Parenting is Hard

Part 4

You can watch the video of this podcast at: youtu.be/_FXYjc3Gpso

[00:00:02] **Krissy Dilger:** Welcome to the SRNA "Ask the Expert" podcast series, "Research Edition." I'm Krissy Dilger with the Segal Rare Neuroimmune Association. This is the fourth 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.

[00:00:26] Joining us for this special series is Barbara Babcock, a family therapist with the UK's National Health Service. Barbara has conducted insightful research into how parents navigate the needs of their undiagnosed children, alongside those of a child with a rare neuroimmune condition.

[00:00:43] Through this series, she'll share her findings and offer guidance for families facing these unique challenges. 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.

[00:01:14] This episode was made possible in part by the generous support of Amgen, Alexion, AstraZeneca Rare Disease, Genentech and UCB.

[00:01:24] Thank you, Barbara again for joining me. So now we're going to talk about theme two with your research and theme two is “I can only split myself so many ways”. So, can you just introduce this theme, please? How did families in your research contend with the additional factors that come with having a child with a rare neuroimmune disorder?

[00:01:54] **Barbara Babcock:** I think that theme title says it all that I was using the language of the parents. I can only split myself so many ways. I can't be at hospital attending to one child and at home attending to the other children.

[00:02:13] So like I can only split myself so many ways. So that gives a flavor of their experience. There is so much on. But the parent can't do it all. And there were two, code labels supporting this theme. So, we have, I can only split myself so many ways. And the first one supporting that was, the “non-stop nature of caring responsibility sucks our time away”.

[00:02:47] And that “non-stop” was language parents were using and “suck our time away” was again, language that they were using. So that gives you a real flavor of their experience that these caring responsibilities don't end. It's forever, it's ongoing, it's just non-stop, and it sucks our time away. So, all this time is going to caring responsibilities.

[00:03:19] And then linked to that, the other code label supporting this theme, “juggling caring responsibilities alongside work and parenting demands is exhausting”. Soall of the parents worked. So, there were seven parents from six families who took part in this research. Five of those parents worked full time.

[00:03:50] And then two other parents worked or volunteered part time. These are busy households. What is also an important consideration is the context of the family's circumstances. Only one family had extended family living nearby who could give practical support. Not everyone has that luxury. Here, take the kids where we have a date night, time to ourselves.

[00:04:19] If you're a single parent and you don't have practical support nearby, it's even more intense. You have all these caring responsibilities requiring so much time and then you need a job in America possibly to get the health of the dental care that you need. So, you need to work, and you need to work to clothe and house and feed your family.

[00:04:47] But then you have parenting, the day-to-day parenting demands. Get your shoes on, get out the door so we can get to school, do your homework, you two stop fighting, the cooking the food to feed your children. So, there are all these demands alongside the caring responsibility. Parents find it exhausting.

[00:05:12] **Krissy Dilger:** I can imagine. I can imagine.

[00:05:14] **Barbara Babcock:** Yeah.

[00:05:16] **Krissy Dilger:** You mentioned they have all these responsibilities that they feel like they have to juggle, family, work, caregiving, how do parents describe this experience, or their experience with this?

[00:05:33] **Barbara Babcock:** I have a few here I'd like to share with you. Okay, so listen to the language. I referred to this family in the previous Theme 1. And the names I refer to, they have been changed to protect the family's confidentiality. Olivia's under 10 different specialists. It's been a full-time job in the past, and it's only been this year, coming up for five years now, since that I've been able, felt I've been able to go back to work.

[00:06:07] It's a never-ending task. So here are the caring responsibilities. It's a full-time job. It's taken five years to get to a place where the mother feels able to go back to work. It's a never-ending task. Another one is, and then Theo, the sibling, is caught obviously into this exhaustion. So that's something we need to start paying more attention to, I think.

[00:06:37] We're both his parents. We're both exhausted. So, both parents are exhausted with all the caring responsibilities and what is going on with the child with the condition. And they're realizing, what does this mean for our other child? We need to really start paying attention to this. So, it's really challenging because you think about these factors.

[00:07:03] The non-stop nature of the caring responsibility, not having the time, all the other work, parenting, demands, these factors, they relate to time being a finite resource. That and exhaustion constrain parents' choices in attending to the siblings’ needs. To be fair, in the way they ideally would like to do.

[00:07:30] So even though this theme was very brief in the research, it's a really important one because it highlights the family's context and how the parents do want to, give the sibling more time and attention. But the factors in their life really constrain that and so the parents feel I can't be fair towards the sibling and it's really hard and it highlights how it contributes to this parental differential treatment being necessary and unavoidable.

