Focus on the Family with Jim Daly

The Beauty of Raising a Child with Special Needs (Part 1 of 2)

Amy Brown, Sara Clime and Carrie Holt are all raising children with special needs — which means they are lonely, exhausted, fearful and hopeful, and at times deal with doubts in their faith. But all three also acknowledge God is in charge and it's only by His power are they able to love and raise their children well. (Part 1 of 2)

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John Fuller: Today, on Focus on the Family with Jim Daly, we're going to explore the challenging, uh, often overwhelming experience of raising a child with special needs. And, Jim, as we kind of set the topic, here's a quote from a special needs parent, uh, that got in touch with us. "I don't remember who I was before you, my child. You've changed every part of me. My eyes look at the world differently than before. I have more compassion than I ever knew I possessed. The capacity of my heart has expanded tenfold because of you. Thank you for your gifts. Please be patient with me while I learn how to do this thing." Well, your host is Focus president and author, Jim Daly and I'm John Fuller.

Jim Daly: And that is quite a statement. And it highlights the unique struggles and joys that special needs parents go through. And I don't have that experience other than Jean and I did foster care. And, you know, to Jean's great credit, she shouldered most of that while I was working. You know, she was with these foster kids helping them. She also did respite care when we were in California and has always had a heart to help those families that were struggling in that way. Uh, the fact is families with special needs are all around us. Uh, they are definitely in your church. I hope your church accommodates families that have special needs. Unfortunately so few churches do. That'd be a great thing for pastors to look into. I think it's something like 13% of the population. Over 40 million Americans have some form of disability. That's a, that's an amazing number. And, you know, again, this is just part of life. And then the question is how do we as the Christian Community come alongside these families and help them? And how do we encourage them and how do they find encouragement? And today is that program for you.

John: Mm-hmm. Yeah. We're, uh, really thrilled to have, uh, three ladies with us, Amy Brown, Sara Clime, and Carrie Holt. Uh, they're all three raising one or more children with special needs and they host a podcast together. So they're friends. Uh, the podcast is called Take Heart Special Moms. And then they've written a book that, uh, will form the basis of our conversation today. It is rich with stories, emotions, insights and encouragement. It's called *The Other Side of Special: Navigating the Messy, Emotional, Joy-Filled Life of a Special Needs Mom*. And you can learn more about our guests and also the boo, uh, at our website we've got detail at focusonthefamily.com/broadcast.

Jim: Amy, Sara, Carrie, welcome.

Amy Brown: Thank you for having us.

Sara Clime: Thanks for having us.

Jim: Yeah. It's so good to have you here. And, uh, you know, we're going to have an active discussion about what your lives are like and I'm looking forward to it. I really am. I said this a moment ago off mic but you're heroes and, uh, your husbands as well. And just in that you don't have what some people consider normal, right? (laughing) The normal situation.

Amy: Yeah, sure.

Jim: So you get a lot of curveballs and we want to talk about that today. Let's start with a quick overview of each of your family's situation. Amy, you have the A name so let's, (laughing) you know, we're right back in school. Uh, what's your situation for the listeners and viewers.

Amy: Well, I'm Amy Brown. I live in Michigan with my husband, David. We've been married 38 years. We were high school sweethearts. Um, we have three biological kids and then we brought three adopted kids into our home. When we brought them in our home we did not realize that they had disability because they didn't have physical disabilities.

Jim: Right.

Amy: Um, two of our daughters have attachment disorder and mental health struggles, fetal alcohol. And then our son we adopted from an orphanage when he was 10. He lived in Bulgaria and we adopted him. And he also has attachment and mental health issues but he also has a physical disability called arthrogryposis which kind of looks like polio. He's small statured, um, very difficult time walking, um, can't bend his joints. Um, he's fairly self-sufficient.

Jim: Yeah.

Amy: So we knew that he had that physical disability and we knew that he would have some issues because of being raised in an orphanage.

Jim: Sure

Amy: So that's our family, six.

Jim: And we're going to dive more into that story because the demands that that has placed on the family are quite steep.

Amy: They are.

Jim: And, you know, it helps people connect with what's required when this happens. And, uh, so all right, Sara, let's, uh, talk about your family history.

