Helping your teen take charge of eczema care

Lynita: Hello and welcome to the podcast. Today we are revisiting a podcast recorded in 2021 about the difficult process of handing over skincare to your child. As a parent of a teen myself now this interview speaks to my current experience in a way I couldn't understand four years ago.

The topic is still so relevant and I'll interject where there have been any updates since it's been recorded. Enjoy.

Korey Capozza: Hello and welcome everybody. I'm Korey with Global Parents for Eczema Research and I'm glad you could join us today. We have a really great topic, which is the transition from child from adolescence to the teen years and that transition in helping parents let go and our adolescents and teens take over their own eczema care, which can be a rocky period but our guests today hopefully will help us learn how to make it as smooth as possible.

I wanna introduce my co-host, who is Freya Moxam. She's a student of medical genetics in the United Kingdom, and she also has personal experience living with eczema. So welcome, Freya.

Freya Moxham: Thank you. Hi.

Korey Capozza: And our guest is Dr. Miriam Santer. She's Professor of Primary Care Research at the University of Southampton and a general practitioner at Denmark Road Medical Center in Bournemouth. A little bit more I'll say about you, Dr. Santer, is that you lead research that focuses on developing evidence to inform management of conditions like eczema, especially around support for self-management. So we really appreciate the practical nature of your research, which is so needed for this condition.

Dr. Santer is a principal investigator for the ECO Eczema Study, which is a research project that will test online resources to address the needs of teenagers and young adults with eczema in managing their own condition.

Dr. Santer, welcome to the podcast.

Dr. Miriam Santer: You so much for inviting me. It's great to be here. I really like your podcast.

Korey Capozza: Well, thank you so much. So I'm gonna ask the first question from the parent perspective and then pass it to Freya to talk a little bit more about her perspective on the young adult teen side of things.

So, you know, I have an adolescent with moderate to severe eczema and just speaking from experience, this transition can be really challenging. Some of it is on the parent side, on my side, I'm so used to being hypervigilant about his eczema and so involved in his skincare as I was, especially during the baby and the infant years and I, I feel like I'm always still on high alert because I'm worried about going into a period of terrible flare where we can't get it under control because we've been there. And I think back to that pit of despair, for lack of a better term. And so it's hard for me to let go because I'm still on that high alert state. And worrying about going back to having a child suffering with itch and pain and loss of sleep, and just having so few ways to help. So I'm kind of always still, even now, 10 years later, in this slight fear state around it, which makes me hyperfocused on his skin and unable to let go personally. And I know other parents feel that way too.

You feel like you have to do everything you can at all times to be on top of it. But in come the adolescent years and your child is too old to be managed in that way. They don't want to be managed in that way. And you have to step back and you have to let go. And it's really hard, I think, as a parent to do that because they're not gonna manage their skin the way maybe you would. Or at the level that you would, especially with the complicated skincare routines that we have for eczema.

I'll just share one thing I sometimes find myself doing and I catch myself because, I think to myself, if I was an adolescent or teen and my mother did this to me, it would drive me nuts. It's like my son is talking or doing something and the whole time I'm thinking about his skin as he's talking.

It's like I can't help it. I've just been in this like, I think hyper vigilance is the right word, state around his skin. It's hard to back that off. So with that, I wondered if you could talk about what you know about this period of transition and how we can help parents adjust to it and work through their own challenges with letting go and letting their child take over.

Dr. Miriam Santer: Yeah, it's a massive question and like with a lot of things with eczema, there are no easy answers. Really. I can tell you what we've

learned from, we've done lots of qualitative interviews with children and young people and parents of children, young people with eczema, and I think we've come more and more to seeing is that it's a process like a lot of things around growing up.

It takes years and you work together at it. And I think it's partly constantly assessing what the young person is ready for. 'cause you know, eczema care is burdensome. There's a lot of different aspects to it. And so some things they'll learn pretty young, like avoiding triggers. They have to learn to avoid soap and stuff at school.

