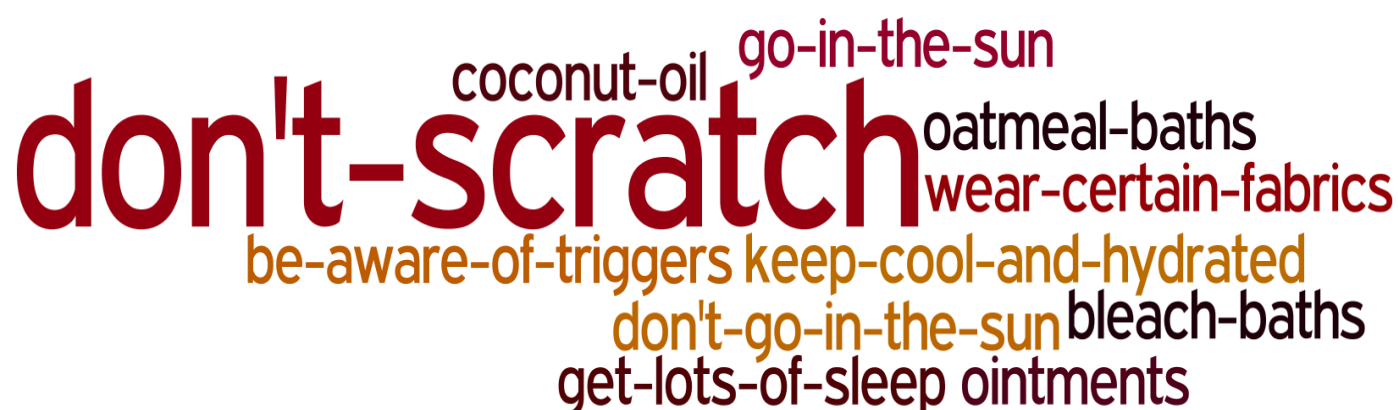


Figure 10.2: Various things that participants have found helpful in relation to their AD. Some participants mentioned 'don't scratch' however this was done with humour.