Parenting is Hard

Part 5

You can watch the video of this podcast at: youtu.be/EYet3CWzmjc

[00:00:02] **Krissy Dilger:** Welcome to the SRNA "Ask the Expert" podcast series, "Research Edition." I'm Krissy Dilger with the Siegel Rare Neuroimmune Association. This is the fifth episode of "Parenting is Hard," a mini-series exploring an often overlooked but deeply important topic, the experiences of parents raising a child with a rare neuroimmune disorder and how this impacts their other children. Joining us for this special series is Barbara Babcock, a family therapist at the UK's National Health Service. Barbara has conducted insightful research into how parents navigate the needs of their non-diagnosed children, alongside those of a child with a rare neuroimmune condition. Through this series, she'll share her findings and offer guidance for families facing these unique challenges.

[00:00:52] Barbara holds a Master of Science in Family Therapy from King's College London. And a Master of Arts in Coaching Psychology. You can find her full bio in the podcast description. SRNA is a nonprofit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our website at wearesrna.org.

[00:01:16] This episode was made possible in part by the generous support of Amgen; Alexion, AstraZeneca Rare Disease; Genentech; and UCB. Please note at the end of this miniseries, we will host a Q&A episode where Barbara will answer questions from the community. To submit your question, please visit srna.ngo/submit. You can also find this link in the podcast description.

[00:01:45] Hello, Barbara. Thank you so much for joining us again for this next episode in the series on parenting siblings of a child who has been diagnosed with a rare neuroimmune disorder. And we previously talked about your research, and we started with the first two themes that you found within your paper.

[00:02:10] And I would love to move on to the third theme to just continue this conversation. Can you just start us off by introducing theme three: We work hard to find a balance in attending to siblings needs.

[00:02:26] **Barbara Babcock:** Sure, and thank you for having me back. It's lovely to be back here talking about this. Now, theme three, we work hard to find a balance in attending to the sibling's needs, focuses on how hard the parents worked to attend to the sibling's needs. And one family emphasized, we're doing this out of love. We really love all of our children. Out of the six families I spoke to, five families struggled with not being able to give the siblings more time and attention.

[00:03:01] And all of the families described how they worked together and find ways to spend time with the siblings to support attending to their needs. But also, they also talk about how they compensate the siblings for spending less time with them, for giving the child with the condition more time and attention. And I noticed throughout how their language suggests the influence of fairness.

[00:03:30] **Krissy Dilger:** Fairness can be a tough one I think for parents all over the place, whether it's between siblings who have one child who potentially needs more attention because of a diagnosis or even just some child has more sports going on in their life or just has more learning disabilities, something like that.

[00:03:55] This is really interesting that you bring up fairness. Can you talk about how working together plays a part in two parent households?

[00:04:07] **Barbara Babcock:** In two parent households, a lot…like a sub theme within this theme is the couple working together supports attending to the sibling's needs. So, five families would describe how their partner supported them both to attend to the sibling needs. So, it could be by sharing, caring parenting and family responsibilities and tasks. And there were a number of two parent families. And in that case, each parent takes a child and that works out really well.

[00:04:42] And you know, they would just talk about discussing with their partner how they would share tasks and responsibilities. They might say, ok, we chose to split it this way, but actually we find that, or one of us finds, this isn't working. It's a bit too much. So, they have to have a serious conversation about can we do a bit of a swap here?

[00:05:07] "I'm feeling a bit overwhelmed or a bit overloaded." And I think that's really important. With the families I spoke to, the couples seem to be able to have those kinds of conversations and there are some, a term parent mutuality, being able to have those open conversations in a really constructive

[00:05:28] manner, so that they could each find a way to get on with all of the different responsibilities that come with having a family, work, et cetera, et cetera. If couples find it difficult to communicate, that's where they could find a lot of tension happening and that tension in the parental relationship could then filter out further among the children.