They may learn to apply emollient moisturizers at school. They may gradually do that at home. There's some things like applying topical steroids, or systemic treatments where parents are understandably gonna want to leave that a bit later before handing it over to young people.

And really interestingly, when we spoke to parents and children together, the child would say, I really like it when my mom reminds me and the mom would be really surprised and say, well, no you don't. So sometimes they may react a certain way. And yet being reminded to use the treatments and having their parents or carers step in at times when it's flaring up, when they talk to a third person, they acknowledge that that's helpful, which is really interesting for me to hear, I guess as a parent myself, because I was sometimes surprised by that too.

But I think we looked at other conditions where people learned to self-manage. For instance, in diabetes, there's this concept of emerging adulthood where people, some aspects of their treatment, they're very happy to take on at a young age. Other things like managing healthcare consultations, getting all their repeat prescriptions or refills they really want their parents help with, or carers help with for quite a long time, sometimes even into their twenties because all the different tasks involved are quite different and when they're happy to, hand it over when they're confident to hand it over.

So that's what our research has shown us. There's just nothing easy about it.

Korey Capozza: Is there anything for parents? It's almost like a therapeutic approach, for parents to let go of that fear a little bit if they can. if their child is in a position where it's not quite so dire with their eczema and they can take on some of the control. Any thoughts on that, Dr. Sander or others on the line?

Christine Cutaran: I used to say that I suffered from PTSD and I almost questioned whether or not I was worthy of using that phrase, just because of the trauma that I endured with my first. I totally agree with what you were saying, Korey. I still have those moments where I'm like on hyper alert. I feel like over time having shared our story so much and I just, it's kind of become the norm, if you will. That's kind of the only way I've been able to cope with it. I don't know if that makes any sense, but you just learn to live with it.

Korey Capozza: Yeah, and I should preface it, I'm really talking about the moderate to severe kids here. Which I think is quite different than a child with mild eczema where parents are probably less traumatized by the experience of it all, hopefully. But those of us who have had moderate to severe kids, a lot of us have had our kids in the hospital. It's a tough thing to make that transition of backing off because you are still so worried about it.

Lynelle, did you wanna comment?

Lynelle: Yeah, I was just gonna say, you know, pretty much everything you said, when you were saying it, it was kind of like I had told you the issues I was having before you were like, okay, I'll repeat them all. I think the thing is, like my severe kid, he just turned 15, so he's a 10th grader, but because of the pandemic, this is his first time going to high school. So there's a whole lot of changing of the guard here. You know, this is his first time self caring for EpiPens. This is his first time with a lot. So handing over the reins to a teenager are difficult anyway. you know, me expecting him to treat his skin the way that I did. I'm looking at him, when he hops in the car, I can do a physical, like a body scan in like two or three seconds and I'm like, patch there, patch there, patch there. And so I'm trying not to look and I'm trying not to say anything and I'm like, I'm gonna try different approaches of handling this.

And I'm like, you know, I think you need to put on some moisturizer. And he is like, no, I don't. And I'm like, oh, and I'm gritting my teeth. And I'm like, okay, we're gonna try this again. And then finally yesterday, I'm like, you know what? We're gonna do a wet wrap. This is going down, it's just happening.

'I don't need you to do it.' I said, you know what? I'm gonna have to do it for my sanity. We've been awake now for about 15 years and you know, we've come so far and you know that a small thing can turn into a big thing, so we're gonna do it. So he went ahead and he did part of it on his own. Is it the job that I would've done? No. But I also have to understand at some point. I have to let him go, you know? But have to be honest, I'm still gonna fill in the gaps. There's still gonna be those times when I'm gonna hug him and my hands are

gonna be full of moisturizer and I'm just gonna rub right down his arms, you know, and all of those things.

I still go in every night and I look at my kids at night, so there may be that night when he wakes up, his face is greasy. It's hard. It is challenging.

