Parenting a child with alopecia: Supporting your child without transferring the weight

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LISA ANDERSON, PHD: (00:02)
Okay, let's get going. Welcome to the National Alopecia Areata Foundation's webinar, Parenting a Child with Alopecia, Supporting Your Child Without Transferring the Weight. Joining us today is licensed mental health therapist, Jonelle Massey, and I'm Lisa Anderson, Vice President of Research and Education for NAAF.

Before we start the webinar, I'd like to cover a few housekeeping details. We have disabled chat for this webinar session. Please post questions for Jonelle in the Q &A section. Please keep your questions general for the benefit of all audience members. This webinar is being recorded and all registrants will receive a link to the recording via email sometime tomorrow. And finally, please share your feedback with us. At the conclusion of the webinar, a link to a short survey will pop up in your browser window. Please complete the survey there.

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This webinar is part of NAAF's You're Not Alone education and empowerment webinar series. NAAF gratefully acknowledges the support provided for this webinar series by our partners, Lilly, Pfizer, and Sun Pharma.

Before we get started, I'd like to tell you a bit about NAAF and our mission. The National Alopecia Areata Foundation is the leading advocacy organization for alopecia areata. NAAF's mission is to drive research to find a cure and accessible treatments for alopecia areata, support those impacted, and educate the public about the disease. NAAF's vision is an empowered community with a choice to embrace or live free of alopecia areata.

To learn more about NAAF's support resources and research and advocacy activities, or to join us as an advocate or supporter, please visit our website at naf.org.

We know that it can be confusing to hear all the terms used to talk about alopecia areata, patchy, diffuse, ophiocis, totalis, universalis, mild, moderate, and severe. The NAAF team wants you to know that even though there are many words used, they all refer to one disease, the autoimmune disease, alopecia areata, and that's what we're here to talk about today.

And now on to today's webinar, parenting a child with alopecia, supporting your child without transferring the weight. We're very pleased to have Jonelle Massey presenting today's webinar. Jonelle is the parent of an alopecia princess and is a licensed mental health therapist and nationally certified school counselor with 25 plus years of leadership experience that come from playing basketball at the division one collegiate level. Jonelle is a leadership coach of school administrators, a national speaker and author.

In 2023, Jonelle opened up the Agility Counseling Group. Jonelle balances out her work with meaningful volunteer efforts, including her leadership as a board member for NAAF, for which we're very grateful. Jonelle, thank you so much for being here today. I'm going to stop sharing my screen, and I will turn it over to you.

JONELLE MASSEY, LPC: (03:16)
Thank you. And I am sharing my screen.

Welcome everyone. I am excited to do this webinar today. And this is my third one with NAAF. Like Lisa mentioned, I am on the board of NAAF and have been for going on six years. Again, I am a mental health therapist, a former school counselor.

and someone who has gone through the journey of parenting a child with alopecia. So I'm excited to empower some parents and give some strategies on how we can support our kiddos without giving them more weight to carry emotionally.

So the content for today, very simple. We're gonna go over the psychosocial impact of alopecia at the various stages of development with children all the way up to young adults. We're going to look at emotional weight that the parents carry. We're gonna define that and really dive into that. We're gonna talk about transparency and then also some healthy support strategies in order to prevent transference. So I do want to tell my story and I do this quite often at the National Alopecia Areata Foundation patient conference that we have yearly. I have the honor to be able to do several sessions and all of them are usually surrounded around parenting. So,

As you see these beautiful pictures before you, this is my story. At age 11, in that old school picture to the left with the Christmas vest, sweater on and turtleneck, is me at 11. I was recently at that time diagnosed with vitiligo. And I had a little brother, our chunky Kareem, at age 11. And so there was a lot of things going on.

And I remember my parents and how they parented through this change of my appearance and me inheriting a autoimmune disease within the skin family of vitiligo. And so my mother was a hot mess. She was taking me everywhere. We were trying all kinds of treatment. This might sound familiar to some of us here online and I was, didn't know who my parents were. It was almost like I lost my parents because of their ~ really survival and crisis, mold that they were in, in trying to fix the problem. And I just wanted to play soccer and not get burned. So I had to put on extra sunscreen on my face and on my arms and legs and I just wanted to play, but things changed a lot. And you would think as a parent who kind of experienced the same thing with my little Kayla that I would know better. So that's why having the left, should know better. And I know there are many parents on here that have used the word should. I should have done a different diet. should have parent, you know, my kid differently. I shouldn't have.

you know, cause the stress. mean, we go on and on and on. The second picture is, is Kayla at age two and a half, three, and you can see she had a head full of hair. And so that's where all the guilt came in because I used to complain about detangling that hair. It was a two to three hour process. She was a happy toddler and I was extremely sad as I started to see spots pop up and thought it was my ~ poor caring of her hair, not detangling it properly. It took us a while to get a correct diagnosis of alopecia areata. And about seven to eight months later, she was completely bald and she was diagnosed with universalis.

