

Season 4 | Episode # 17

Chronic Hope: Parenting a Child with a Chronic Disease

Bonnie O'Neil

Crystal Keating:

I'm Crystal Keating and you're listening to the Joni and Friends Ministry Podcast. Each week we're bringing you encouraging conversations about finding hope through hardship... and sharing practical ways that you can include people with disability in your church and community.

If you're a mom or dad raising a child with a chronic illness, you may be thirsting for practical wisdom regarding how to manage the emotional stress of caring for your loved one. Bonnie O'Neil knows the special joy and heartache that comes with parenting a son with type 1 diabetes. She joins us today to share a vision for navigating chronic disease with strength, resilience, and loving self-sacrifice that God gives.

Bonnie reveals the mistakes and missteps that led her to Christ-centered principles and attitudes for overcoming the daily stressors of a chronic condition. Welcome to the podcast, Bonnie.

Bonnie O'Neil:

Thank you so much, Crystal, for having me. I'm so excited to be here today and to share my story with you and to have this small partnership with the Joni and Friends ministry.

Crystal Keating:

Amen. We are too. So Bonnie, can you help us understand the severity of type 1 diabetes? How does type 1 diabetes affect your son's daily life?

Bonnie O'Neil:

Yeah, sure. I mean, it's important to know that there are actually two types of diabetes, cleverly named type 1 and type 2. And the majority of people who have diabetes actually have type 2 diabetes. Type 1 is an autoimmune disease. It was formally referred to as juvenile diabetes. But it's really a misnomer because while it most often appears in childhood, it can appear well into adulthood. I think the oldest person I've heard of to be diagnosed with it was 70 years old and you don't outgrow it.

There's not a cure. Insulin is not a cure, but it keeps people alive with it. So, what happens in type 1 diabetes is that the body doesn't make insulin or glucagon and a few other hormones. And so, these are the things that keep your blood sugar level. So, in someone without diabetes, they can eat what they want.

They can exercise as they want, and their blood sugar stays stable. In someone who has type 1 diabetes, there's no insulin to bring the blood sugar down after they've eaten. There's no glucagon to raise their blood sugar after exercise, or if they have too much insulin in their bloodstream. So, I've heard it described by a physician by an endocrinologist as the only disease out there where the primary caregiver is responsible for multiple life-saving decisions on a daily basis.

Oh, my goodness. And it's, it's been estimated that there can be as many as 180, 180 health-related decisions every day that a person with diabetes has to make about what they're eating, about what exercise they're doing, about their sleep, about how much fat is in the food they're eating. So, when you have a young child with type 1 diabetes, it is the caregiver, the parent who is making all of those decisions. And then gradually that gets transitioned over to the child as they grow into adolescents and adulthood. So, it affects every part of, of a person's life living with diabetes.

Crystal Keating:

Mmm, absolutely. So, for maybe families who aren't thinking about what their child is eating and drinking as strategically as you had to, what would happen if your son ate or drank something that wasn't right or had exercised, and what's happening? Are they fainting? What are they experiencing when things aren't regulated well?

Bonnie O'Neil:

In the short timeframe, if their blood sugar goes too low, they internally feel what they will describe as shaky. Mm-hmm. I don't have any other words for it because I have never experienced it personally. But they will say that they feel shaky, and they have an urgent need for glucose to elevate their blood sugar. You know, there's sort of a prescribed amount to take whether that's in glucose tablets or in a juice box.

But it really depends on how low that blood sugar is going, whether they've been exercising beforehand, or whether they already have insulin in their system because they just took a lot of insulin for a meal. So even that correction, it's very difficult to, to know how to make. And then in the long term, if your blood sugar stays high for too long, that's where those long-term complications come about, like to the organs and the eyes and the limbs and all of the things that we don't really wanna think about.

So, there's this constant battle that has to be weighed between the short-term need and the long-term need. So, you can't just let the blood sugars rise a little bit higher to avoid those lows because in the long term, that's not in the best interest of the human body. So, you're always thinking.