[00:05:54] So how the parents make time and discuss together, how are we going to manage this, is really important. And it's also hard because you can be so busy. Where do you find the time to talk? How do you find the time to talk? How do you, if you find that our way of communicating maybe isn't healthy or maybe we can't find a good enough resolution to move forward.

[00:06:22] It can make things more difficult. And that's where someone like myself would come in and say, work with the parental couple on, ok, how is the communication working or not working? How can we speak about this differently?

[00:06:38] **Krissy Dilger:** Yeah, and I think that's a great point. That these types of conversations and ability to work together, it can be hard to figure out for parents. So, it does, it's not always feasible to just figure it out on your own. Talking to someone who can help facilitate those conversations so that the parents can learn a good way of communication. That's perfectly acceptable and encouraged if that's needed.

[00:07:09] **Barbara Babcock:** Absolutely. Because sometimes parents, a couple, and this happens in every couple, even with myself and my husband, we have to sometimes say, take a step back at the third person involved to help us see where we're tripping up over ourselves. And it's common for that to happen because many times when we talk, we're assigning meaning to what the person is telling us, and we're responding to the meaning we assign rather than checking out with the person.

[00:07:42] What exactly do you mean by that? Now, sometimes we think, oh, we know the person. We've been married 20 years. And yeah, you do know the person and chances are there's probably an element of truth

to the interpretation you're making in your mind. But it sometimes that can be a dangerous place because you might get it a bit wrong because your other half could be trying something differently.

[00:08:06] Yet, if you're acting on an old narrative, an old story about what you think they mean and they're trying something new, you will have that cross communication that won't be beneficial. So, I always encourage couples, what exactly do you mean by that? Tell me a bit more. I'm not quite getting it. I really want to understand, ask the curious questions. We have two ears and one mouth. Let's use them in that proportion.

[00:08:39] **Krissy Dilger:** Exactly. No, that's great. Are there ever situations in which parents struggle with working together? Maybe one parent is too overwhelmed or isn't emotionally equipped to deal with the situation they found themselves in. How might that manifest and what would that look like?

[00:09:07] **Barbara Babcock:** That's a really good question, and it's an important question because I'm sure there will be some people experiencing this where one parent maybe is unable to help out due to physical or mental health issues of their own. Or some people, a parent, may experience such grief over what has happened with their child, that they could be in a denial or shock or depressive phase where they just can't bring themselves to address it. So, they may leave the other parent to do that.

[00:09:50] But even in families where maybe the parents have split and they're living separately, and the children move between them, for example, shared custody. They may leave the child with a condition to just stay with the parent who does the primary caregiving and withdraw from that. And it's a really difficult situation.

[00:10:18] And there could be so many things which come into that such as the parent who withdraws. Is it about dealing with what they find to be a traumatic situation? So, they're in a bit of a freeze response. Is it the shock at what's happened, like this couldn't have happened to my child and the parents' attitude towards disability.

[00:10:52] So if in some cultures the attitude towards disability, it can vary. And it could be helpful to the situation and maybe not quite as helpful to the situation. It depends and it's a very delicate area. It's a very sensitive area. What could also feed into how parents work together or their value sets as parents when in a difficult situation.

[00:11:24] So what did they learn in their families of origin about how you deal with difficulties? Do you just be quiet and soldier on. Bury the difficult feelings so you can soldier on? Many people will do that. It's a survival strategy. It's helping them to get on with other aspects of life. So, we don't want to judge too harshly, but it could be attitudes towards disability, attitude towards recovery and illness.

[00:11:58] You're meant to recover, you just got to get on with it and that is shaped by the families we're raised in and the cultures we're raised in as well. So, it's, sometimes what I find is when you have a situation like this in a family, it can highlight where there might have been difficulties.

[00:12:23] It can make them even bigger. So, you know, if a couple were struggling in their communication with one another beforehand, sometimes these situations can make that struggle even bigger and harder. And it feels like, a chasm you're trying to navigate and it's really hard to, other times it could bring a couple together and really support them.