So no eyebrows and eyelashes and all the things. The next picture is very hard for me to look at because today we're talking about carrying the emotional weight. And when I look at this picture, we were doing a television interview for our first fundraiser in Toledo, Ohio. So my husband coaches college basketball. Lisa mentioned that I have a background in playing, both my husband and I played at the same college and we were doing a huge fundraiser for a night of the game and my daughter was excited. Both of the girls were very excited. I have an older child in the background and I cried most of the interview. I could barely get through it. And as I look at Kayla putting her arms around me and Jeff, my husband, it reminds me how she was - always comforting us and mostly me. The other thing about this picture that gets me a little choked up is my oldest in the background. ~ oftentimes parents of multiple children, we are so concentrating on our child with alopecia that we don't pay attention to what's going on with the other siblings. So we had to find out the hard way when Aubrey, my oldest, finally shared with me that she felt that she wasn't being parented. So with my vitiligo childhood story and being a trained psychotherapist, you would think that I would know better and I would be able to do better. But that just wasn't the reality of it all. Now, fast forward, you see the spicy little diva to the right who's 14 years old in eighth grade. We did our journey of trying treatments and failed quite a few of them. We followed her lead. She wanted to keep trying. I wanted to stop relapse after relapse. I couldn't take it, but we'll talk about following their lead. so sunglasses on.

covering up all the anxiety and worry that I still carry with me today on will I find another spot? And she is obviously living life. There is this old school psychologist, father of CBT, cognitive behavior therapy that says, he always said, don't shit on yourself. That's something that I remind myself. It helps subside the guilt.

and kind of gives myself permission, give me permission ~ to feel all the feelings and to move forward. That is my story, y'all, and I'm sticking to it. And it has caused me to be stronger in being a parent and also giving myself, again, permission to do all the things. So if you guys have notes and you were thinking, ~

This speaker looks like she knows what she's talking about. I'm gonna take notes. I want you to put to the side permission slip if you're taking notes because today I want you to write out your permission slip. And that is permission for you to feel all the things that you're supposed to feel as a loving parent who wants to protect their child from any kind of adversity.

And so you have probably felt some guilt, some sadness, even some vigilance in trying to fix the problem, even some numbness. And I have found talking with parents over the last seven years, it's quite a few folks feel a little relief that it wasn't something worse, that it wasn't anything that stopped their child from being able to participate in activities.

or be able to read. So when we think about a permission slip, one of the things that we do first is we acknowledge who we are. So if you're anything like me, a parent who has lost the original permission slip from the school, and you're just writing the note, and you say, hi, I am Jonelle, and I am the parent of an eighth grader at your school, this is her name. And I think that's where we need to begin.

with making sure that we don't transfer this emotional weight is to say, hey, I am a mother of a child who has alopecia areata, and this is what I'm feeling right now. This is who I am. And later on in the permission slip, you're gonna write what the expected outcome is. So if you think about those slips, and remember, I have a school counseling background here. So when we send out permission slips,

Well, typically we have to tell the parent while we're going, you know, we're going to the museum because these are the outcomes. You know, we want our kids to learn about the dinosaurs that we're studying in this chapter over this semester. So it's the same thing. It's like we have to get to the end of the permission slip where we are saying these are the outcomes that we want. And it might be that we are a little less sadder.

that we're finding a way to cope with the disbelief of it all. And we are reaching out for support more. So those are the outcomes of your permission slip. As far as the developmental stages and in the emotions that are happening, we hear over and over again that preschoolers seem to be unfazed.

by what's going on and everybody around them is going through lots of tearful moments, trying to fix things, worrying about our kid. I remember thinking, looking at a three-year-old, is she gonna have a prom date? That's wild, right? But that's kind of the thing that we do is we take worry to the next level while they just wanna play with dogs.

and do other things. So in the preschool ages, we know that they're more curious, but a little less distressing for them. And that goes the same for peers. I know I used to be worried about taking my child out in areas where there were other children, because I was wanting to protect her. I remember being at a playground and I waited until there wasn't very many children there. And here comes two little kids running her way.

And I started to stand up from the bench and think, okay, now mama bear's gotta kind of facilitate the conversation. And I heard every word of it. And ~ I didn't need to intervene. The kids asked, are you a boy or girl? And she said, I'm a girl. And they said, why don't you have any hair? And she said, I'm allergic to my hair. And one of the kids said, my sister's allergic to peanut butter, you wanna go play? And then I was like, ~ okay, I can breathe again. So it's, you know, we just, it's hard, but sometimes we have to know that it's gonna be okay, especially at that developmental stage. School age, things start to get a little tricky. Children are beginning to compare themselves to their peers.