Korey Capozza: Yeah. Yeah. We're living the same life. Lynelle. I hear you. I'm biting my tongue all the time. And the other thing is, as a parent, especially with a teen or an adolescent, it's such a tender period where they're so aware of their appearance that you don't wanna be pointing out their appearance to them and making them more self-conscious. So it's a very fraught period for us parents. The transition to adolescence and teen hood is hard enough as it is. And then you layer this really complicated self-care equation on top of it where you really do have to let go and let them take the reins.

So appreciate that discussion. I'm gonna pass it to you, Freya,

Freya Moxham: Hi. Yes. I just wanted to talk about the adolescent teen side of things and in the simplest form is how we can empower teens and young people to take on self-care of their eczema. And I think it happens in lots of ways from taking up routine care in the home, but then obviously.

Also, like you said, going to appointments and talking to healthcare professionals and making treatment decisions and looking at different options. And so how can empower our teens and young people to start taking on that and start thinking about these things as they're growing up and as they're starting to take care of themselves a bit more?

Dr. Miriam Santer: That is such a great question, and. And again, no easy answers, but we spoke to young people about exactly that thing, and one thing they pointed out to us was that often they hadn't had much information about eczema themselves. When they were little, their parents were told all about it, and then their parents passed it on to them.

But they felt that they needed to be told the information as they learned how to manage their own eczema. And there's a role for healthcare providers there, but there is also a role for good information online or organizations like yourself. Providing stuff for young people so that they can learn it themselves and not necessarily learn it from their parents. 'cause there comes a certain time when you don't wanna learn anything / everything from the parents. There's of course psychological services that some clinics have and others don't. And then there's the other kind of feeling of just needing to be understood, especially people with

more moderate or severe eczema. They wanna hear from other people, not just basic information, but also shared experiences.

In our research, what we found was that this is often why people go online. They want to share experiences, read other people's blogs and so on, from people who they feel will really understand. It is such a minefield online because we found though that although some people will go to websites like we have the National Eczema Society in the UK and there's obviously organizations like your own elsewhere. Often people are just going on somewhere like Facebook. We both looked at the information people were sharing on Facebook, which is a very variable quality. Sometimes it's great advice, sometimes it's not great advice at all.

So I think understanding that young people are obviously gonna go and find information online, but maybe just trying to give them the tools to appraise that information and decide which sites to look at and who to listen to.

Information is really important, but also the emotional support that people need can sometimes be achieved from a healthcare provider or from people that they know that if they go online and hopefully the research that we are doing, which is developing information for young people with eczema, will mean that if they want to, they can go somewhere where they know their healthcare provider is happy with the information.

Korey Capozza: Yeah, it's a real balance. I appreciate that comment because we need to come up with information that is evidence-based and valuable. And communicate it in a way that resonates with that audience.

Freya Moxham: And I think it is so variable with teens and especially because the age you take on your own healthcare can be so variable for some people, like you said, with maybe more mild eczema, it might happen earlier or depending on sort of the relationship in the family. That could be of a much younger age or a much older age, and creating that information that's digestible, research like what you are doing is so important because we have to look at what content is appropriate for what age group and what's gonna be useful.

Because we don't want to be chucking things at teens that's just gonna overwhelm them and make them more despondent to what they're looking at.

Korey Capozza: Piggybacking on, Freya's point, kids are ready to do this at different ages. You know, one 10-year-old is gonna be different than another

10-year-old and, it's just the age that this is possible is gonna be really different, I think, from family to family.

That said, I think a lot of kids with eczema, they grow up quickly. They've had to deal with managing the sensation of itch while at school. You know, that's a self-regulation thing that's really difficult. They've had to figure out how to talk about this visible skin condition at an early age to people who don't understand.

They've had to figure out how to cope when they haven't slept. So I feel like in some ways these children are wise beyond their years and able to do more than others. At least that's my observation. So it's been very glaring to me to see how sometimes, at least with my son, he's treated still as a child when he is really beyond that.