Sara: Yes. I'm Sara Clime. I live in Missouri with my husband, Craig. He, um, we've been married for, we just figured this out last night, 27 years this year. (laughing)

Jim: (laughing) Congratulations.

Sara: Um, and we have two sons. Our oldest is almost 24 and our youngest is almost 20. And our youngest is the one with disabilities. Um, his name is TJ and he, he was diagnosed at his eighth birthday. Um, he just wasn't walking properly and we took him in for physical therapy and somebody noticed his calves looked very defined, and somebody just knew what to look for. So it's a rare form of muscular dystrophy. It's aggressive, progressive and it's terminal.

Jim: Mm-hmm.

Sara: And at the time of diagnosis, he, they were, he was given a life expectancy of average of 23. Um, so much has been done that now we see men living into their 30s, sometimes even 40s. So, um, that was our story. We had no clue until one day everything flipped on its head.

Jim: Yeah. All right. Carrie.

Carrie Holt: Hi. I'm Carrie. I'm from Ohio. I've been married to my husband, Bruce for 24 years this year.

Jim: This is not a math test by the way. (laughing)

Carrie: Yeah.

Jim: We're not trying to make sure you guys know how long you've been married.

Carrie: Yeah. Well, it's easy 'cause we were married in 2000, but, yeah. (laughing) It's easy to calculate.

Jim: (laughing) That was a good plan.

Carrie: Yeah. We have four kids that are 20, 19, 17 and 14. Three sons and then a daughter at the end. And our 17-year-old son Toby was born with spina bifida. He was actually prenatally diagnosed. I went in for my 20-week ultrasound and then when he was two-and-a-half weeks old, he went into respiratory failure and we went back and spent over 2 months at the hospital there in Columbus, Ohio. When he came home we had a medically fragile baby. He was hooked up to a feeding pump 20 hours a day, had a trache and a ventilator. He still has his trache. He's still on his ventilator when he sleeps. And we've also… I usually call myself the hospital state expert because he's had over 60 surgeries in his lifetime. Most of those were within the first 14 to 15 years of his life.

Jim: That's amazing.

Carrie: And we've ridden a lot of roller coasters and had a lot of curveballs. (laughs)

Jim: Yeah. Let me, let me start the other direction now. So, Carrie, I'll start with you. When you received the diagnosis and your world changed, uh, how did it make you feel? How did you respond to that? Is it a… You know, again, for those of us that have not had that situation, help us better understand what that is like when the doctor sits down with you and says, “Well, this will be what the rest of his or her daughter/son’s life will be like?”

Carrie: So, well, first of all it was devastating. My husband said that he could tell by the doctor’s face that something was going on. I was a little bit oblivious to it and actually he did almost pass out. And I can tell that story with his permission. (laughs) It was kind of some levity-

Jim: It was overwhelming.

Carrie: … in the moment but it was. His stomach dropped.

Jim: Wow.

Carrie: It was completely overwhelming.

Jim: Yeah.

Carrie: And I remember going and sitting in the car and just, you just have a certain expectation of what your life is going to look like. Our kids are 18 months apart and then 22 months apart. So we had these two little healthy baby, you know, toddler boys at home.

Jim: Yeah.

Carrie: Life was great and then all of a sudden… And I had some experience with disability. I knew a girl with spina bifida in our church and had grown up with a friend that had down syndrome. But I remember thinking growing up, “I don’t want to be a mom. I don’t want to be a special needs mom.” And just a lot of grief that is actually I’ve learned on going through the journey, it wasn’t just a one… In the beginning I thought it was just one and done and it’s not one and done.

Jim: Yeah. How about you, Sara?

Sara: I actually worked for an orthopedist at the time and he was the one that put my son into physical therapy just ’cause he had an awkward gape and I took a phone call. Um, the receptionist just happened a step away and it was New Year’s Eve, um, 2011, and I took a phone call and they said, “We have a concern with a patient,” and I knew it was the pediatric physical therapist and we only saw adults. And my son was the only one that they we had referred over there.

Jim: Oh.