[00:08:04] We can't avoid it, but what it also highlights is, is how those societal parenting norms I spoke about under theme one, it makes it very difficult for parents to work, to parent according to those societal norms, it's like they're trying to be fair towards all their children, they feel they can't be, but actually, do those parenting norms apply towards this situation?

[00:08:46] **Krissy Dilger:** I definitely think hearing in their own words, some of the families' descriptors of how they talk about this aspect, illuminates this theme and how this is a common experience between families.

[00:09:06] **Barbara Babcock:** Yeah.

[00:09:07] **Krissy Dilger:** So just touching back on the caregiving aspect for many families, this is an additional mention that affects parents time and responsibilities, but they didn't, you know, have to have to factor in before the child's diagnosis. How does that additional factor affect the family? Do, obviously, parents will have to spend possibly more time with that child in their caregiving duties. Does that factor into how they split, themselves, so to speak, in the parents, in the role of a parent?

[00:09:50] **Barbara Babcock:** I think of the families who took part in this research. They were all like husbands and wives, heterosexual couples. So, they were two parent households. And that has, okay, that you might think, okay both parents get involved. We, you have to look at the couple's relationship. And how each person responds, each parent responds to the situation. Some parents, this could be, it's over, overwhelming for many parents. And what do people, how do they respond to that overwhelm? Some parents may shut down.

[00:10:35] I can't cope with this. This is really hard. I don't want to think about it. So, they might focus on, "I'll be the breadwinner. I'll go out. I'll get the income. I make sure we have our health insurance, our dental plan," whatever. And the other parent becomes responsible for all the caregiving responsibilities.

[00:11:01] And some parents, they do it that way. Sometimes that might be done along gender themes, where the man goes out to work and the woman stays at home and cares for the child with the condition. It might not be, depends. If it's a heterosexual couple, it might be that way. If it's not a heterosexual couple, maybe two women who are married, two men who are married, it may be different.

[00:11:30] Then you have to think about, let me backtrack a little bit. Sometimes a parent may not want to take part. Sometimes a parent can't take part in the caring responsibilities because maybe they have a chronic illness, mental health issues, and they're unable to because of that. It could be because they work away from home in another country.

[00:11:56] They got such a good job with such a great salary, they couldn't say no. Maybe, the couple decided this is how we're going to split responsibilities, and they had a discussion around it, "Okay, I'll go out to work. I'll take care of all the practical stuff around the home. You're primarily responsible for the child who needs their additional needs."

[00:12:24] When something like this happens, for whatever reason they decide it, and one is primarily responsible for the child with the condition, what that could end up doing. And this did not factor into my research, I personally didn't find this, but this can be an issue. Is that parent who's attending to the child with the condition and their needs, if they're with them all of the time, and they don't have as much time for the other child, that could affect that parent's relationship with the other children.

[00:12:58] Now, it might be the other parent is stepping in and they have the stronger, closer relationship with the siblings. But there is something around, the child has both parents and if both parents are living in the home, how do both parents maintain their relationship? As much as is feasible under their circumstances with all of their children, and I do talk more about this in under theme three.

[00:13:31] **Krissy Dilger:** Okay, I look forward to hearing when we discuss theme three. So, one other word you've used to describe how parents were feeling, was exhausted. So how do parents tend to cope with this exhaustion that comes with having to juggle these responsibilities?

[00:13:55] **Barbara Babcock:** This came from parents I interviewed, cry, and the kids all go to bed. They go in their room, and they cry. Drink wine. Some people cope by drinking wine. Some, they may also if they're female, for example, and they're in the perimenopause or the menopause, that can contribute to exhaustion as well.

[00:14:25] So there is how does that person attend to their own personal needs around anything related to the perimenopause or the menopause. I think that's really important. Looking at that because that can be an exhausting experience in and of itself. Then if you have work and you're caring for a child with additional needs, it can make it that much harder.

[00:14:55] Sometimes parents give each other breaks. I'll take all the kids for now, while one parent goes off and does something. Friends for support, if you can pick up a child for me, please, or if they do have family nearby who can offer practical help. Sometimes you can have family nearby. They cannot offer practical help because they're not willing to, or of a certain age, or they might have their own issues that they're attending to.

[00:15:28] So they don't have the availability. So, there's a range of. things that parents did, but there is, parents did talk about the importance of, they learned, I have to look after myself. If I don't look after myself, I'm not in a position to look after my children. So, they're like, do the basics, eat, drink water, make sure you get sleep.

[00:15:54] They literally, all the parents, when I said, what advice could you give other families in dealing with this, they were talking about the absolute basics. And making sure that parents do that as a starting point.

[00:16:09] **Krissy Dilger:** Yeah. I think it definitely brings into the conversation, now, taking care of, a lot of your research is focused on the family unit and how you spend time between siblings and such, but it warrants also discussion of how parents take care of themselves. Yeah. It's a whole other, I think, topic.