[00:12:51] Like, we've really got to work on this and find a way through it. Let's pay some attention towards that, so we can have a different impact. Yeah, sometimes you can see some, what feels like heartbreaking situations where it's hard for everybody involved.

[00:13:13] **Krissy Dilger:** Yeah, I can imagine. I can imagine it, it'll be an adjustment period for anyone, but it might look differently for different people.

[00:13:22] **Barbara Babcock:** Yeah. And that adjustment period, it's not uncommon for that to be several years. It can take time. There's a lot of learning that is happening.

[00:13:33] **Krissy Dilger:** So, I guess can you, can you also maybe talk about how different cultures or values or that kind of context of the family unit, how that might affect things like how a couple will work together or communicate.

[00:13:52] **Barbara Babcock:** Yeah. I think this is really, really important because we don't know where in the world our listeners are from. And I also think of the context of this research. The participants, the six families who took part, were white, British, or white other, maybe they weren't originally from Britain, and they were two parent families.

[00:14:14] A man and a woman. And so that already tells you there is something there. How will these findings apply to a single parent family to a family where it's two women or two men who are the parents or a family from Oman or a family from Japan or China or in Africa? In different cultures, different religions, there may be different values around how a couple works together.

[00:14:53] Some people may subscribe to where men go out and work. And the women, their primary role is to be a nurturing caregiver. Look after the home, look after the children. In other cultures that might be swapped, the woman may be going out to work and the man might be staying at home. So, I don't want to make assumptions that everything I found were applicable to every culture.

[00:15:23] So that's something to be mindful of. Some of what I found may be applicable and bits of it may be applicable, but other bits might be less so. Because I think of single parent families where you have one parent who is doing the role of two parents, and if they have several different children and one of them has a rare neuroimmune disorder,

[00:15:52] they have a lot on their plate and it's really hard. And they may need the siblings to step up and help out because they can't do it all themselves. There are only so many hours in a day and so much energy. And so, I'm very mindful of, gosh, it's really hard for single parent families.

[00:16:13] So that theme around the couple is working together, supports attending to the siblings needs. For them it may be about who else in their life is helping them attend to the siblings needs. It might be grandparents; it might be aunts or uncles. It might be friends. It might be the teachers at school.

[00:16:36] It might be the people at the nursery. It could be the babysitter. It could be a wide number of people who may be supporting the single parent and helping attend to the sibling's needs. And that is wholly appropriate. For children it's about having a safe adult in their life, and it doesn't hurt to have more than just the parents be the safe adults.

[00:17:05] There can be other adults who could be safe adults that they could go to with issues. And that's appropriate. It takes a village to raise a child and expecting yourself as the parent to do it all. I, think, gosh, that you're giving yourself a lot of responsibility. And, of course, you want to do it all.

[00:17:25] You want to be a good parent. But there is that expectation, a “good” parent, and I'm putting my hands up in quotes around good but actually is that realistic given a family's context?

[00:17:43] **Krissy Dilger:** Yeah, that's all great points. I think the context is important to this discussion and I am hopeful that this is just the beginning of the topic being brought in research. Because it would be great to have this replicated in China and Brazil and other places that we can really cover how this dynamic is affecting families. It's definitely important.

[00:18:14] **Barbara Babcock:** And I'll talk about it more when we get to the fourth theme, which relates to siblings supporting the parents.

[00:18:22] **Krissy Dilger:** Right. Yes. Yes. Stay tuned. Great. Building in time to spend with the siblings is important. I know that's something that you, that came up in your research and came up with the families. So, can you contextualize how that belief or how that sentiment came about from parents and what they, what they expressed to you?

[00:18:52] **Barbara Babcock:** Let me just find back to where I was. So, building in time to spend with the sibling is important. And this is related in part to the fifth theme, which is around parental guilt. But because parents did feel guilty. I'm spending a lot of time and effort on this one child. What about my other children? And that was a discussion I had with parents originally when I was developing the research topic with parents.