We're starting to wondering, you know, do we email all the parents in the classroom? Do we email all the teachers? Do we also include the cafeteria staff? Do we go in and do we read books to the class about alopecia? And a lot of times we're thinking about these things and not consulting with the kid that it affects the most. And so here we go again with trying to follow their lead as much as those little ones can lead us and giving them options. Do you want me to do this, this or this or nothing at all? And I think that helps kind of shorten the conversation with our school age so that their whole identity is not about alopecia. And we're gonna talk about that in a minute. But as they get closer to middle school, they become more self-conscious.

Self-confidence might reduce, and then obviously increase vulnerability to teasing or bullying. As far as the adolescent, this is where we get really nervous and we understand that outside of alopecia, being a teenager in itself, in this day and age with social media and all the things that are going on is a difficult stage and a critical time for them forming their identity. They really reverence social belonging. I'm hearing a lot of chatter about, know, is that really important to them because they have social media? Listen, I'm here to tell you that even with social media, I think it's even more that they want to belong to a certain group. They want the likes, they want people to be a part of their friendship group and their Snapchat group or whatever that they have. And so hair loss can affect who they are, their self-worth, and how they interact and move with peers. We understand and we know that the feelings associated with hair loss often include embarrassment, fear, loneliness, anger.

~ I think the tendency is to be guarded and then socially withdrawn. With young adults, we don't talk a lot about young adults. So I'm here to tell you, we need to talk about young adults, because my parents of young adults and college-age students, they are going through it too. And it is a period when individuals are very intentional about who they are personally and professionally.

but also very seriously looking at romantic relationships. So at the conference, oftentimes we have a young adult panel. It is always full because us parents of younger folks want to be in the room to ask them a lot of questions. I think by far it's one of the best sessions. Yes, the research is important, but to hear the young adults talk about their struggles, talk about how they wanted to be parented as a child, what they want their parents to stop doing and to do more of is really valuable information. And I do wanna share that when I do my sessions at the conference with parents, I always start off with reading something from the younger kids. run down to the kids camp and I say, hey, does anybody want to tell their parents something anonymously about how they're doing? And I get about 15 or 20 kids that raise their hand and I have them writing down what they want to tell their parent. And it's very heartfelt. And I'm going to read one today because I keep them for me so that I can be reminded.

~ but one of them says it's a son, a 14 year old son to mom. He writes, I'm really okay. I want you to stop worrying and stop crying. You have been there with me through it all the tough times. And I know you will always be there when I need you. Love you. Why a, and then he states his name. And this is the sentiment that we get over and over.

from letter after letter from our young folks is that they're gonna be okay. And oftentimes it doesn't feel that way because when they're going through the trenches and maybe experiencing bullying or friends not wanting to all of a sudden not be their friend or they feel pity, those are rough times. But I think oftentimes they can see the bigger picture.

They hold on to the moments when they do have that friend, when they do make the basketball team, when they have people that are allies that stick up for them and tell the other kid off. So they're gonna make it. They're gonna make it with the right support.

So one of the things that I think we need to talk more about is the intensity of emotional responses based on when the hair was lost first. So I think one of the dangers to sharing kind of these developmental stages is that we don't point out when the child lost their hair. And I just wanna give

~ some value to that and some credit to that. That there's a lot of misconceptions that if a kid started out at age three or four with hair loss, that by the time they're 15 or 16, they have mastered navigating hair loss and they're gonna be fine. And that's not necessarily the case. There's a shift.

that usually happens with each developmental stage. And so just because they received the diagnosis and had hair loss ever since they were three doesn't negate the fact that it's just as intense as someone who lost their hair at 15 and 16 years of age or 18 or 19.

We don't want to minimize the fact that if somebody has had hair for 18 years and then they're transitioning into young adulthood, maybe going out of the home for schooling, that it's not devastating. And so we just wanna keep that in mind. The same for when a first relapse happens or takes place. We know that this is a very finicky disease, autoimmune disease, and have a college friend who lost all of her hair at 14, spontaneously grew all of her hair back at 15, and did not lose her hair again until her stylist found a spot on the day of her wedding doing her hair at age 30. And so now she's universalis So it's just, it can be traumatic.

No matter how you look at it. And we just want to be mindful of that. And as we're writing our permission slip as parents, we want to acknowledge the fact that we thought we were past it. We've prayed about it or whatever we've done. And now we're in complete disbelief and maybe going through some of the grief responses that we went through five years ago, four years ago, or two months ago.