Sara: And so kind of to stick my head in the sand, I just said, “Okay, well, can I have the patient’s name?” And he said my son’s name. And I said, “Well, I’m his mom,” and he just wouldn’t talk to me. And I could tell in his voice. So I called the doctor that I worked for and he said, “While we actually have another doctor that noticed two days ago because we had him in to a different doctor for some dyslexia.” Um, and they said not to panic and not to get on the internet. So the first thing I did (laughs) was get on the internet. And, but I realized I didn’t know what I was looking for. I didn’t even know how to spell it. And so we waited two months before we were able to get in to see a doctor, um, about two hours away. And she took one look, he got up off the floor, she had him walk a little bit, and then she had a nurse take him out to a play area. And she said, “Well, you have a Duchenne boy and here’s a free camp and we’ll see you back in six months. Just take him home and love him.” Um, there was basically… She said, “There’s nothing you can do but love him.” And so-

Jim: Wow, that sounds so, in many ways right, but empty.

Sara: Mm-hmm. It did.

Jim: I mean, that’s all I can do?

Sara: Right, right. And we had no… I had looked at it because I had gone on the internet and I noticed he was doing something called a Gowers’ maneuvers, how you stand up off the floor and I recognized it immediately.

Jim: It was different than other kids?

Sara: It was different, yes. And it was very specific to this specific diagnosis. And my husband just refused to believe it. So he started fi- he started arguing with the doctor. (laughing) He’s like, “Well, can’t it be this? Well, can’t it be this type of muscular dystrophy?” And I just finally put my hand on his leg and I said, “No, it’s Duchenne.” So, um, we knew we needed to do something. Not… We weren’t under any illusions of, or delusions (laughs) of curing it.

Jim: Right.

Sara: Um, but we knew we needed to… We have loving him down path. We needed to do something, um, to give them a quality of life, if not quantity. So we started flying out east to specialists out there. We were very fortunate we could do that.

Jim: Yeah.

John: Mm-hmm.

Jim: Right. I can’t imagine that feeling of the unknown but known.

Sara: Right.

Jim: Right? It’s a weird comment.

Sara: Yeah.

Jim: Amy, how about how about you that moment when you’re, you know, you adopted your, your kids and you’re going, “Okay, there’s something going on here?” Yours is very different because it’s not physical.

Sara: Right.

Jim: And in that context, I'm so glad that you're part of this because it's, it's a different thing, uh, an observation that trauma has caused mental , um, disconnections for these children. So describe that moment when you and your husband are going, "Okay."

Amy: Right. I didn't have like a minute where that someone handed me a diagnosis. Um, my first aha moment was one that filled me with a lot of guilt and shame because she had a seizure. She was having some kind of X-ray, MRI, I can't remember. And she was in the machine and when they, um, pulled her out of the machine, the technician said, "Okay, mama. Pick her up and hold her like she likes to be held." And I stood there like frozen and my gut just dropped like, "I don't know how she likes to be held." And I felt so much shame like, "What kind of mom doesn't know how to hold her child?" And that… It didn't occur to me at that moment and I did not know in that moment that she had fetal alcohol and, um, attachment issues, and she didn't like to be held.

Jim: Right.

Amy: And, and, and looking back, I can remember she'd push us away and she was one of four and the older siblings where I thought I was always holding her, right? So I, I just… She was one of the fourth one. You need to hold… It's different when it's your fourth one than your first one. (laughs)

Jim: Yeah, yeah.

Amy: So, and, um, but she would go to strangers which is really common in kids with attachment issue, you know, because we're the… They're not, they don't feel safe with us the people-

Jim: That know them.

Amy: … that love them the most, the nurturing caregiver.

Jim: Yeah.

Amy: So for us it was just a journey of, "What's going on with this kid?" And with mental health and invisible disabilities, it's a hard journey to figure out what the actual diagnosis is.

Jim: Yeah. Yours is kind of unraveling as you go-

Amy: Right.

Jim: … over the years.

Amy: Right.

Jim: Because it's not a physical, again, a physical diagnosis.

Amy: Right.

Jim: Let me, let me ask you about the issue of grief. I think, uh, Carrie, you, you started that. You mentioned that briefly about grief. I, you almost feel guilty having grief, you know, like what kind of Christian am I-

Carrie: Mm-hmm.