[00:19:31] So they realized, gosh, I really need to really think about how I build in time to spend with a sibling. And that's the language parents use, build in time. And so, in the language of the themes, I am using the parents' language because they were concerned about the impact on the sibling and their needs.

[00:19:54] And many families did this via preexisting everyday activities and routines. So having meals together. The evening meal, for example, or breakfast, movie nights, extended one-on-one time. For example, it might be that in one family, if a child is in school and they have the condition, they're living with a disability, but the other child isn't in school yet, or maybe just nursery it might be easier than to have more one-on-one time with that child.

[00:20:32] Take them, do something special with them. One with older children, a holiday, maybe a weekend away. Let's go away together. But again, every family financially may not be able to do that. The bedtime routine was really important, particularly when children are under 10, like 10 and under, nearly every parent I spoke to mention the importance of the bedtime routine.

[00:21:01] So it's having a story together, singing a song and having a ritual around that. One parent, I really want to share this idea because it's a really lovely idea, they had what is known as a worry doll, and this originally comes from South American culture, I think Ecuador, where you have a worry doll, and you know the child can talk about their worries with the doll and then at bedtime the parent would say, gosh, you know what?

[00:21:35] What did you talk about with your doll today? What worries and anything else that's happening? What went well today? So, it's really lovely quality time with the child that is already part of the daily routine. Other parents like car journeys, particularly if they're teenagers.

[00:21:55] Because you're not looking, you know each other in the eye. Sometimes that can be uncomfortable for people, whereas sitting side by side is a lot easier. So, using car journeys or if you're out walking somewhere, walking the dog, for example. So, I often think about how we can use the existent daily routine for points of connection with our other children.

[00:22:22] **Krissy Dilger:** That's very interesting. And I think what it sounds like to me is just because you might not have equal time with all the children, it's still equally important that you designate some time. And

that's ok, because unfortunately, yeah, it might not always be equal, but that doesn't mean that it's those, that quality time, that one-on-one time, isn't important still.

[00:22:49] **Barbara Babcock:** Yeah, there was, there's a point that I want to make and I'm just trying to find it here. Part of this is about the imbalance in the attention given when you notice that as a parent. I think in my role as a researcher or a family couples' therapist the parent's awareness of the sibling experience and perceptions that parental emotional, what the parent's sibling relationship is like and how the parents can support the siblings.

[00:23:33] Because when you come to this parental differential treatment, which is this official jargony term I'm using to talk about when one sibling requires more time and attention than other siblings. If a parent is emotionally available, if they can see yes, this one child is getting more, and I'm going to try and build in some time to spend with the sibling.

[00:23:57] And if there is an open enough parent sibling relationship that can all limit the sibling seeing that parental differential treatment in a negative way. So that's all you know because it's the sibling perception of that parental differential treatment and its fairness and legitimacy and family circumstances, which impact how the sibling respond, not the parental differential treatment itself.

[00:24:28] **Krissy Dilger:** I love that point because I think that's something that people might struggle with. Is that it is going to happen, but it's how you frame it and just how you change your mindset that can really make the difference.

[00:24:43] **Barbara Babcock:** Because sometimes that parental differential treatment is absolutely necessary and unavoidable and very appropriate. And parents can still feel guilty for that, but it's not so much the act in itself. It's how the sibling perceives it. And there's a lot of different things that will influence that.

[00:25:05] But also, we have to consider the age and development stage of the child. So, the research has shown that children age seven plus, so seven and older, have a greater understanding of equity. So, children seven and younger or maybe a bit older, maybe if they're young, eight or a young nine-year-old can struggle to understand because they equate the amount of parental time and attention with love and self-worth.