[00:16:30] **Barbara Babcock:** Yeah. Exactly. And I think the other thing that, it can impact with dealing with exhaustion, is parents could be striving so hard to be a good parent and give their children equal time and attention, desperately striving to parent according to these societal parenting norms.

[00:16:53] That can be exhausting. There is something around, "Stop that, that parenting norm isn't relevant to you anymore." You have to design your own parenting norm and that can be tough because you can have family members saying you shouldn't be doing it like that. You should be doing it like this or friends and there is something around you and, the other person who supports you in parenting the child, if they're around and on the scene, a standing firm, "No, this is what we're doing because this is right for our family."

[00:17:32] **Krissy Dilger:** Yes, all great points for sure. So beyond basic responsibilities like work and caregiving and parenting roles, how do families integrate social and extracurricular activities into their lives?

[00:17:51] **Barbara Babcock:** I think that has been challenging for some families. It wasn't a specific question I asked, but it came through with some families. It's really about how the parents work together to enable that is a big thing. But also, it's finding out. What activities can we all do together? Because there might have been activities you did together as a family, which are no longer accessible to the child with the condition, maybe due to fatigue or chronic pain or using a wheelchair or using a tracheostomy.

[00:18:34] So it's finding what is accessible out there. And that's where I think charities, community groups that support families who have a child with additional needs can be a real lifesaver because they appreciate it and can design activities where everybody can take part. So, for example, for a period of time here in the UK, I used to run the family weekend where families could apply to attend, much like the quality-of-life camp, the SRNA runs in the U. S. I ran it here from 2015 to 2019 in the U. K. And we went to a specialist center that had a range of activities that any child could do, and it was adapted. So, if you want to go abseiling in your wheelchair, you could do it.

[00:19:33] Adaptations were made. So that they could take part and it was about helping them find their way. If a child had a weakened upper limb due to acute flaccid myelitis, but they want to go on that climbing wall, they would make it happen. So, it's very much around how can supporting the child with the condition to find their own way in doing activities, activities that are accessible to them. How can the whole family take part? Because I think it's very much about individual well-being for every family member, but also the family well-being.

[00:20:13] **Krissy Dilger:** Yes, for sure. For sure. And I think, making sure to make room for those extracurricular and social activities. Yeah. Aids in the general exhaustion and just mental health of everyone.

[00:20:33] **Barbara Babcock:** Yeah, there was something around the family has to redevelop their confidence to go out into the world to, with the child who may have additional needs and the rest of the family members to have that quality family time It's kind of like oh, oh, okay. We're gonna go out and do this. We're gonna navigate the tube system in London with our child who's now in a wheelchair. We're gonna try and see how this works, and it won't work brilliantly.

[00:21:02] The first time every time there will be hiccups, but there is something around going out and trying, planning for it as much as you can. There's a lot more planning involved, a lot less spontaneity than before to see how it works and bit by bit develop that confidence to go back out into the world again as a family.

[00:21:24] **Krissy Dilger:** Yeah. Yeah. It's really interesting to think about that, that the word confidence really stood out to me there. You do have to, as a parent, I'm sure it's scary when the diagnosis first happens, and you probably don't feel very confident in your own abilities, but yeah, the confidence to, to get out there and to become an advocate for your child, it's great.

[00:21:55] **Barbara Babcock:** I think an important thing around confidence I'd like to share is sometimes we can, we have to consider what is my relationship with confidence. My individual personal relationship with confidence, sometimes we can view confidence as a state to achieve. And we must achieve that first before we can do X, Y, Z. And many times, its actually confidence is something we build and something that is, this is an ongoing process. Around creating our, state, not so much a state, but like this experience of confidence is something we build and it's something that will ebb and flow from day to day and things impacting it is our familiarity with the activity, the context, our energy levels on any given day.

[00:22:53] Do we have, do we feel awake enough to be confident? We might not. So, there's all these building blocks that go into building our confidence and it ebbs and flows. So, there is something around, compassion for oneself and maybe you don't have to be super confident to do something. You need enough confidence to take the next step.

[00:23:19] **Krissy Dilger:** That's a lovely way to think of it. I really resonate with that. Sure. I think that wraps up my line of questioning for theme two. Do you feel we covered everything you wanted to cover?

[00:23:39] **Barbara Babcock:** Yes, I think we have. And thank you.

[00:23:41] **Krissy Dilger:** Okay well, thank you so much, and I look forward to delving into the rest of the themes next time we speak.

[00:23:51] **Barbara Babcock:** Brilliant. I look forward to it too.

[00:23:58] **Krissy Dilger:** At the end of this mini-series, we will host a Q and 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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