Sometimes when we go to medical appointments, the healthcare provider is still having a conversation with me about him while he's in the room as if he's not there. And it's very disempowering to these kids when that happens. It's like they're not responsible for their own body and their own health, they're not asked about their own experience that they're having. And so I guess my question for you is how do we change that paradigm and start to bring in the perspectives of these adolescents and teens into the healthcare process, and really let them speak for themselves instead of treating 'em like an object.

I think that's a practice that really needs to change.

Dr. Miriam Santer: Yeah. So I work in a medical school and I, I, I feel kind of optimistic about this, because they do, medical students, now do get much more communication skills training than in the past. So I'm hoping this is something that will change.

But I was talking to my son about this recently. My oldest son is now a medical student himself, and so he sees it from a different side now and he had a number of health conditions when he was younger and he was reminding me how he'd seen it done really badly sometimes, and really well at other times of the doctor actually talking to him rather than talking to me.

And I was very aware of that at the time that some doctors did it way better than others. And so I did used to try, if someone did it badly, I would say, ‘Hey, Alex, what do you think?’ And even if the doctor's in a rush, I just think it's not asking too much to involve the child, even if it takes a tiny little bit longer.

And I would prepare him for that when we were on the way to appointments to say, if he asks you how you've been, what are you gonna say? And if he says this and that, what do you wanna say? And if you don't wanna answer and you want me to answer, what are you gonna say? I think in a way, waiting for the medical profession to change, hopefully it will happen sometime, but we do have some power as parents to direct the consultation and to involve the children and the young people in it.

Korey Capozza: I love that sort of preparing ahead of time for how you're gonna handle it as a parent child team and to be prepared to tag team in a way that's accurate.

But also sort of a partnership. I hadn't thought of that. That's a really good point. I've become aware as my son's able to articulate what's going on with him, how different his experience actually is from what I think it is. And so it's also about delivering quality care because if you just ask me, it's not actually true. It's what I observe, I'm not actually him. But when you ask him, it's a totally different story and he actually even has different priorities than I have. So we have to start to integrate that.

Freya Moxham: As a young person listening to that myself, I think it's so important, and I couldn't agree more because. It is a way of empowering our kids. When a doctor asks you a question, it can actually be quite intimidating, and as a younger person going to consultations and talking to doctors myself and going through that process of being completely ignored and wanting to say something myself and feeling like I never got the chance.

It sort of leads on from communicating, and talking about the role that schools play in the the period of transition and what are the tools and best practices that we can use to get schools involved and how they can take care of their skin and their eczema whilst in the school. Especially moving up to secondary school, high school, wherever you live, that definitely becomes more of your responsibility. As you're younger, the teachers are kind of semi responsible, but how can we equip our teens and young adults to do this themselves, and how can the school aid and help young adults in doing this?

Dr. Miriam Santer: Yeah, well I'd be interested to hear what you think as well, Freya, but from the research we've done so far, it's just quite variable how schools deal with it. And, we had horrible stories about people actually having to put their creams on in quite public places, and other people having a much better experience of being told that they could go to a special office and do it on their own or whatever.

So I think. communicating with the schools and just expecting schools to do slightly better. And sometimes there are useful resources that you can give to schools. National Eczema Society has a good information pack that you can share with schools. I think though again, you were talking about the shift to secondary school when the kids are a little bit older, I think, it's partly preparing them for that and saying, what will you do if someone says this to you, what will you do if people ask you about your eczema?

Something that people said was difficult for them was when they got unsolicited advice about their eczema. Or you should put moisturizer and you should use this, you should stop scratching. You know? What would they say to people in that situation? So I think talking to young people about it before it happens, communicating with the schools. And being aware of how variable knowledge is amongst teachers and other people in the school about eczema and providing the information for them about how it's managed, and what the young person can do. And I think it's true that primary schools tend to do that slightly better than secondary schools.