So emotional weight that we carry parents, listen, I've been there, I understand. These are the things that I have said and that I've also heard. And I like to use this analogy. If any of us are trying to stay fit and been in the weight room, I think this is a great analogy. If you look down below, how many of us have said, this is not even what I ever expected for my child. I hadn't heard about it, never known anyone in my family to have it. This just comes as a complete surprise and you're likely experiencing all types of grief, but ambiguous grief as well. it's like losing something that you had imagined for your child, that you had envisioned for your child. And now that imagery and that dream and what you thought your child would be is now lost. And so that's kind of an example of ambiguous grief. Side note, my mom has Alzheimer's and so it's like she's here physically, but she's not here. That's another example of ambiguous grief. Another thing that we carry a lot is wishing it was me instead. I thought I was the only one that had said that before, but I hear it over and over again is like, we want to just take that experience and why couldn't it been me? And then there's a lot of guilt associated with that as well. I am responsible for this. That was my story. I knew I had an autoimmune disease in the skin family with vitiligo. Why did I risk it by having a second child? First child didn't have an autoimmune disease. Why would I double down and do have a second one?

As much as you can think of, you know, we've been there. We have claimed responsibility in so many ways to what we have fed our child, to the homes that we lived in, to the stress that we've caused the two year old. So that is very, very normal. I'm here to validate that for you. I can't stop crying. ~ You know, the heightened emotions that's something that we also carry.

So it's a lot of weight that we're carrying. And then you notice that person on the bench is not doing it himself. So spotting our children versus transference, that's what we're here today to talk about, is how do we spot our children? How do we stand there while they are carrying heavy weight and just lifting it and holding the weight if they need us to hold it?

Because it is building capacity. It's hard for us to watch, but they're going to be stronger for it. So what kind of support do our children want? We need to ask them, how do you want us to spot you? How do you want me to spot you? Do you want me to go into the classroom? Do you?

Do you want me to try and navigate your friendship circles and do play dates? What can I do to help you? So I think oftentimes we go into fix it mode without asking the child how they want us to support. Disagreeing with the type of support that they want, that's gonna happen a whole lot, a whole lot because we're thinking that this is gotta be the best way. Like we can foresee maybe a lot of adversity coming and we just disagree. And I'm telling you, that anger and you being upset, it weighs on them. It transfers to them. There's a story of a father who approached me after I spoke in DC a couple years ago. And he said, "My daughter is wearing a hat during a basketball game and the hats just drawing more attention to her. And I really think that if she didn't wear it, no one would notice how many spots she has. It just doesn't make any sense." And I looked at them and I said, she's still playing. She's still playing the sport. She's still involved in socialization. It's like, it's hard for us.

But we have to follow their lead and be excited about the fact that they are still trying to socialize. They're not withdrawing themselves and they're not isolating themselves. So following their lead as they build muscle. Here's the key parents is that we have to find a spotter of our own, whether that's a professional person to go and talk to.

Or its support from family and friends. I have found that the closer the family is, a lot of times they're not the greatest spotter because they have enmeshed feelings as well and they're not as strong as we think they are. And so here we are both trying to carry the weight in our weakest time. So we need strong spotters for ourselves. Your child should not be the spotter for you. so, spotting our partner and spouses, I find that hubbies tend to try to be the spotter, you know, but what's happening is a lot of suppression of feelings until they get to conference and then all the fathers cry. But oftentimes, they're suppressing a lot of what they're experiencing for the sake of the moms who are more expressive.

And they're trying to spot their loved one and suppressing more and more of their feelings. And then they themselves do not have anyone that they're talking to and supporting them. So it's important that we have appropriate support that's kind of a separate journey with our child.

So other spotting strategies, we have to understand grief in the sense that it's not linear. So oftentimes you hear people talk about stages of grief and trying to get to acceptance. And I'm here to tell you that you might feel like you're there until a relapse happens, or even if it never happens, something outside of alopecia could cause you to feel some way about

~ your, your daughter's or son's hair loss. So understanding that it's, it's not stages that it's, it's really a ball of chaos where you can experience the response of denial. You can experience the response of bargaining and it does not go in any particular order. That's kind of the old school mindset of grief. ~ Kubler Ross who developed the stages has gone on record to say, should have never done that. Grief is too complicated for that. Give yourself grace, be careful of minimization. I wrote a book about empathy. And one of my favorite lines is, minimization is the thief of validation. And so we have to be very, very mindful of minimizing just for the sake of feeling better about what's happening.

Reducing overprotection, there's lots of studies coming out because as you guys probably know, there's a lot of talk about this generation being the most anxious generation. There's a Netflix series, they're talking a lot about social media. What the research says is that one of the biggest indicators or influencers of childhood anxiety is parent overprotection. Now how overprotective are parents of children with alopecia? We are very overprotective. So we want to be very mindful of those things and over identifying our child with alopecia. Managing our desire to fix it, not being a fixer upper. And sometimes the kids just want us to listen. They don't want to talk about the diets, that's what the young adults talk about all the time, is not wanting to go on all of the diets. They don't want to talk necessarily about new treatments, things like that. You want to follow their lead. Be cautious of oversharing your emotional distress. I think when they're younger, especially because they're confused and often translate your heightened emotions to their them being the responsible party for that. So they think they're the reason why you're so upset. So being able to kind of downshift to neutral, turn the other way, go into another room sometimes is very advantageous when you have smaller kiddos. The older ones know what's going on. They know what's going on. And so being able to to work towards regulation and being able to process those feelings in a very healthy way is the goal with the older kiddos. Reducing excessive reassurance, being the cheerleader. We're reading a lot about toxic positivity. And so we wanna be very careful of the glass is half full kind of thing.