You're always thinking. Yeah. Always thinking. And then as they're growing, you know, they're going to need more insulin and you never know really when they're, when they're growing. I mean, you can kind of see it after the fact, but not during. And you know, if they're sick, that's going to change how well their body uses the insulin that you give it.

So, they might need more insulin if they have a virus. And so, all of that is just, judgment calls that the parent has to make, because there's no real prescription for that. You leave your, your doctor with suggestions and settings for what they should take as far as insulin to carbohydrate ratios or how much background insulin they need for every day.

But then there's a lot of judgment that you have to make yourself each and every day. Just because it's, it's bedtime and the house is quiet, it doesn't mean that the body is cooperating. And so, parents who have, especially a young child, who's very active, will routinely be setting their alarm throughout the night to get up and check their child's blood sugar. And if they can't get it back in, in a safe zone, then that means just setting your alarm for another 20 minutes or 30 minutes and continue to check throughout the night until you feel like they're in a safe place for you to go off to sleep.

Crystal Keating:

Wow. Wow. So that's affecting your regular sleep and we know when there's lack of sleep, the implications of that. Yeah. Bonnie, did you or your family have any history of diabetes or any concerning health issues that you were aware of?

Bonnie O'Neil:

Yeah, we did. I knew more than I cared to know about type 1 diabetes or T 1 D as we call it when my son, Austin was diagnosed. It had deeply impacted my family of origin. I really lived in fear of it throughout my whole life. So, I was born, really to replace the son that my parents had lost to type 1 diabetes when he was only eight years old. Wow. So, my brother Johnny had gotten a stomach virus and because he had undiagnosed type 1 diabetes, his body went into DKA or diabetic ketoacidosis.

And this is when the body is in such distress because of extremely elevated blood sugars that the organs start shutting down. And so, by the time that my parents got him to the hospital, he was already in a diabetic coma, and he died three days later. If you can even imagine my mom, then had to return to that same hospital a week later to deliver my sister Betsy.

So, they had this newborn. They had my sister, Barb, who was six, and are grieving, you know, the loss of their son, Johnny, who was, who was eight. And then my sister Barb actually developed type 1 when she was 16 years old. My two siblings had it, so my sister Betsy and I just always lived in fear that we were going to get it. But I was born 18 months after Johnny's death.

So, it was just something that always was a kind of a shadow in my life. I, in some ways, felt that I had to live up to this life he didn't get to have, that because I, in some ways, weirdly as, as only a child can do, you know, I kind of replaced him and got to live the life that he didn't have. But we lived in fear of it. I remember when I was 25, that I just breathed this sigh of relief on my birthday. I thought, well, I'm too old now to get juvenile diabetes, you know, cause that's what we called it back then. But when I had my first child, I remember asking my pediatrician, because the fear came back then.

Right. Because then I had a child and I was like, what kind of tests do I do to make sure that my child doesn't have type 1? And he said, well, you'll know the signs. You'll see them, frequent urination, and intense thirst. And when you see them, then you come to me.

We can't do a test. It just, it comes on acutely. There was no test at that time. There are some antibody tests you can test for now to see if someone has a propensity to get it. But those tests didn't exist back then. And so, when in my second son, Austin, when I started to notice those signs in him, I just tested him at home in our powder room, and the strip that, that I dipped in his urine turned bright crimson, and I knew that he had type 1 diabetes.

Crystal Keating:

Well, let's talk about the impact of your son's diagnosis on your relationship with Jesus. Bonnie, we've heard from many others that a difficult diagnosis can leave you feeling estranged or alienated from God.

And you're concerned for your son. You're thinking about your history. What were the first two years like for you after the diagnosis and how did you move forward? How did you find hope and reconnect with God?

Bonnie O'Neil:

Yeah, that's such a great and important and big part of my story that really, in some ways led me to write my book, *Chronic Hope*.