Jim: … if I can't do this. And, you know, we again, we tasted that with our foster experience but we di- didn't have to live it every day. That could be quite a load. Uh, A, the grief which is normal. So I guess the question is how do you grieve that in a way that's healthy and not adding more shame to whatever shame you might have already?

Carrie: I think one of the things we've talked about and I've learned is there's a lot of shoulds around grief. I should not feel this way or I should feel this way, or my husband should be using this support for me, or he should be grieving at the same rate that I am grieving. And I think that's one thing that I've learned is that we can't live in the shame of the shoulds of grief. I, I know. I had a friend tell me once, "You know, because I haven't lost a child I don't feel like I should be grieving 'cause my child is still alive." But that there's still loss there and I think identifying and naming the loss and what that looks like is really important. And speaking into that, I can remember my son was five years old. We had just gotten out of a week-long hospital stay where we had taken the ambulance to the hospital and then we left the inpatient hospital state and went to a doctor's appointment and found out he needed surgery. And I remember I actually went to the library to return some books that my daughter had kind of like ruined as a toddler, you know, how they (laughs) they just kind of do whatever they want with books. (laughing)

Jim: We have no idea what you're talking about. (laughing)

Carrie: And I walked up to the desk and the lady just, she had no compassion whatsoever. I was going to have to pay full price to replace these books. And, and I remember sitting in the car and I just, I was just crying. And I remember the Lord just said, "Grief is an ongoing part of your journey throughout your child's entire life." And 17 years later, I see that so clearly because recently it's him not getting a driver's license. You know, it's him saying to me, "Mom, why can't I be like my older brothers and play basketball?" And I'm also identifying that he's on his own grieving journey because he's verbal and he can process this with me. I think one of the things that I've learned about grief is that it's important for us to feel those feelings and when the waves of grief come, you know, I sing, I journal, and then also just to turn it over to the Lord repeatedly. And I've found so much comfort in scripture-

Jim: Yeah.

Carrie: … of David and Job and, and being honest with God, but that also takes trust with God.

Jim: It's so true.

John: Well, what a remarkable panel of women we have here today talking about their journey through special needs and, uh, some of the challenges, the difficulties. But God is in it offering comfort. Uh, this is Focus on the Family with Jim Daly and we're talking today with Amy

Brown, and Sara Clime, and Carrie Holt. Together they host a podcast and they've written a terrific book called, *The Other Side of Special: Navigating the Messy, Emotional, Joy-Filled Life of a Special Needs Mom*. And we'll encourage you to stop by our website to get a copy of that great book. The details are at our website.

Jim: Amy, let me ask you about your lilac bush, uh, comparison there because I thought it was really good and explain it to us.

Amy: Well, we had moved into a new house and I was really looking forward to the lilac bushes that were going to, um, bloom in the spring. I love lilacs and I noticed after we'd been in the house a few months that the lilac bushes looked dead. And I got kind of crazy about it. I looked at all my neighbor lilac bushes (laughs) and I, I was like, "Can I get fertilizer?"

Jim: She's so human.

Amy: (laughing) Yeah. Can I put fertilizer? I actually told my husband, "Can we rip them up and buy new ones?" I was so focused on wanting this beautiful flower. And I, I tell that story in the book because with grief like I was so focused on what wasn't there.

Jim: Mm-hmm.

Amy: That's all I could think about, how can I make what's not here be here? And I think it's really common in all special needs families. But with kids with behavioral issues and kids that don't attach to you, there's not a loving bond there, and that's very painful to walk through.

Jim: Oh, yeah.

Amy: And so a lot of times just like my lilacs, I just didn't want to wait. By the way they did eventually bloom. They were just late bloomers. Um, I wanted to take all my focus and energy to make it, make them bloom. And I think grief can sometimes look like that. It can look like trying really hard. It doesn't always look like crying. It looks like anger trying really hard. And so I've had to learn, I am not going to have the relationship with my kids with attachment disorder that I wanted, but I can see what is there. And sometimes it's as simple as the raging didn't happen for two hours. It was only a half hour. (laughing)

Jim: Mm-hmm.