And getting to being a neutral party and being able to validate how they're feeling. Model emotional regulation, common confidence, and make sure that we're practicing in empathy and not sympathy or pity. Parents can act as the emotional barometers, especially for the school-age kiddos. Additional spotting strategies times when we talk about parenting, I think we're focused on what do we do with the child. So we encourage normal participation in activities. That's what we do with the child. Hello, parents. I need you to do the same thing for you. Encourage you to get out in normal activities, activities that you once did that kind of fell off. I appreciate the heart on that one because I had to remind myself of that. Build identity around strengths.

So also with, so we wanna talk about that with children, right? But also with yourself, your identity beyond being a parent. Prepare children for questions, curiosity, staring. Don't spend lots of time on this, but I think it's very, very important. They appreciate the preparation. From an empowering approach, not a fear-based approach. And parents, we do the same thing. We prepare ourselves for the dreaded advice giving. You know, like I am of a community of faith where people wanted to constantly pray for me. I had to prepare myself for how I'm going to respond to that and how I'm going to be able to navigate the questions that people have about my child. And sometimes it's your family.

It's not necessarily you preparing to respond to strangers. And I hear parents oftentimes get so upset about the folks who are closer to them and what they're saying and the questions that they're asking and the advice that they're giving. So we want to be prepared for that. Provide accurate information to dilute the mystery about the piece. don't know how many stories I've heard of kids saying, wasn't just, I wasn't sure what was going on. My parents just told me to put a hat on.

And that was that. They didn't know how sick they were. So we want to make sure that we're not being so mysterious that we're carrying that extra weight to the child of worry and not knowing what's going on with their body. Provide stability and presence. So don't isolate yourself. And then model regulation and rebounding.

So even if you have a very cheerful moment, I'm back. I got myself together and you're sharing that with them. So you're modeling them being able to do the same thing. So we wanna continue to help our children build muscle, right? Build capacity, be their spotter. We want to be able to acknowledge where we are.

Self-awareness is golden so that we know where we're going to go. What are the objectives? What do I want to get to a point where I can do X, Y, and Z with my child without worrying or crying about it? So we're finishing off that permission slip so that we can sign it, so that we can be the best support and spotters for our children.

So I'm excited about being able to share some little nuggets of building capacity with our kiddos and finding a spotter ourselves so that we can be a better support for our kid. Hoping to see you in Disney. We've been going to patient conference for seven years now, my family and they, all the family.

The oldest one too is pretty excited about being able to go to Disney. So that completes my presentation. If you want to get a hold of me, my information is there. I always respond to my parents because obviously we're in this together.

So thank you.

LISA ANDERSON, PHD: (37:11)
Thank you, Jonelle. We have plenty of time for questions. So to the audience, please put your questions for Jonelle in the Q &A section. I just wanted to say, listening to you personally, don't know that I've really heard you tell, I haven't heard your whole story before. haven't attended one of your talks at conference, but boy, it's just amazing to hear all of the experience that you bring to this as somebody who had an autoimmune disease as a child.

that impacted your parents and now to come full circle and have gone through it and then also be expert in how to think about it, think is really, it's so, you have so much insights into this. So ~ thanks for sharing. So we have a couple of questions here. I wanna read the first one, the person wrote, it's not a question, but it's a statement, but it's maybe something that you can comment on. It says my 13 year old,

JONELLE MASSEY, LPC: (37:54)
Thank you.

LISA ANDERSON, PHD: (38:07)
Within a two week span, lost all her hair and was diagnosed with alopecia universalis. I talked with her middle school teachers, principal, assistant principal. My daughter wanted to explain it to her closest friends. A few times my daughter's friends defended her in school and got in trouble. Please consider talking to the parents of your child's best friends so the parents can also help explain and talk with their children. So maybe can you comment on that? Like, you know, how far out of the circle do you take the support part?

JONELLE MASSEY, LPC: (38:36)
I put my school counselor hat on this one. So we do a lot of bullying prevention. I feel like that was all I did. And the research is clear on what is the most effective intervention in stopping bullying. And it's not adults, it's not principals, it is by far peers, allies. And so it does not surprise me

that her friend or your kiddos friend stepped in and was probably very passionate about defending their friend to where they possibly got in trouble. I think as parents, we make the assumption that kids talk to their parents. And our child, because of their vulnerable state, might talk to us more than usual. I have a lot of boy mom friends and

those who don't have alopecia and they're like, we never hear from ~ our kiddos. And then it's quite different when I talk to parents of boys with alopecia and they're much more talkative, but most kiddos do not talk to their parents. So I think that is very good advice. Often talking to your child first about what your intentions are.