It's important to note though, in my own particular life, Austin's diagnosis with type 1 was really like the final blow in a five-year time period, a five-year season of medical testing in our family, a time where we lived in three different states. My husband had three different companies that he worked for.

And one of the things that happened just before Austin's diagnosis was that my mother-in-law had come to live with us, was diagnosed with an extremely rare form of cancer. I cared for her and then she died of that. So, I was in a very emotionally and physically exhausted state. When Austin was diagnosed, my husband had already accepted another new job and was living down in Pennsylvania.

We were in Connecticut; we were apart for nine months. So, when Austin was diagnosed, this was the week before we moved to Pennsylvania from Connecticut. And so, when we were in Pennsylvania, probably about the second week after his diagnosis, I remember standing in my upstairs bathroom in Pennsylvania and just hearing this voice that I know now was the voice of the enemy that just said, so this is the good Christian life. Mmm. And I just bought it hook, line, and sinker. And I remember just looking in the mirror and saying, go away God, go away. If this is the best you can do, I don't want anything to do with you.

This has been the worst five years of my life. And all I asked for, all my friends were praying for was that this move would go smoothly, that we wouldn't have another crisis like we had had the

other two moves and it would go well. So, for me, this wasn't just, you know, an inconvenience or that this was an awful disease.

This was my family's disease. This was the reason why I was born. And so, I was bringing it into the next generation through me. So, I went into an existential crisis and spiral, and so it was just really all kinds of ugly for quite a while. But, but God is so good, you know? And so about six months into it, after I had had lots of time of just being angry, he was such a gentleman, you know.

I said go away. And he did. I mean, theologically, I know he didn't, right? Right, right. But it got really quiet in my head and I, I have never known a time in my life other than then when I couldn't sense his presence with me. And it just undid me. Oh yeah. But terrifying.

Yeah, it's just it's it was so dark and quiet inside. So that went on for about six months and then I really entered into just a, a time of repentance and again like a, like a, a gentleman, he, he stayed. He kept that veil thick. That's all I can say if he just kept the veil thick because I wanted to return to him in exactly the same state I was that caused me to say, go away. If this is the best you can do for me go away. And I still had lessons to learn. I still had to learn, is God good all the time, even when life doesn't feel really very good. And I, I had to learn that. I had to learn that God loves my children even more than I ever can or will love them.

And I hadn't learned that yet. And I also had to learn the, the big wrestle was will I surrender my will to God? And this was really the crux of it is - will I follow you regardless of how my life is going? But you can have my will and I surrender it to you. And sort of in, in the language of any of those stages of the Christian spiritual journey, whether you're looking at Theresa of Avala or in a book that I read as I was training to be a spiritual director, *The Critical Journey* by Janet Hagberg.

There's this time in one's life, if, if we really want to walk with the Lord, he will allow a season that you can refer to as a wall, where you are just pitting your will against God's and where you have to decide, am I willing to surrender and let God direct my life. And so, I had to come to those things.

So, it really was another 18 months of wrestling through all of that, and God really developing some, some new theology within me, before I think I came to the end of my wrestling period with the Lord. And really the, what unlocked everything for me, it was prayer. It was the beautiful spirit-filled prayer of some friends who came alongside me and just in prayer ministry, just prayed for me and prayed for release.

And that really unlocked everything at the end.

Crystal Keating:

Thank you so much for being so honest about that because regardless if you're a parent with a child with a disability, or you're going through an unwanted divorce, or you're going through

infertility or singleness or cancer or a new disability, we all come to God with good and right desires and hopeful expectations of what our life could be.

And we all know that that is in heaven. But there is a point where our life and what we pictured is really different than what God is allowing for our good. But there comes a time where we must wrestle with him. And I, I really appreciate that you even talk about long it takes for God to teach those things and sink them deep into your heart so that, you know, without a doubt, God is good, and this is hard and it's not what I would've chosen, but he is real.

