



Season 3 | Episode 9

## Living Joyfully with Dystonia

Abigail Brown

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Crystal Keating:

I'm Crystal Keating and this is the Joni and Friends Ministry Podcast. Each week we're bringing you real conversations about disability and finding hope through hardship and sharing practical ways that you can include people living with disability in your church and community. Be sure to subscribe wherever you listen to podcasts or find us at [joniandfriends.org/podcast](http://joniandfriends.org/podcast). It's my pleasure to welcome Abigail Brown to the podcast today, a young woman who lives with purposeful joy in Christ, with the limitations and challenges of dystonia. Abigail is speaking to us today with the help of her communication device to champion a faith in God that says even when life doesn't make sense, he has a plan. Even when you get an unexpected diagnosis, he has a plan. Even though you're feeling isolated, he has a plan. Even though you feel like it's hopeless, he has a plan. We as sons and daughters of the King of Kings need to remember, he has a purpose and a plan for each one of us. So Abigail, let's jump into this conversation and I'd love for you to introduce yourself to our listeners.

Abigail Brown:

Hello, everyone. I'm so excited and honored to be speaking with you today. I want to thank Crystal for this opportunity to share my story. As Crystal said, my name is Abigail Brown. I was blessed to grow up in a Christian home. I would not be the person I am today without the Lord, but I also would not be the woman I am today without the training and loving discipline and countless prayers and loads of encouragement from my parents.

I'm 28 years old and the second oldest and I have three loving and supportive sisters. I live in Stillwater, Oklahoma. I have been living with a unique condition called dystonia for 25 years. I am a blogger, artist, and own a small business called Silent Inspirations. I enjoy listening to audio books, encouraging music, and podcasts. I also enjoy drinking coffee, shopping, and hanging out with friends and family. Growing up with a disability, I was inspired and still continue to be inspired by Joni's life so much that I dreamed about someday encouraging kids and adults with disabilities and giving them hope like Joni has done in my life. Thank you again for this opportunity.

Crystal Keating:

Absolutely. Abigail, I'm so glad to meet you, to talk with you. If I lived closer to Stillwater, Oklahoma, I would love to drink coffee with you and go to the mall and talk about the books that you like to read, and I like to read too. I love your passion to share about what God's done in your life with others. So I'm so glad that you get this opportunity. Well, we'd love to hear more about your journey through 25 years of living with dystonia.



Abigail Brown:

I was born February of 1993 and was developing into a precocious three-year-old, until God allowed a different plan, which drastically changed my life and entire family's life in May 1996. When I began suffering from the effects of an undiagnosed case of Rocky Mountain spotted fever, my family was heading on vacation and when I became more and more lethargic a doctor at a standalone clinic, tried to reassure my parents I would be fine. But unfortunately, by the time they got to Tulsa, I was not fine. In fact, by the time they rushed back to Stillwater, I had to be carried into the doctor's office. The doctor at the clinic I was at barely noticed the tick bite of two weeks before causing a very serious infection. On May 31st, my pediatrician rushed me to Saint Francis Hospital in Tulsa, there, I was in a drug induced coma for a week.

When I began to wake up, my muscles were tight with my arms, pulled up to my body. My legs were rigid, I could not move, could not talk, swallow, eat, turn over, or even scratch. My parents told me I cried and screamed constantly. A feeding tube was put in place. Then I was transferred to a rehabilitation center in Oklahoma City where my maternal grandparents lived. I stayed there until August 9th, 1996. In rehab my speech and language pathologist was talking to me about the alphabet blocks she was lining up on the floor in front of my wheelchair. She asked me my name and age. My arms were still drawn up to my chest, but with my left foot, and great effort and determination, I pointed to the letters, slowly spelling out my name, Abby, and pointed to the number three. The therapist continued to ask me my older sister's name and age and my parents' names. And I spelled them all. My cognitive abilities were undamaged.

My parents were told that I would recover within the year, which meant the rigorous therapy program I was in during the first year would likely determine the amount of muscle function that I would probably recover. For several months, my mom, sisters, and I traveled to Oklahoma City for me to do therapy three days every week. Family and friends worked tirelessly with me. After many tiring months of continuous physical and occupational, and there for a while speech therapy. I did relearn how to walk and regained the use of my left hand. But my ability to speak verbally has never returned. I was a very confused little girl; I can imagine the questions that were going through my little three-year-old mind. "Why can't I talk? Why is my body like this?" I'm positive my parents explained it the best way they knew how. To me, they are extraordinary people. I'm so blessed to call Brad and Cindy Brown my parents.