~ so that again, we are following the lead of our child, especially, think Lisa, you said the child was 13, like teenage. Yeah. having them have a say in, Hey, I'm, I'm going to talk to, know, this parent, just so that they know.

LISA ANDERSON, PHD: (40:11)
Yeah, that sounds, that makes sense. Sort of related to that and following their lead, like at what age, is there an age at which you might say, well, they're too young to be able to provide that lead?

JONELLE MASSEY, LPC: (40:26)
Yeah, and I'm gonna take the individual card and pull it here. But you know, some kids are more assertive, more social, more mature, less guarded. So I think getting a pulse on your kid is important. And to know, know, this is what would happen with my daughter. I'd say, do you want me to do this or that?

and she would do the shrug. And I always took the shrug as a yes. I wasn't gonna get a full yes from her, but I didn't get a no. And so I didn't, I went forward. So it does depend on the child.

LISA ANDERSON, PHD: (41:09)
Okay, thank you. Okay, here's another one. I feel like I have to make excuses for my child with alopecia universalis and explain why she doesn't have hair loss upfront so people aren't surprised when meeting her. How would you handle that?

JONELLE MASSEY, LPC: (41:25)
make excuses rather than share her diagnosis? Do you think that's probably what it is, like in order to explain it?

LISA ANDERSON, PHD: (41:34)
You know, that's a good question. It's not quite clear. Maybe the person might also just mean explaining it.

JONELLE MASSEY, LPC: (41:43)
Yeah, and so first of all, there's whole webinars on that, on how to share the diagnosis with families and things like that. I will say,

It can be very, I don't use the word triggering a lot because I think it's overused nowadays, but I do think people asking what's going on and you having to explain triggers a lot of emotions. And so you might feel like you're at the stage where you're explaining a lot. And I think we have had statements for kids to share.

Like if they're really young, they say, I'm alerted to my hair. Like I think it's on the website somewhere, but I think parents ought to get together and come up with a list of things of what to say. You know, we're trying to figure it out. She's, she's had some hair loss and we're, taking good care of it and seeing some experts. I appreciate your concern. Thank you. So I think there's a way to address it without even entertaining an explanation.

LISA ANDERSON, PHD: (42:49)
A couple of questions here that maybe you mentioned that we have other webinars that maybe will address some of the topics that might come up in the questions. So there's a question here about when should you check with a doctor if you suspect your child has alopecia, like the ages, what if your child's not really concerned? I don't know if you would like to say something or else I can say what I

JONELLE MASSEY, LPC: (43:14)
Lisa

and I, neither one of us are dermatologists, but I tell you what, we've been around a lot of dermatologists and early diagnosis we know is a thing that is very important. So I, a parent, speaking from a parent perspective, I would seek a professional dermatologist to see if that's the case or not, because early detection is,

is really key.

LISA ANDERSON, PHD: (43:45)
I think that's 100 % correct. And we do have many webinars on the NAAF website. you can find them at naf.org backslash webinars that talk about ~ early detection and pediatric alopecia areata, alopecia areata in children in particular.

JONELLE MASSEY, LPC: (44:02)
Do not go to Facebook and ask them to diagnose.

LISA ANDERSON, PHD: (44:07)
Yes. just, sorry, I didn't say that. No, I think that's good advice. And someone said, thank you. This was so helpful. Where can we learn more about the conference? I will share a slide at the end after we finish our questions where you can scan a QR code to get more information. But again, this is on the NAAF website about our conference, which is taking place in June in Orlando, Florida. But we'll come back to that. OK, another question.

My daughter just turned five and for the first time is expressing her desire to have hair and it's apparent her visible differences are starting to impact her emotionally. We're pursuing a treatment plan but my fear is setting an expectation that whatever we try will fix this. How do you frame the treatment in a manner that keeps her engaged in her emotional growth process as a little girl with alopecia and the hope that she may one day again have hair?

JONELLE MASSEY, LPC: (44:59)
Yeah, that's a tough one. have seen parents. So Kayla said to us at age seven, I was rushing to get my oldest one ready for something. And I was pulling her hair and trying to get in a ponytail. And Kayla for the first time, I think she was six. I'm going to say six or seven for all those parents who have kids. Six or seven. think she ran to us and she said,

I want to have here too that was the first time and my husband and I did not know necessarily what to say we hug her. I think I probably cry and I said I know we are trying to read up and figure out you know how to have your hair grow and there's a lot of smart people out there.

that are really trying to figure it out. And we are in communication with them. We're reading about them and no one has found a cure to fix it totally. And then I would try to like correlate that with other things that are not fixable. So, you know, like someone wears eyeglasses. It's like,

They have to wear their eyeglasses in order to see. Johnny, he always sits in the front row and he always wears his eyeglasses. If he takes them off, he can't see. So you have to be creative. I don't think there's one solution, but you try to be as honest as possible and as age appropriate as possible that they understand.

