

Season 4 | Episode # 25

## **How to Help Relieve Exhaustion and Isolation for Families Living with Disability**

### **Jennifer Evans**

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#### **Part 2**

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.

Did you know families living with disability consistently name respite care as their top unmet need? Caregivers in these families long for breaks from the 24/7 responsibilities of caring for their loved ones.

A recent Joni and Friends survey identified respite care or the provision of short-term relief for primary caregivers as the number one unmet need among special needs families. Many parents and caregivers who lack respite care options have to just keep going despite exhaustion, isolation, and discouragement.

Some families have expressed that when raising a child living with disability, the demands are so great, it often causes a mom or dad to feel overwhelmed and consumed. So today, I'm joined by disability advocate Jennifer Evans, to talk about the gift of respite and how providing this type of rest can be the gateway for families to experience the love and grace of Jesus Christ.

Jennifer Evans:

Hello Crystal, thank you so much for having me and I'm so grateful to share about this topic cuz I'm very passionate about respite and helping special needs families.

Crystal Keating:

So happy to have you on this show. You've been involved with Joni and Friends for many years. So, let's start out by defining respite. What is it?

Jennifer Evans:

Yeah, so respite can be just as simple as in-home care, like babysitting. It could be in a small group meeting at a park. It could be a structured event at a church or facility. And really it just gives parents of children with disabilities a break from their day-to-day caregiving responsibilities.

And it also gives children or adults with disabilities, either one can participate, a chance to build new relationships, which you know, is critical for all of us.

Crystal Keating:

Oh yeah. I mean, we've talked so many times through the years on how families living with disability feel so isolated. And so, this is a great opportunity not just to find rest, but to build relationships with other parents of children with disability.

So, let's set the scene for respite. Jennifer, what kinds of challenges are parents of children or teenagers with disabilities facing? We just named a couple, but let's talk about that.

Jennifer Evans:

Yeah. So, you mentioned that Joni and Friends report. So, there was a 2020 Needs Assessment Report that Joni and Friends did. And there's an estimated 44 million American adults who serve as unpaid, informal family caregivers.

It's big. And these family caregivers, they experience chronic stress, depression, social isolation. As you said, it's a 24/7 job. And what I've found with working with these families is, oftentimes they're not invited to social functions and told their child doesn't fit into typical programs.

They also experience grief with dashed expectations. You know, that once they realize, okay, my child's not gonna be able to go to college or get married. And I've seen that oftentimes parents are on a different cycle of grief. So, you know, sometimes one parent's feeling good. Sometimes the other parent is in a different place.

And so, marriages are really strained, medical bills are high, and a lot of families have been asked to leave churches because churches said they're not equipped, or they don't have special needs as their focus. So, these families are struggling. They're struggling.

Crystal Keating:

Wow. And this is the perfect opportunity for the church to step up and step in and meet a need that God meets for us. That he actually cares for us, that he sees us in our distress and wants to help and comfort us and bring us together with other people, just like the body of Christ.

So, what do you actually do at a respite event? What are some of the activities that take place at something like this?

Jennifer Evans:

Yeah, so the respites I've been involved with through Joni and Friends in Arizona and some of the partner churches that they've been equipping, it's typically like a three-hour event and it provides children with disabilities and their typical siblings can get dropped off too.

And so, they're doing, arts and crafts. They're doing recreational activities. Sometimes there's you know, traditional and adaptive sports activities. There's story time, music, dancing. There's always food. The goal is to really allow these children and their siblings to have a great time so

when their parents come back to get them, you know, they also get more respite cuz maybe their child's sleeping on the way home.

You know, it gives the parents a chance to go out and, you know, they can go run errands. A lot of 'em have gone to Costco. They could go on a lunch date and just have some time off. But then also each person that comes to respite, they get paired up with a one-on-one volunteer buddy.

And so, they get that relationship building with a buddy. So, we know that they're safe and cared about. And then they're building relationships with peers and other people with disabilities. So, I mean, so many times the people with disabilities are isolated at home or they're just with their parents or caregiver. So, this opens them up to new relationships.

Crystal Keating:

And that's transformative too because when you're interacting with the same people all the time, it's easy to get in, kind of a rut. And so, God's blessing of multiple people in various relationships helps us to bring joy to life, but also to change and to know him better.

And I think that's what I love about our respite events. It's not just providing rest. It really is a doorway to experiencing the love of God. It's getting families reconnected. You've been serving with Joni and Friends as a disability advocate through the years, especially connecting with local churches like we just said, in Arizona specifically to provide support for families living with disabilities. What kinds of benefits are you seeing as these families come each month? I bet you have a couple awesome stories or examples of families that came for one thing and got so much more.

Jennifer Evans:

Yeah, I would say community is the number one thing.