When I was five years old, my parents discovered that the brain trauma I experienced led to the development of dystonia, a condition which causes muscles to tighten and the body to control it in different ways. Currently, there is no cure for dystonia, though I have undergone numerous surgeries and procedures to alleviate some of the more painful and debilitating symptoms. For example, one of the treatments that helps the most is Botox injections. I get around 30 Botox injections every two months so I can function better. And yes, it does hurt when I get them. I have been getting Botox for 15 years and every time I get my injections, I thank God not only for the strength he gives me to endure the injections, but also because there are several people living with dystonia and are unable to find a doctor or to get the treatment they desperately need. I am blessed to have a doctor who understands what I have and knows how to help.

Crystal Keating:

That is so true Abigail, thank you for sharing a little bit of your story. You have been through so much, starting at such a young age, and yet I love your perspective that you live with such a grateful heart. And it's amazing to me that even though your body doesn't work the way you wish it would, your mind and your heart are fully engaged. And I just wanted to also thank Cindy, helping Abigail with this conversation. So what a wonderful example you are to your



daughter of constant love and support. So Abigail, I'd love for you to talk a little bit more about dystonia, explain it. What is it and how does it impact your day-to-day routine?

Abigail Brown:

The way I'd like to portray dystonia is like being imprisoned in a body with a mind of its own. While I am imprisoned by dystonia, I'm thankful that the Lord shackled me with joy when I accepted him as my savior. And He saved me from all my sins at the age of seven. But as I started growing spiritually, I began asking God several questions about my disability. Questions like, "Why me? Why does eating take a long time? Will I ever get married? If I do get married, how will I say the vows?" And the list continued to grow as I got older. But I'll never forget when I was a teenager and I heard Joni say on one of the [radio shows](#) about how she's struggled with the why questions and how she learned to say, "Why not me?" Also, the verses from John 9:1-3 are one of the many verses that God used to help me change my perspective about my disability. Living in a body with a mind of its own doesn't mean I can't live every day trusting in the Lord.

Crystal Keating:

Amen.

Abigail Brown:

I have to choose to depend upon the Lord daily. My dungeon of despair can turn into a prison of peace and praise because God is with me in every circumstance. I can walk and do certain tasks around the house. One of the lessons my parents taught me to do growing up was to focus on what I can accomplish and not focus on what I can't do. Dystonia is a movement disorder, meaning my muscles aren't moving consistently. Except when I sleep, then my muscles are relaxed. There are several forms of dystonia, it can affect one general part of a body or it can also affect several parts of the body. For me, the type of dystonia I have is called secondary dystonia, which is dystonia that develops mainly as the result of the environmental factors that provide insult to the brain. Like the brain trauma I experienced.

As I grew up, I became interested in learning about my disability. I learned that the tightness I was experiencing mainly affected my mouth, tongue, jaw, neck, back, right arm, and hand and my right leg and ankle and toes. When I was 16, it progressed to my eyes causing me to have eye spasms, which was something that was hard to get used to because I communicated with a communication device, which made typing become even more slow as my eyes became very squinty. It was definitely an adjustment. Then in 2015, I noticed my left hand, which is my good hand, start to lose some dexterity. Right now, my left hand has 20% dexterity, meaning I do everything I'm able to do with my pointer finger and thumb. I am able to take care of all my personal care. Some days that's all my body can take because doing those seemingly simple tasks is very exhausting. Eating and drinking can be tough at times, for example, on a good day, I can eat lunch for 35 minutes or less. On a bad day, when my muscles are really tight, I can eat in 45 minutes or more.

Yet, I'm grateful for the continuous grace and strength God gives me every day. Also, I am unable to drive, which has taken years for me to finally accept. And I've learned that there are much more important things to do than having my "freedom to drive," like getting to know God better through the trials and circumstances in my life. I still live with my parents and they graciously help me take medicine and cut up my food and drive me places. I never thought I'd still be living with my parents, but I'm very thankful I am able to live with them. I'm very thankful for the independence I still have. In the mornings, I've made it a point to turn on



encouraging music, to get my mind on right things. I don't know what I'd do if I didn't have encouraging music in my life.