But I think preparation is key to think about these questions as they come up and what you might say and how your child will respond to them. So like if they have an interest in one area, like how can you explain the answer in the thing that they're really, really interested in? My daughter's interested in dance. Is there a way that I can explain that to make it individualized?

LISA ANDERSON, PHD: (47:08)
That's interesting. Okay, here's another question. My daughter with alopecia universalis is four. I want to normalize options for her as she grows so she feels comfortable doing whatever she wants, whether she wants to go out bald, wear a wig, wear glitter on her head, switch it up every day, et cetera. At the same time, I don't want her to put too much thought into her physical appearance at this age. How do you introduce things like that to kids?

JONELLE MASSEY, LPC: (47:36)
Yeah, think a lot of, don't know that we really realized like how much attention, especially, well, I would say girls and boys pay attention to being a princess. Like unfortunately the world that we live in with the media, there's a lot of focus even in the cartoons and the movies that the little ones watch. So I understand not wanting them to be fixated on their looks.

but I say have fun with it. It sounds like you're doing already with a variety of things. I've seen kids wear colored wigs and all kinds of hats and all kinds of things. Representation matters, okay? So like when Kayla was six, we got a youth mentor through the NAAF website.

~ and we were lucky enough to find someone who was an hour and 15 minutes away. And we made that trip as much as we could. And so she saw herself and, and the youth mentor that we had wore her hair or wore her, wore bald. She didn't wear any wigs, often. And so to see them do makeup together and have these dates, and even during COVID they did.

make updates on zoom and so that might be also another avenue is getting representation. Of course on social media there's a lot of bald divas because my my kiddo knows them all.

LISA ANDERSON, PHD: (49:10)
Yeah, it's very interesting. ~ And then just sort of that connect making that connection with someone with alopecia areata as you said, the mentor program that we can share more about in our follow up email to this, but and then also the conference, not that we're just plugging the conference, but as another place where people come together and opportunity for kids to meet other kids and more and adults see adults. Yeah.

JONELLE MASSEY, LPC: (49:33)
And we've been talking a lot about girls, but also with the boys. I have a lot of friends with boys who have alopecia and they are fixated on all of the athletes who have alopecia. again, seeing themselves, seeing how cool they are, or they wear a headband or they don't, it's important.

LISA ANDERSON, PHD: (49:53)
Yeah. This question, it's maybe a little off topic, but it's someone who says that they are an adult with alopecia. How would I as an adult with alopecia relate to a child that I may encounter in public?

JONELLE MASSEY, LPC: (50:08)
I'm curious about are they trying to regulate heightened emotions when they see a child or are they trying to respond to a child's curiosity about them having alopecia? So very curious about both of those scenarios. But I will speak to the fact that like,

LISA ANDERSON, PHD: (50:27)
I don't know the answer.

JONELLE MASSEY, LPC: (50:33)
I know we have had parents who have alopecia that have children with alopecia and the guilt that they carry is very heavy. And the support that I have given them is that they need a spotter, you know, of their own. And so that that's one thing. I'm not sure that I'm answering the question, but I'm curious about

you know, how are they trying to explain, how do they explain their alopecia to a child?

LISA ANDERSON, PHD: (51:08)
Yeah, it's not clear. So perhaps they'll write something else. We're getting close to the top of the hour. There's another question I want to ask you. You, of course, mentioned, you you showed those beautiful pictures of your family and mentioned your older daughter. And the question is, what did you do to help balance supporting your daughter with alopecia while still giving your older daughter the attention she needed? She needs.

JONELLE MASSEY, LPC: (51:31)
So

this, listen, follow their lead because once she said what she had to say and voiced her opinion about, hey, I'm over here, I'm here too, then I went into full blown mode, right? I'm like, there's a sibling group for alopecia and we can go and take you to the conference and you can be with other siblings.

And she was like, pump the brakes, right? Like, all I really want from you is X, Y, and Z. And so being able to ask them what they need and how you can do a better job in seeing them and being a parent for them, I think is crucial. I hear the term shadow sibling a lot from young adults.

~ at the young adult panel, because that young adult panel oftentimes has siblings on the panel too, who do not have alopecia. so that's very valuable to hear their experience and what they, they specifically needed from their parent. It is an individual thing. but you know, it's like, I've made sure that we had our own thing and that we, that we had things in common and that,

you know, we did our own thing because we were doing these big things for alopecia with Kayla had to make sure that we balance it out with with some attention on that end. The other thing is that they kind of have similar emotional responses that parents do. Some of them feel guilty about not having alopecia themselves and having hair. They feel embarrassed for their kid and then they feel guilty about being embarrassed, excuse me, for their sibling.