Amy: And sometimes it is something more typical like, "This child gave me a quick hug which is very, very uncommon." But I think when we continue to look at, "I wish it was this, I wish we could just get here." And, and I do think with behavioral issues, because it's kind of a silent suffering you're doing because their behavior is hard, people don't understand what's going on. They think your parenting is terrible that you kind of isolate yourself and say, "If I just try harder, if I just find the right combinations, this is going to be better."

Jim: Yeah.

Amy: And I had to learn to say, "This, these are the small moments of grace and beauty that God has put in my life every day. They may not look like I thought they were going to look, but that…" This has helped me. It's like small sips of grace every day, um, instead of looking at this big destination. I, I just had to learn that to be attentive to those moments-

Jim: Yeah.

Amy: … of what we have.

Jim: You know, uh, uh, as you're describing it for us, it, it sounds like an amplification of what we all experience, but you guys have this magnifying glass on it that makes it bigger and right in your face, whereas we're all learning these lessons, some of us without as much acuity as you're seeing it because it, again, it's so right there for you.

Amy: Mm-hmm.

Jim: It, that's what I'm hearing from your hearts. And, uh, I don't know that we that don't have this situation are as aware of our own shortcomings (laughing) and issues as you will be because it's just right there. Is that fair? Have you noticed that as moms? Do you, do you feel like some of the moms that don't have special needs children like they're, they're kind of back in, at square one with some things? I mean, not to pump you guys up too much but it does require you to be in tune with things that many of us would not be in tune with. Does that resonate with you?

Sara: Yeah. I think it's like a crash course.

Jim: Yeah.

Sara: It's almost, you know, where you're just… It seems like you're flying through life. And I (laughs) I have joked around that my life sometimes seems like that Whac-A-Mole game that you, you know, go?

Jim: Yeah.

Sara: And it's like, I'm like, "Okay, I, I like I got, I got it. I'm gonna pop my head back up and nope, life says, 'No you don't.'" And, but that's just it is it's amplified and I, I think that's a really great word. Um, it's not… Ours isn't worse or better than anybody's, it's just we are in this 24/7.

Jim: Yeah.

Sara: And some of us it's, even in the middle of the night, it's alarms going off or things happening, or, you know, just surgeries. And here we go again. And so, yeah, it, it's-

Jim: Well, and it gets down to some basic things about us as human beings. I mean, at the core… I mean, John, how many programs does this theme come up? Our selfishness. I mean, you look at the context of marriage, whoa, I mean, our selfishness rises. And then parenting our selfishness rises. You guys, you get it beat out of you. I mean, there's-

Sara: That's true. Yeah. (laughs)

Jim: Selfish? I'm not selfish. I'm just trying to survive.

Amy: Right. Mm-hmm.

Jim: And it's just there day after day. But the irony of it, the good thing of it is you learn it. I mean, what God is trying to teach all of us and becoming more selfless. You have to, right?

Carrie: Mm-hmm.

Jim: And what a… It, it's an odd thing to think of that as a blessing.

Sara: Yeah.

Carrie: Yeah.

Jim: Do you feel like, okay, in the big scheme of my spiritual development, this is a great blessing?

Carrie: I think so. It's taken me a long time to get there and there's certainly days I don't feel that way, you know?

Jim: Oh, of course.

Carrie: It's, but I think if I'm completely honest, I know I've, I have said this before. I don't think if we would have had Toby, I would have relied on God the way that I've learned to because as Amy said, I was grasping for control. As soon as I kind of got over the sorrow of his diagnosis, all of a sudden it was like, "Okay, here you go. You have this doctor's appointment, this tour of the NICU, this surgeon to meet with. And I just started controlling everything.

Jim: Yeah.

Carrie: And so if the Lord hadn't allowed this in my life, it would be a really different person. It might have been another trial that He (laughing) allowed to happen, but-

Jim: It, it just sounds… I mean, again, I, I think it's an amazing thing. It's like the Lord to turn everything upside down.

Carrie: Yeah.

Jim: Those of us that don't struggle with the things you're struggling with, you know, "Wow aren't we happy?" But we're not learning the lessons that we should learn. And then in God's economy, you're so far out in front of some people, maybe most people. Let's end with something, and I want to keep the discussion going so we'll come back tomorrow and talk with you again because there's so much more to uncover. But I want to, I want to end for the listener, for the viewer, um, in this space of hope, you know, we're right here on earth, everything. Our existence is about here and now. It's hard for us to think of heaven and eternity, and no more tears, no more sorrow. How does the idea of thinking to the future for your children, where they are healed, they are complete, they are with the Lord, they are forever going to be okay. Do you think about that?