Crystal Keating:

Oh, I feel the same. I know how much music helps us to get our hearts and our bodies and our minds focused on what God is doing, despite our challenges. And Abigail, I know the things that you've said, even just feeling imprisoned by dystonia. I'm sure so many of our listeners can relate to that, but I love your perspective that God has shackled you with joy. And I think that is very evident in all you say and do, especially on your blog. If you want to see a picture of Abigail, you can check out our podcast page, but you can also go to [abidingwithjoyinchrist.com](http://abidingwithjoyinchrist.com), to read a couple of stories about Abigail and to see pictures of her. So well, let's talk about your communication board. How have you learned to communicate with others in a world that is so fast paced?

Abigail Brown:

After about a year, the speech pathologist recommended obtaining the chat box, a device produced by Prentke Romich Company with up to 64 pictures that I could point to. My parents had recorded appropriate expressions, which were activated by my touch. Now I could say I'm hungry and other basic wants and needs. Pretty soon it became apparent that I would not talk again and since my intellectual abilities were quite intact, I needed a more effective way to communicate my many thoughts. My parents were given a free communication device produced by Prentke Romich Company and used a language system called Minspeak. Minspeak uses icons like a picture of a girl pointing to herself, a picture of the wanted sign, and a picture of an apple meant I wanted to eat. I was able to memorize the language quickly. A good word to sum up how I learned to communicate with others is patience, not only for me as I learned the language system on communication device, typing everything out with my pointer finger, but also for the person I was communicating with.

Growing up, I had three communications devices that gave me the ability to speak to others. But now I use an app on my iPad called Proloquo2Go and it's what I'm communicating with today. I typed everything out with my left thumb and copied and pasted each answer in a folder with several individual buttons. I'm so thankful for the technology in my lifetime. Here are some ways I've learned to interact with people. When I'm at church and it's loud and crowded. It's not always easy to hold my phone and type while standing. So the person I am talking to holds my phone for me while we talk. Growing up, my parents taught me to be welcoming and to initiate conversations with others to put them at ease.

At first it was really hard, but over time, it got easier. And now I can confidently start a conversation. I also wrote a personal pamphlet sharing my story it's called "I Can Smile Because..." I wrote it because I realized almost any time we went anywhere, people would ask questions about what I had or say, "You have such a beautiful smile." And sometimes my parents didn't have time to explain. That's why I decided to write the pamphlet, so I can be the one answering the questions. Now every time I'm shopping or even with a friend, I have them in my purse to share with people in case they have questions.

Crystal Keating:

That is so great. I love that. You wrote a little pamphlet called "I Can Smile Because..." to share your story. And Abigail, I just wanted to tell you that I didn't realize you had used your thumb to type out all of the answers to what you wanted to share on this podcast. That takes a lot of



tenacity and determination. I so appreciate you investing that time. And I know some of our listeners have children who use communication devices or they themselves use them. And it's so true that patience is the key to communication. Both speaking and listening, and God puts a high value on being patient with one another because He knows how much we need that connection. Well, Abigail, as you reflect on your life, what are some of the ways God has shown himself to be faithful to you? And how have you discovered God's purpose through the challenges of your disability?

**Abigail Brown:**

As I reflect back on my life, I'm in awe of God's great faithfulness. I'm reminded of the verses in 2 Corinthians 1:3-4: "Blessed be God, even the Father of our Lord Jesus Christ, the Father of mercies, and the God of all comfort; Who comforteth us in all our tribulation, that we may be able to comfort them which are in any trouble, by the comfort wherewith we ourselves are comforted of God". He's the God of all comfort. Praise the Lord, not just some comfort or not a particular circumstance, but he comforts us in all our tribulations that we may be able to comfort others going through their hardships. God has intervened in so many amazing ways. They are too numerous to mention. He not only uses people I know to send an encouraging text or card at the right time, but he also uses people I don't even know to provide for the care I need.