I think this is what so many of these families are lacking, especially if they're not involved in a local body because sometimes it's just too hard to get there. And there's a family that actually found out about respite on Facebook, and they're not Christians. But they really needed support and they just decided to show up.

So, it's really, you know, a great way to get new people in the door too, that may not know Jesus. So, the family just started showing up to every monthly respite and they started building relationships with other parents. At first, we would encourage the parents to just leave and go out, go to lunch or do whatever they want.

But then we found that they were starting to wanna hang out with other parents in the coffee shop that was right by the respite event and build relationships. They have a like-minded situation and so I think having those connections and building relationships have been such a benefit for the parents.

And then we found that this family decided that they wanted to go to Family Retreat and the kids started reading the Bible and so it's really a way to also help show the love of Christ. But

then sometimes there's a point where you build that relationship where you can actually give them a Bible and start speaking to them about the Lord.

Crystal Keating:

Amen. And you've already laid the groundwork for displaying love and kindness and care, and grace and truth in the gospel in action, even before you get to the message, which I think is so important. I mean the last few conversations we've had with Dr. Rosaria Butterfield about hospitality speak exactly to that, that these relationships help us to adorn the gospel.

So, it's not just getting a message. It's actually seeing it lived out in community, which is really powerful. So maybe we could talk about the benefits to the child with a disability and their siblings too, along with respite volunteers and the church.

I mean, everybody is getting a different aspect of benefit and challenge and blessing and seeing God work.

Jennifer Evans:

Yeah, definitely. One of the things I love about Joni and Friends is they're not only focused on serving people with disabilities but allowing them to find their place and use their gifts in the body of Christ.

And so, at respite events, we like to give people, if they're able, a job or leadership ability or a volunteer role that maybe they're helping organize name tags or helping with setup or breakdown. And this really gives them a sense of purpose. You know, cuz we all need purpose and as you know, when we go out and serve, we always feel better.

That's definitely been something that I've seen that I've loved at respite. I feel more blessed than the person that I'm serving.

Crystal Keating:

Yes. Isn't that so true?

Jennifer Evans:

Yeah, and it will really actually end up changing the culture of a church when you really start to not only serve people with disabilities but welcome them to find their place in the body of Christ and they have a seat at the table. I've seen churches transform. And it becomes just a beautiful thing when everyone's accepted and welcomed.

Crystal Keating:

I love that God works in so many wonderful ways. And so, when we think about tools maybe to help volunteers, like maybe we have people listening who are saying, wow, I'd really like to be involved with something like respite. I don't know what to do. I don't know where to start. What are some of the ways volunteers are prepared and equipped for the actual day of the respite event?

Jennifer Evans:

Yeah. So, if someone's interested in serving at respite, but they're nervous or feel unqualified, I just encourage you not to worry. You don't have to be an expert. I'm certainly not. And what I've found is like serving people with special needs it's really about developing a relationship.

Everyone is different and unique and sometimes it takes spending time with them to learn that or finding out from their parents. Hey, what types of things do they like? And so, it's really not about having a special skill or a background in it. It's really about our hearts. It's not about the numbers. It's about coming alongside one child, one family at a time.

And I also wanted to mention in regards to the typical siblings, there's this term called glass children where they feel kind of like they're not seen because parents are usually so focused on their child with a disability. They often unintentionally neglect that child that's typical.

So, we also encourage our volunteers to love up on the typical siblings. They're just as important. So, if you feel more comfortable spending time with a typical child because that's easier for you, you can do that at first. So, there's lots of different ways to serve at respite and I just wanna encourage anybody that anybody can do it if you care and you're willing.

Crystal Keating:

That's so good. Thank you for mentioning the typical siblings too. I think that's really important to be mindful of and to know, you don't have to know everything about every disability. You really just have to have the heart. As you said, it's about a relationship and building a friendship more so than a program. And to me that puts the stress much lower and the desire to build something and to be authentic with people like that just elevates that aspect of it, which is what God is really trying to do. He's after our hearts.

Jennifer Evans:

God will equip anyone if we're willing to invest the time.

Crystal Keating:

That's good. I'm encouraged by that. So, Jennifer, what are some of the first steps a church or community can take as they think about providing respite for families living with disability?

Jennifer Evans:

One of the things I've seen churches do successfully is give a survey to their congregation and really first find out who in the church has special needs because there's visible disabilities. But there's often unseen disabilities that we're not aware of. And so, I've seen churches that have done this have found out a lot more things about their congregation and families and so, just to be able to identify who in your church has needs and start meeting with them. Have coffee and ask what they're going through.