[00:25:39] I. So, with younger children, it can be harder because they think mommy and daddy aren't spending time with me. They don't love me. And that's heart crushing. That's really hard. But the cognitive development isn't there yet to understand. They have a nuanced understanding of the concept of equity and fairness.

[00:26:07] **Krissy Dilger:** Interesting. Very interesting. And that kind of leads me to my next question. In what, in regard to what you found in your research. Parents expressed this idea of trying to make it up to the sibling. So can you talk about that concept and how that got brought up within the context of your conversations with the parents and what that really meant for a family. What does making it up to the sibling mean for the family?

[00:26:39] **Barbara Babcock:** So, making it up to the sibling. This was related to guilt. Again, they demonstrated how they reduced, managed and or compensated the sibling for the parental differential treatment for the time and attention given to the child with condition.

[00:26:59] And I was thinking, that made me think of balancing. Parents often use the word balancing our attention. So, I was exploring what does balancing mean? And it was very much reminiscent about being equal times, equal times spent on homework, equal number of play dates. And they tried to use different conceptualization of fairness in attending to the siblings needs.

[00:27:27] So like one quote from one family, and the names I use, the names have been changed. So, we can't identify the families who took part. Where a parent was saying, “I want Zoe to know. It's not all about Emily either, is it? It's about her as well.” And that's an important point that we don't talk about.

[00:27:46] “We don't focus on Emily, the child with the condition, too much.” Because Zoe wasn't in school, we had a couple of days where we've taken her out without Emily, just to owe her that time back. So again, it's reminiscent. We owe her, we have to make sure we spend time with her. And that's not a bad thing, but it is that interplay of we owe, what's fair and appropriate here?

[00:28:14] And then another family was saying, “So mostly we just trying to overcompensate sometimes. Just keeping her super busy because she's really active.” So, making sure the sibling has loads of activities. They enjoy them. Great, let's do lots of that for them. But yeah, there was that theme of: we've got to compensate the sibling for this.

[00:28:37] **Krissy Dilger:** Okay, great, thank you. And with your research, did anything come up in terms of compensating the sibling that could be, per chance, perceived as negative?

[00:28:55] **Barbara Babcock:** No, not really. And I think we have to think about what we would see as a negative way of compensating the sibling. Different cultures, different family values will have different thoughts about this.

[00:29:16] And there might not be any one super right way or the best way to parent. Sometimes for example and I'm pulling, I'm thinking of different examples here. A parent might say, “I'll buy you this. Oh, you wanted these new headphones, or these ear pods, or you wanted this new phone, or you wanted this new toy.

[00:29:45] I will get you that.” So, um, sometimes it might be through gifts, and the person shows their love through gifts and that is not necessarily a bad thing. And we also have to think about how were we parented in our families? How did our parents show us love and attention? Was it through gifts?

[00:30:12] Was it through physical touch, a hug? Was it through spending time with us? There were many ways that we show love and affection in our families, and we learn it in our family of origin, and our parents learned it in their family of origin. And this could be passed down the generations, but also shaped by the current times we're living in.

[00:30:37] So there are many things which can impact how parents show their love, care, and attention and affection towards the siblings. And also, but how does the sibling want to be shown love, care, and affection? Do we know that? Do they feel they can say that? It might be some children might receive a gift.

[00:31:06] But they might not want the gift. They might actually be quite happy with the gift, and they might be happy for time and then they might want another gift or "want mummy’s and daddy's time and attention. “Hey, hi, there's me. Focus on me.” There could be all sorts of things. But it comes back to what is the level of open communication in the family.

[00:31:31] How the parents feel about talking with the sibling, but also how does the sibling feel about talking with the parent? Do they feel they can be open with the parent? And I do address this in theme four, so stay tuned for that as well.