Korey Capozza: Kyle is joining us from Canada and is a recent high school graduate. Kyle, I wanted to ask you, thinking back to this period when you had to take over management of your own eczema, what were the challenges and what worked well for you when it, it was no longer about your parents helping you, but really you taking care of it yourself?

Kyle: When I first started taking over it, it was probably the consistency. Because my parents used to make me do it like certain times all the time. So it was managing that consistency of doing it all the time and keeping up the schedule with the 70,000 baths a day that we had to do and all the cream after that and managing it, it was definitely different.

I still don't want to do it, but, and we had a checklist, so it was just easier to like go look at and know what I have to do for this day. Managing everything. It just, it made it easier when I was eased into it so it, so I could get a firm grasp on it because I was so used to just my parents doing it.

Korey Capozza: I love the idea of a checklist that's so smart 'cause it gives you a plan for what you need to do without your parents having to nag or get involved.

Kyle: It was definitely tough managing it with school and everything. 'cause I was still going to school, but, I don't know. The checklist helped and just

knowing that if I missed that day, I just, I had to learn how to get in a rhythm of doing it.

So some days I'd miss a couple of times, but it's gonna happen. With school and everything, it's hard to manage it all at once. When you're a kid, you don't have as much going on. So it's easier for your parents to help, but when I did it, I was trying to, I always stayed busy 'cause I, it helped me not be itchy.

So to actually managing all of that, putting on my creams and everything, if, if I miss something, I was, it's gonna happen. You're not always gonna get everything in on that day, but just focus on managing it the best you can. If you miss a couple, don't be down on yourself,

Korey Capozza: you know? Ugh. It's such a simple thing, but it's such a relief to hear you say that in a way because I think that as parents and as teens too, like that needs to be part of how we think about it.

It's okay. I guess that, getting back to the first question around the parents and the hypervigilance, we need to come to terms with the fact that it's gonna be okay if the child misses a couple days, it's not gonna be perfect. So, thank you Kyle, for raising that point. It's an adjustment, I think, for both the parent and the teen to know that you're gonna do the best you can, but it's not gonna be perfect in this period. Probably.

Christine Cutaran: I wanted to ask Kyle, we touched base earlier about doctor's appointments. Kyle, I have to ask you, I know your mom's great at doctor's appointments, but she goes to every single one with you. At what point did you start advocating for yourself and are you intimidated to ask those questions? Because it can be very intimidating, as Freya mentioned earlier.

Kyle: I think I really got more comfortable and I turned 15. We went to just a family doctor and she tried giving me these little containers of betaderm and I was just like, where do you expect me to put that? Like she gave me that for a month and I was just like, that's not gonna work.

And she was like, well, that's the most I can give you. And my mom was just like, Kyle, relax. That's when I walked outta the doctor's appointment and at that point is when my doctor started to actually listen to me and I feel like I just, I built that relationship with my doctors. It made it easier.

Korey Capozza: So it's something that you put together over time. It really is about establishing that relationship and having somebody on your team for the

long haul through all the ups and downs and bumps and so on. Dr. Santer are there any resources from the ECO study now that are available from your online intervention piece that we can direct people to?

Dr. Miriam Santer: Not yet because we are still, we're still testing it and we're still adapting it and building it, but it will be available within the next year.

Lynita: You or your teen, can now find the wonderful resources from the ECO project that Dr. Santa and her team put together at eczemacareonline.org.uk. It's listed in the links with this podcast.

Korey Capozza: I wanna thank you, Dr. Santer for joining us as well as Freya for co-hosting and Kyle, for being part of the discussion as well as everyone else on the line. Really great topic and I personally have learned a lot, so please join me in, thanking our guest today, Dr. Santer.

Christine Cutaran: Thank you so much, Dr. Santer

Dr. Miriam Santer: Thank you so much. I really enjoyed it.