He is faithful and he is with me. And even just the support of your friends. Mm-hmm, I know we've heard from some families affected by disability. They really wish their church understood that kind of faith crisis better. Mm-hmm. What was your experience like with the local church? It sounded like you moved a bunch of times and whenever we don't have that kind of consistency in life, it's really hard to build community. So, what was your experience like with the church at that point? And maybe what would you have liked to see, or even what should they know about someone who's going through the kind of faith crisis that you went through?

Bonnie O'Neil:

Yeah, I mean, in my own experience, we moved house literally the week after my son's diagnosis. So, in the earliest, most broken, raw point of my story, we were church shopping. So, you know, I had to, I had to put on my, my sweetest smile and kind of do the things to not look like you're just such a mess inside. But I definitely was a, a stewpot inside, ready to boil over.

I think, you know, churches typically, are very well equipped to minister to people on the early end of their spiritual journey, whether it's the evangelism or discipleship. But if you get to that stage that I described as the wall, where usually it's brought on by some sort of crisis, it looks like you are really abandoning your faith.

Right. But for many people, that's not really what's happening. For many people, it's that they're trying to figure out how can God be good when my life is such a mess. Well said. And they, they want to believe it. I think, I think I wanted to believe it. But my paradigm had just been like completely upended and so I think one of the things that has helped me so much is spiritual direction.

It's newer in the Protestant churches. But it is such a beautiful gift to begin working with a spiritual director. It's a contemplative practice. So, it helps you really see where God is at work in your life, through the questions that a spiritual director will ask you and, and help you go deeper into those painful places and examine them with God, revisit them with God.

That's such a beautiful way of bringing healing to those deep hurt places. I know some churches may have counselors as part of their staff. But spiritual directors can be extremely helpful in that process. I think also just having that awareness, like really understanding that if you're going through a hard time, just because somebody says things are okay, doesn't really mean they're okay.

It just means that if they begin to talk about it in that after-church setting, they will fall apart. Yeah. You know, kind of just having some folks on staff who can help in that way, who can offer, who can ask, what can we do? In my case, the church where we did settle in, I couldn't take my kids to vacation Bible school because it was more like a, a, a long camp day. It wasn't just like two or three hours in the morning. It, it went for about six hours, and I couldn't leave my son for that long. And so, we didn't have that experience. And I was too new to ask, what can we do to make this work out?

And they didn't ask me what can we do to make this work out. And so, I think sometimes just understanding that and, and being proactive as the church and saying, how can we make this work? I know at the church that we were a part of when we lived in south Florida, there was a boy there who had severe needs, extreme needs, and the church felt compelled enough that we need to love every member of our church, that they just hired somebody every Sunday to come and care for that boy, so mom and dad and the rest of the family could go to church. And I just think that was beautiful.

Crystal Keating:

Mm-hmmm. Those are some great suggestions and I think you know; may God give us watchful eyes because for those of us who are planning those programs, we're focused on the curriculum and keeping kids safe and kind of the basics, you know? Right, right, right. It's like, oh good, everyone's still alive. You know? And so, it, it really takes the holy spirit and compassion to look past that and say, wow, I wonder why Bonnie isn't participating. I wonder if there's something we could do that sort of tweaks our normal routine to get her involved, maybe even just for an hour or two and I think that goes a long way.

We always say that you know, people who say, I wanna start a disability ministry and it's like, well, who do you know in your church that is a family with special needs? What do they need? Have you talked to them? Have you had conversations? That's a great place to start to build a relationship and it shows that care. Thank you for saying that.

Now, Austin wasn't your only child. You, you had three children. So how did you balance the demands of being a mom to all of your children while you managed unpredictable medical needs of a son with diabetes?

Bonnie O'Neil:

Yeah. Well, I think one of the things I say all the time like to, to friends as I'm counseling them as they are beginning in the stage of raising a child with a chronic illness or things like I wrote about in *Chronic Hope*, just be good to yourself. That, that became something I said to myself over and over again.

If I had a sleepless night, I had to be good to myself the next day and know that this was not a normal day, and something had to go. And if I didn't feel like exercising that day, then I didn't. If I needed the kids to buy lunch at school, rather than making it, then they would. And generally, I wanted to participate in my kids' activities, if I couldn't, then I didn't.