LISA ANDERSON, PHD: (53:18)
complex. So I think just to wrap up the person who asked about an adult with alopecia approaching a child that has clarified and said, you know, they they wanted want to know how to encourage the child. So maybe encouragement or support from somebody else living with the disease to a child. you have any comments on that?

JONELLE MASSEY, LPC: (53:19)
It is. It is.

Yeah, I mean, it's very interesting. We have to make sure that the kid wants some advice. I think oftentimes they see adults with alopecia run towards kids who have alopecia and think that they want to talk about it, that they want you to acknowledge it, and they might not. So we have to be mindful of what they want. And then if they seem like they

They do want to hear your story. Honesty is important. I think a lot of times adults will shy away from maybe a hard time in school with bullying. And I think we set our kids up for failure if we're not honest about the possibility. Not that it will actually happen, but there is a possibility. And these are some ways that we can navigate them.

last patient story, patient conference story, but oftentimes our young adults will go down to the kids camp to talk to the kids, the younger kids. And they talk about comeback lines that they say to bullies. And it's hilarious because I had my little five-year-old Kayla running up to me after I'm picking her up from kids camp and telling me all these sassy comeback lines.

And I thought, okay, hold up, we're not really having that problem yet. You not be the aggressor here. But I think ~ it's pretty neat that the kids get to hear the honest truth about what's happening in ways that they have survived it and they're more resilient for it. And they're coming back and giving back to other kids.

LISA ANDERSON, PHD: (55:21)
That is great. Getting a note here that says we're having a special session that's going to take place at conference again in the youth camp. So there's a kids camp associated with conference where the kids can hang out when the parents are off listening to sessions. But the session within camp is going to be called when people ask about my hair. some folks will come and talk to the kids about that specific topic. And it's led by the youth mentors that you mentioned.

That's a program. It's nationwide where people in the community can reach out to NAAF to connect their child with a young adult who's living with alopecia areata, just to sort of for a support system to talk about anything, what they're going through and what it's like living with the disease. Well, I think we need to stop there.

Thank you so much, Jonelle. As I said, it's inspiring to hear your journey, your family's journey, and then ~ to see you bring your professional perspective to it. I think it's really informative for the community, and we thank you for being here today. Of course, I am going to share my screen. Give me one second. And then we will.

JONELLE MASSEY, LPC: (56:30)
Thank you for having me.

LISA ANDERSON, PHD: (56:39)
I will talk about conference one last time, but it is a great event. And if you would like to hear more from Jonelle and meet her in person, we would love to have you join us at the annual NAAF conference. So this will be our 41st annual conference. taking place in Orlando, Florida from June 25th to June 28th.

The conference is the largest gathering of the alopecia areata community in the world. And of course you are invited. It's a unique opportunity to hear directly from experts like Jonelle, as well as connect with community leaders in alopecia areata and meet others who are sharing, who share similar experiences. We do have an early bird registration discount going on right now. That's been extended to March 15th. The discount will give you a hundred dollars off the registration fee.

So you can use this QR code to register today and find out more information. And of course, we would love to see you in Orlando. I want to tell you about our next webinar. It's called The Power of Peer Support, Teens with Alopecia Areata Supporting Each Other. This next live webinar will take place on Wednesday, April 22nd at 7 PM Eastern, 4 PM Pacific. We'll be approaching Mental Health Awareness Month, which is in May.

And we invite you to join us for this webinar, join behavioral health therapist, Mary Wills for a conversation about the power of connection and peer support for teens living with alopecia areata. We'll explore how friendships and shared experiences can support emotional wellbeing, build resilience and help teens and young adults create supportive spaces where they feel understood. This session is designed for teens, young adults and the adults who support them. So registration for this webinar is now open.

Thanks once again, Jonelle, for being our webinar speaker tonight. To the audience, we want to say thank you for joining us. Please share your feedback on today's webinar. This will help us plan future presentations. There will be a link to a short survey that will pop up in your browser window at the end of the webinar, and your feedback is greatly appreciated. We also encourage you to stay in regular touch with NAAF. You can use this QR code here to subscribe to our email list.

you to get regular updates on alopecia ariana news and research the monthly naf electronic newsletter and notices about upcoming webinars and other programs to learn more about naf and the resources we offer please visit naf.org or email us at support at naf.org and also feel free to email us if you have questions about the youth mentor program and you cannot find it anything you can't find it on our website but it's there

This concludes today's webinar program. Thank you all for joining us. We look forward to seeing you on the next webinar. Take care, everyone.