That's just even a start for them to know that they're seen. Then you wanna make a step to help them and really find out their needs. There's also been a special needs director who I just think so highly of. Her name's Missy Farrington from Highlands Church in Scottsdale. And she once

shared with me and other church leaders at a special needs network meeting in Arizona, that the number one respite is for parents that have children with disabilities, to be able to go to church on Sunday and be fed the word of God while their child is not only being taken care of but learning about Jesus.

Crystal Keating:  
Amen.

Jennifer Evans:  
And being cared about. So, I think that it's important for churches to first evaluate if they're able to meet the needs of families with special needs on Sunday before they really embark on maybe starting a respite. But at the same time, I've seen churches do it the other way around and God can work anyway. Some churches feel more comfortable starting with a respite. But we just wanna make sure that if churches do provide respite, that they have the ability to serve families on Sunday because if they get turned away because they're not able to be served, they could look at that as a rejection from God and maybe not wanna come back to church.

Crystal Keating:  
Well, that's so good. You know, I think what you're saying is really interesting because there are some respites that happen like on a Saturday for a couple of hours, like once a month. I've seen that consistently with churches. And so, what you're saying is for churches to prepare and to be ready to receive those families, especially on Sunday.

And so, starting a respite, like a buddy program on a Sunday for children with disability so their parents can enjoy the service is probably a good first step for churches, as they're able.

Jennifer Evans:  
Exactly. Yes. And a lot of the times that could be the same volunteers if they're doing a buddy ministry and maybe serving twice a month in a buddy ministry. And then maybe they're serving you know, at respite and churches could start with respite quarterly events and then build up to monthly.

But yeah, I think it's definitely important that they're able to be served on a Sunday too, and not just with these little events.

Crystal Keating:  
Right. And so, if you're listening today and you're thinking, okay, I'm on board. I wanna try this. I wanna introduce this to our church. I see the need. I feel God may be calling me to this. We have a lot of resources on our website. So just go to [joniandfriends.org/church](http://joniandfriends.org/church). We have so many great booklets and videos and instructional PDFs. Everything is there for you to get started. So that's [joniandfriends.org/church](http://joniandfriends.org/church).

And we even have a little booklet about organizing respite, called *We've Got This*. I love that title. It's so encouraging. *We've Got This*. So, check out our website for more. You know, when



you think about the kinds of volunteers who might thrive at providing respite for families, who are you looking for, and what are some of the roles and responsibilities?

Jennifer Evans:

Yeah. So, it could be all ages. You know, we have even teenagers that will come to serve with their parents up to, you know, seniors. So really anybody that just wants to go out and love and serve. They can be trained to be a one-on-one buddy. But we have roles for everyone cuz there's a registration area. There's hospitality. There's arts and crafts stations, set up, and clean up. So, you can, you know, let the person know that's leading the event what your skill sets are and they can match you up with something you feel comfortable with. And we also have a need for nurses because sometimes there's medically fragile people that come.

There's something for everyone. You could even just show up and be a greeter, you know.

Crystal Keating:

I'd like that job, please. A happy face, right? I could give hugs.

Jennifer Evans:

Yes, someone does technology. There's a little training usually 30 minutes before, just some basics on disability etiquette. You know, you can help set up the PowerPoint right, or the audio.

Crystal Keating:

That's great. I didn't think about those other roles. That's great. Well, so as you're providing this respite event, what are some of the hopes and goals you have, even expectations for what will happen?

Jennifer Evans:

Yeah. I think these relationships we've seen continue outside of respite where one-on-one buddies are going over to these families' houses and maybe babysitting or going over and bringing a meal. And so, it doesn't just stay at respite, that there are real community and relationships being built. And also, I think we should be hopeful and pray for salvation for people to come to the Lord and for people to draw closer to God and also be able to maybe think, you know, maybe I can go to church now if they're not attending a church.

And so, I think God can do anything. And we've seen some pretty amazing miracles happen. So, just providing the space and praying that the right people will come in. God will work.

Crystal Keating:

Yes. Amen. Well, I am so encouraged by everything you've shared today, and again for those interested in learning more about serving families with disabilities through your church, visit [joniandfriends.org/church](http://joniandfriends.org/church).

We have so many wonderful resources and not just things to read and watch. But we have wonderful people all over the country who would love to help you support reaching out to people with disabilities in your churches. It doesn't have to be a program. It's about a relationship.

So, Jennifer, thanks so much for joining us on the podcast today.

Jennifer Evans:

Thank you so much, Crystal. God bless.

Crystal Keating:

Thank you for listening to the Joni and Friends Ministry Podcast. If you've been inspired, would you leave a 5-star review? And don't forget to subscribe! You can also visit [joniandfriends.org/podcast](https://joniandfriends.org/podcast) to send me a message. I'm Crystal Keating and thank you for joining me for the Joni and Friends Ministry Podcast.

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