God is always working in the background in ways we may not see. He can provide for your every need in his timing. I share many of these stories about how the Lord has provided in my life on my blog, *Abiding With Joy In Christ*. Another way the Lord has shown His faithfulness to me recently, was at church on a Wednesday night, we were singing this hymn called, *Teach Me Thy Way*. This time when we sang it, I noticed the second verse, which says, "When I'm sad at heart, teach me thy way. When earthly joys depart, teach me thy way. In hours of loneliness, in times of dire distress, in failure or success, teach me thy way." As I was humming along, not really paying attention to any of the other verses, the Lord halted my thinking and brought times and hours of loneliness to my mind. In those moments of loneliness, he reminded me that he is my ever-present father, even when I've had it with dystonia and I'm just weary of dealing with it all. He is in those moments, bringing songs to my mind that I've listened to that day.

He is so faithful in those lonely moments when I think, "Is this really what the rest of my life is going to be like?" He has continued to give me the strength and patience to live with this disability. I honestly was so blessed that night during the song that I really couldn't focus on anything else during the service, but the second verse. That night, I was so thankful the Lord used a familiar hymn to encourage my soul. Five years ago, the Lord used 1 Peter 4:12-13, which says, "Beloved, think it not strange concerning the fiery trial which is to try you, as though some strange thing happened unto you: but rejoice, inasmuch as ye are partakers of Christ's sufferings; that, when his glory shall be revealed, ye may be glad also with exceeding joy." Through these verses, the Lord showed me that dystonia is a gift and yes, it can get challenging and frustrating at times, but I wouldn't trade the hardest times for the deep relationship I've gained with the Lord.

**Crystal Keating:**

That's amazing. Well, I have tears in my eyes just hearing you talk about the loneliness that have felt, but how God is ever-present through your dystonia. And though it makes you weary, he is ministering to you in a special way. That is a supernatural gift that God is with you, Abigail. So thank you for sharing that. Well, as we close our time together, I'm wondering if you want to





share some words of encouragement to those who might be listening today, feeling lost or hopeless in their situation.

Abigail Brown:

Of course, I'd be happy to. To the person who is feeling isolated, alone, left behind, unworthy, disappointed, and hopeless, or think to yourself, nobody around me understands what I'm going through. My friend, I want you to know you are not alone because I have also felt those same feelings and I have started several conversations with God. And the God who sees, knows and understands completely. But he wants me to have a victorious life. I have to forfeit those lies that the devil feeds me and proclaim truth from the Bible to myself every day. Friends, you may feel unseen by others, I get it. But I want to encourage you to continue believing that the Lord sees what you're going through and knows what you continue to deal with day after day. He knows how weary we are of living in this broken world. Believe me, his promises will not fail you. His grace is sufficient. His love for you is unending. He will continue to give you the strength and patience you need every single moment of the day.

I would like to read these verses over you that have encouraged me this year. I've written these verses as if the Lord was saying them to you personally, they are from the books Isaiah, John, Hebrews, and Philippians. To my precious sons and daughters of the King, remember these things, child of God for thou art my servant, I have formed thee. Fear not, for I have redeemed thee dearest one and called thee by thy name. My precious one thou art mine. When thou pass through the waters, I will be with thee and through the rivers they shall not overflow thee. When you walk through the fire, dear one, you shall not be burned. Neither shall the flame kindle upon thee, for I am the Lord thy God, dearest one, the Holy one of Israel, your savior. You are precious in my sight. You are honorable. I have loved thee.

Fear not, for I am with thee, I, even I, am the Lord and besides me, there is no savior. I am the Lord your Holy one, the creator of Israel, your King. Behold, I will do a new thing in you dear one. Listen to me, my servant, whom I have chosen, the Lord that made you and formed you from the womb, which will help you. Oh, my dearest daughters and sons, thou shalt not be forgotten by me. Remember Christian, no one can pluck you out of my hand. You are safe in my grasp and I'm never going to leave thee or forsake thee. I am going to come back for you, my friend. Keep pressing toward the mark for the prize of the high calling of God in Christ Jesus. I love you with an everlasting love. Your Abba father.

Crystal Keating:

Oh, Abigail. Those were such comforting, encouraging words. Thank you so much for sharing your story and sharing your heart with us on the podcast today. May God richly bless you.

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