I know that for some people, their lives are extremely complicated and it's not very easy to be good to yourself. But maybe there's one thing that you could do that's different, that's one thing where you at least mark the day that, okay, I just went through a really awful night. And maybe it's just reminding yourself that this is the most important work that God's ever going to call me to do and I'm doing holy work in raising this child.

Even if that's all that you can do, that's important to remember and to start the day saying, I'm on holy ground and I did an important work during the course of the night in keeping my child safe. I feel like letting go of guilt is really, really important, that the guilt not just, you know, cuz we'll, we'll guilt ourselves that in some cases, oh, it's my DNA. This is how my child ended up this way or I wasn't careful enough and there was an accident, and this is why my child is this way or even the, the guilt of, I don't have the disease or the disability. I have no business complaining, but we have, we, we have feelings too, right?

And we have grief that we bear, and this was not the life that we expected for our children let alone for us. And so, all of those feelings just by pretending we don't have any right to them, it doesn't make them go away. So, it's really important to give yourself permission to feel what you feel.

There's nothing wrong with feelings. It's how we attend to them that matters. And so then, you know, notice what you're feeling and, and name it and, and attend to it. And just not being afraid to go deeper in like the only way to get out of the darkness of some of these feelings is to go deeper in, look around.

Do it with a spiritual director, a godly friend. Invite the holy spirit into those dark places with you and revisit them with him. So, I think it's also really important, now I'm not saying I always did this well, but to attend to your relationship with your spouse is really important.

Crystal Keating:
I'm so glad you brought that up. That is right. Good.

Bonnie O'Neil:
We can have so much anger and bitterness over the fact that our spouse is not grieving in the same way that we grieve, that they're not suffering in the same way that we suffer or caring for the child in the same way that we care for them. Really at the end of the day, what that comes down to is there's a choice to make. You know, the more we hold onto and bundle all of that stuff together, it just becomes a big snowball of a boulder that gets in the way between us and our spouse.

So, we can either choose to forgive or let that big boulder of bitterness just stay and keep getting bigger and bigger, but there is no third way. There's no third way. So, I think that's just a really important thing for, for all of us who are married to pay attention to and pay attention to the needs of our other kids, too.

With my oldest son, I realized I needed to take him on what I call dates. He was eight when my son Austin was diagnosed. And so, for him, he remembered life being very different beforehand and suddenly all of mama's attention is to his younger brother. Mm-hmm.

And I could just see that playing out in different ways in his life. So, I would just grab him on an occasional Saturday, and we would go out and we would eat ice cream or go and, and it's a toy store or something and just do something the two of us, because he was missing that time and had a harder time understanding it than his little sister who was three, who really didn't have much of memory of things before.

So those were some of the things I did. And I also got the support that I could through in my case, it was JDRF the Juvenile Diabetes Research Foundation. So, I found some friends who could just really support me and understand what I was going through and that was extremely important.

Crystal Keating:

That is so good and that also, like, you know, we talked about praying for the church that we'd have a watchful eye for, to be in tune with their children to notice some of those differences and to have fun with it. It's like, yeah. You know, restoring joy in an atmosphere that can be often stressful.

To do those things that kids love. I mean, just even seeing them enjoy themselves often brings a lot of happiness to a parent. Right. Mm-hmm.

Bonnie O'Neil:

Exactly, exactly. So good. Yeah. Yeah.

Crystal Keating:

Well, Bonnie, what were some of the adjustments you made through the years to better care for your son and your own spiritual well-being?

You talked about you know, joining with a spiritual director and your friends praying for you. Yeah. What were some of the other things that really helped to solidify what God was doing in your heart to keep you trusting and loving him?

Bonnie O'Neil:

You know, it, it's, it's funny. I joked after publishing *Chronic Hope* that I could have just as easily called it chronic control because it really was learning to let go of control. To your point that you mentioned earlier, I mean, this could be whether you're letting go of control over your career or over this wasn't what I was expecting with my child.