[00:31:48] **Krissy Dilger:** Great. Yeah, that's really interesting. And I think a lot of these themes can relate back to the next. The next theme four. Yeah, which is…

[00:32:01] **Barbara Babcock:** I do want to stress that different cultures, different countries, different religions, they may have a different perception as to the role of the sibling. In this case, they could have grandparents be telling the sibling, look, you need to step up and help your parents

[00:32:21] now. You need to you know, be quiet and not get in the way and help out and do this. So, there may be certain expectations that are expected in that culture of the sibling, which may be different from other cultures, for example.

[00:32:40] **Krissy Dilger:** Yeah. Yeah. That's really interesting. So, there is another sub theme within your research talking about we slotted the sibling in. Can you talk, about what that means?

[00:32:58] **Barbara Babcock:** Yeah. So, in the context of this, third theme how are parents actually attending to the siblings needs? As I said at the start, five families indicated they were struggling with this, and one family didn't. And so, I wanted to speak to that. So, in this family, they used a language, we slotted the sibling in and I'm like, oh, that's interesting.

[00:33:24] Tell me more. What does slotting in mean? They said we just had the one child before and they acquired the neuroimmune disorder and then we have the second child. And so, we just slotted them in. And in some ways, you know, this is normal for her. This is her normal. She doesn't know any different. And so, when we talked about what slotting in means, they said we educate her about what's happening as best as we can

[00:33:57] that's age appropriate. So, there's an educational side to her being patient because the brother cannot run as quickly. We need to give him a minute to catch up. You've got to slow down a bit. The mother said she just had to come along. This is what we have to do as a family.

[00:34:17] And when the mother explained age-appropriate education. Let's wait for your brother. This is how you can help. Because she, she's, the young, younger sibling wanting to help her mother. And kids often want to do that as a form of play. And I'll talk about this in theme four.

[00:34:42] Getting her to help out a bit. These could be suitable ways to have the child be involved and be a part of the family. And it seemed to work for this family really well. So, in all of those, what that family did are ways that the research has shown can limit any negative impact of parental differential treatment.

[00:35:07] **Krissy Dilger:** Ok, great. Thank you. And I think that's the end of my official questions that I have for you, but I did want to open the floor and see if there was anything you'd like to add or any other points that, that you found in your research on this theme that didn't come up.

[00:35:25] **Barbara Babcock:** I think it's important to remember that each family will manage having a child with additional needs differently, and what works for one family may not work for another one, and that's ok. I'm also noticing I'm using the language a lot, limit the negative impact of parental differential treatment.

[00:35:47] And there is something around, yes, of course you want open communication with your children so you know what's going on with them and you can support them. But whether we can wholesale limit the negative impact, we might not be able to. And in some ways, we really won't know what the impact will be like until the children are older.

[00:36:10] We can do what we can now, we could be emotionally attuned to our children, picking up on their emotions, noticing them, attending to them and doing the best one can in what oftentimes are really difficult situations. As parents listen to this podcast, I really want them to be gentle with themselves.

[00:36:34] Yes, of course you will do things to mitigate the impact on the other children. That's natural to do, and there's an element we may not be able to mitigate everything, and that's ok. As long as you know your children are safe, they're not in harm, they're being looked after. You know there is enough emotional attunement, and they have those other safe adults in their life. That's really important.

[00:37:07] **Krissy Dilger:** Great. Thank you so much for your time once again, and I'm looking forward to our next episode, which we'll talk about theme four.

[00:37:19] **Barbara Babcock:** You're welcome.

[00:37:25] **Krissy Dilger:** At the end of this mini-series, we will host a Q&A episode where Barbara will answer questions from the community. To submit your question, please visit srna.ngo/submit. You can also find this link in the podcast description. Thank you to our Ask the Expert sponsors, Amgen; Alexion, AstraZeneca Rare Disease; Genentech; and UCB. Amgen is focused on the discovery, development, and commercialization of medicines that address critical needs for people impacted by rare, autoimmune, and severe inflammatory diseases. They apply scientific expertise and courage to bring clinically meaningful therapies to patients. Amgen believes science and compassion must work together to transform lives.

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