Amy: You know, I've had my older children say, "I want to know what their siblings are like without the trauma-

Jim: Yeah.

Amy: … because their behavior is so difficult and pushes them away. So, yeah-

Jim: That's mature of them to think that.

Amy: Right. Like we are ready to see this person whole without this brain that's been totally changed by, um-

Jim: Trauma.

Amy: Trauma and alcohol, yeah.

Jim: That's… How about for you, Sara?

Sara: I think in our situation because we, we have that, that terminal word that is always over our head, that I know short of something catastrophic, I will bury my child. And so it took me a long time to realize… It was almost like (laughs) God was like, "But he's not, he's not yours. He's on loan, he's mine."

Jim: (laughing)

Sara: "And he's exactly the way I want him, and I will get him back and have him exactly the way I want him." So that took a lot of time to do but, um, or to figure that out but I, you know, I look to Heaven and I think kind of almost what you said your children are. I, I can't wait to see how he is, but I just think his heart is exactly the way his heart needs to be right now.

Jim: Yeah.

Sara: We don't have the behavioral issues. In fact I have the opposite. It's always, "I love you, I love you, I love you," all day long. So it's, it's different. But, yeah, when you have that terminal diagnosis, Heaven is definitely something to look forward to.

Jim: Yeah, yeah. That's so good. Yeah, jump in.

Carrie: Yeah, I think for me, I just think often of that verse that talks about our light and momentary affliction. And it doesn't feel light (laughs) or momentary at times. But my husband said one time, "I can't wait to throw a football with Toby in heaven-"

Jim: Wow

Carrie: "… and see him run." And, and it… I think the hope, the way that hope encourages me is I know that whatever we're going through on a daily basis it is just temporary, it is short in light of what God has for us in eternity and that makes it worth it.

Jim: Yeah. And again, that hope becomes so tangible for you, whereas others, it still may be murky or foggy as you said, Sara.

Sara: Mm-hmm.

Jim: For those of us that aren't in that position to hope for Heaven. I mean, it, it sounds odd. Listen, uh, next time I want to kick off so I'll give you a few minutes to think about it, but faith challenges, you know, where you were struggling with that hope. "Lord, why have you done this?" Um, we could benefit from hearing from that realness. Thank you for being with us today. We'll come back next time and we'll keep the conversation going. Can we do it?

Carrie: Yes.

Amy: Thank you.

Carrie: Thank you.

Jim: Man, I, I'm encouraged (laughs) and I hope you are too. And again there's not a lot of content in this space for, uh, you know, roughly 133% of the population. Over 40 million people that are dealing with a special needs child. That's a big number and, uh, with your church this might be something you'd want to get copies of their book to have available in the church library, or other things like that. You may not be dealing with it, uh, but you may know someone and for that reason get a hold of us, let us get this, uh, book into your hands either for you and your family, or for someone you know. And if we can do it this way, uh, you know, make a gift of any amount and we'll send you a copy of the book as our way of saying thank you for being part of the ministry. It's a win-win-win. If you can't afford it that's not what we're about, so we'll get it out to you with a smile on our face, uh, just so you have this resource in your hands. And we'll trust others will cover the cost of that.

John: Mm-hmm. Yeah, donate if you can and I request this book, *The Other Side of Special: Navigating the Messy, Emotional, Joy-Filled Life of a Special Needs Mom*. Our number is 800, the letter A and the word FAMILY, 800-232-6459. Or stop by focusonthefamily.com/broadcast for all the details. And if today's conversation has, uh, really resonated with you because you're struggling and you don't have somebody to turn to, uh, give us a call. We have caring Christian counselors here. Uh, we'd be more than happy to set up a phone consultation with you. Uh, it's free and, uh, again, help is a phone call away. Our number is 800, the letter A and the word, FAMILY. On behalf of the entire team, thanks for joining us today for Focus on the Family with Jim Daly. I'm John Fuller inviting you back next time as we continue the conversation and once again help you and your family thrive in Christ.