There's so many things that we need to learn, right, about letting go of control. I learned that I really had to do a lot more emptying of myself. When you're raising a child with a complex medical disorder, there are all kinds of things that are going to go not according to plan, whether it's the call to the insurance company or to the doctor or being on hold for 45 minutes and then

the call is dropped, and you have to start all over again. And going to the local pharmacy and they don't have your medicine. And learning that the medicine you've always used now your insurance is making you use a different one, all kinds of things. And it's just this, I think learning deeper patience, learning greater love.

Just emptying myself of myself and in putting my child first. I think we tend to do this as parents. But there's just so many more opportunities to practice that when your child has a complex disorder. Ultimately, I think I just became a better parent, you know, in, in learning flexibility of with my own plans and being interrupted all of the time.

I think in that whole process of learning to let go of things, learning to let go of control, of anger, of fear, of disappointment, of loneliness, all of those things that we have to deal with in the early days post-diagnosis, and that we find ourselves continuing to revisit, like being farther out in our journey, but they do keep popping up.

Every time that we learn to let go of a little more, I think, we hold onto faith a little bit deeper. And we learn to walk a little bit more closely to the Lord every time we let go of, of any of those things. And in this walk of raising a child with a chronic condition, we have countless opportunities to choose love over fear and gratitude over complaining and kindness, over anger and encouragement over criticism. We, we, we learn that how we teach our kids is just as important as what we teach them. And how we teach needs to be with love and with grace and with courage and, and with boldness.

So, I think those are some of the things that I learned that I didn't practice a hundred percent, but that I, that I learned and wanted to do better. Mm-hmm. Put it that way.

Crystal Keating:

Well, and it sounds like God met you in those places to walk with you through them and it's not like you arrived and thought, okay, good. I got this now it's like, Lord you're gonna meet me each day and help me as I rely on you.

Bonnie O'Neil:

Yeah. Yeah. It's so true.

Crystal Keating:

Yeah. And God is good like that. And I know Bonnie, we probably have some weary parents who are listening today or who are raising children with chronic conditions. So, would you like to share some final words of advice and encouragement for them?

Bonnie O'Neil:

I know I've already said this, but really, you need to have the permission to feel what you feel and just attend to what you're feeling. Don't just sit with it in a dark place. Don't deny yourself the feelings that you have or feel guilty for them. Just go deeper with the Lord with them. Find a spiritual director or a counselor or a friend who can walk with you on that journey.

And just don't ever give up. If you feel like maybe you've given up with God, or you feel like you might, don't let the keep you in a place of guilt and shame about that. Just remember that this is not the end of your story. You are in that fiery trial. Yeah. You know, that, that, Peter talks about in his letter, I just wanna read part of first Peter 1:6-7, "Now for a little while, if necessary," which means that it's inevitable.

The language in that means that it's inevitable. It's in the natural order of things. So that's what it means that it's necessary. "If necessary, you have been distressed by various trials, that the proof of your faith being more precious than gold, which is perishable, even though tested by fire, it may be found to result in praise and glory and honor at the revelation of Jesus Christ."

And I just wanna say to any, weary mama and daddy out there, this is not the end of your story. Even if you feel like you can't go on anymore or that God has let you down, or that, how could he love you again after you've turned your back on him? You are still walking through this fiery trial. It's not the end.

Keep pressing in, keep pressing on, that your faith, it will, it will be found for the praise and glory and honor of Jesus Christ.

Crystal Keating:

Oh, that is so, so comforting. And it just reminds me that God will not let us go.

He won't let us go. And Bonnie, thank you so much for the encouragement that you brought to us today and for your vulnerability. I just enjoyed speaking with you so much. Thanks for joining us on the podcast.

Bonnie O'Neil:

You are so welcome and thank you for everything that you do at Johnny and Friends. The ministry is so wonderful and such a blessing to so many.

Crystal Keating:

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