

Season 3 | Episode 6

## God Chronic Illness and the Church

Jennifer Ji-Hye Ko

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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 and find all the resources mentioned at [joniandfriends.org/podcast](https://joniandfriends.org/podcast).

Jennifer Ji-Hye Ko is a writer, poet, and servant minister at her church in California. She lives with her husband, Joon and their daughter remaining tenacious amid her various physical and mental illnesses. And she's joining us again on the podcast today to talk about chronic illness and the church. Welcome to the podcast, Jennifer, it's so nice to speak with you again.

Jennifer Ji-Hye Ko:

Thank you so much, Crystal. I'm excited to be back.

Crystal Keating:

I know this will resonate with so many of our listeners, especially as we think about hidden disabilities, chronic illness, mental illness, the ups and downs that many people face, and especially as it relates to the church. So maybe we can start off our conversation by going back to when you first experienced a change in your health, what was your experience with the church? I mean, did you feel like you could be open about your challenges?

Jennifer Ji-Hye Ko:

My disability from multiple chronic illnesses and my saving faith happened about the same time, so I came to the church body already disabled. But while my chronic pain and fatigue, they were disabling, the only visual indications were braces or pressure gloves that I wore on my hands, but I was able to be fairly open about my condition. Honestly more because I didn't want there to be an elephant in the room. People could see something's not quite right, but I felt comfortable sharing because even when people didn't know what to say, I felt supported and heard.

I understand that I am incredibly blessed in that way because not all church bodies and communities have that kind of patient, Christ-like love and compassion for people who are different. However, as the church grew and as I started using more noticeable ability aids, a walker, a wheelchair, a cane, I did see a difference in the way people treated me. As a single woman, there was a change in the way the single men treated me. I suddenly felt less attractive,



less as viable wife material. People started treating me like a wounded puppy. Others approach to pray for my healing, and some just stared. The staring always left me feeling othered.

Crystal Keating:

Oh, yeah.

Jennifer Ji-Hye Ko:

Like I was an oddity that didn't belong, or like an unsightly zoo animal, rather than a person made in the image of God, worthy of dignity. The unsolicited prayers though at first were encouraging, but after a while I felt this vague uncomfortability. There were times when it was clear I was being treated more as an object kind of person. Like one woman would corner me and pray for me loudly in the middle of a crowd, seemingly for attention. And there are a few women who would check up on me weekly to see if their prayers for healing took. But other times I was confused why someone praying for me would make me feel belittled.

Now I understand that these mostly well-intentioned actions were done with implicit bias, and unconscious stereotyping of me as a disabled person, and resulted in microaggressions, the subtle verbal or non-verbal insults, or denigrating messages. Because I didn't have an understanding of myself as a minority person, I didn't have the vocabulary to understand or express what was happening to me, let alone to communicate that to others. So yeah, I was regularly taking on hurts for years, unaware of what I was enduring.

Crystal Keating:

It almost sounds like the church, maybe, although well-meaning, made the focus of their relationship with you, the focus was the limitations and the illness, rather than Jennifer as a person and sort of letting you lead that conversation, especially with unsolicited prayers for healing. That can be very isolating. And do you think people responded to your vulnerability and your being open by meeting you where you're at? Or did you feel like it caused a sense of being left out of the church life because people didn't know how to step into your suffering?

Jennifer Ji-Hye Ko:

Yeah, it's been a complicated mixture of both. As I became weaker, yeah, it became harder to keep up with the pace of the life of the church. And I had this subconscious understanding that if I didn't try my best to keep up, I was going to be left behind. And not because people wanted to leave me behind, but because people didn't understand my situation enough to know, first, that I was being left behind, and second, how to remedy that situation. And yeah, that felt isolating.

I was doing this back-breaking work to function on a level that the able-bodied majority is able to do with relative ease, and it seemed very few people noticed. And when people did notice, it was rarely followed up with reconstructing for equity. It's like noticing that someone is drowning or is about to drown, and instead of throwing them a lifeline, you give them a high five and congratulate them for not drowning. I got to the point where I was in fact beyond drowning. My husband described it as spiritually bleeding out, and that was amplified once I became aware of my mental illness and how that played into everything.

As a society, we aren't trained to recognize the early signs of mental illness, we're very much influenced by Hollywood where it's this very clear and out there set of behaviors. Mental illness symptoms are displayed in behaviors, not necessarily in pain as we tend to think of it. And that can easily be mistaken as sin behaviors.



So I found myself in a position where I was being encouraged to confess symptoms of a mental illness as if they were evidence of sinful motivations. And this was the most isolating because I knew something wasn't right, and this was before I had even gotten a diagnosis. And even though the wisest and the nearest to me relationally didn't understand, there was this information gap, and I felt that I was experiencing something that, while not uncommon to man, was uncommon in our community or at very least an issue rarely, if ever, talked about.

So even though I know the church body loves me and wants to support me, it has often felt like, and this feeling is perpetuated and amplified by a perspective distorted by psychosis, it felt like no one understood and everyone was against me. And when I'm in the midst of my most difficult psychological symptoms, those feelings unfortunately feel extraordinarily real, and true, and only significant action, not words, but significant action could convince me otherwise.

Crystal Keating:

Yeah. Well, and from what I've heard from others who struggle with mental illness that's yet been diagnosed, church body is looking at this person and they see these behaviors or these symptoms and they are thinking, "What's happening?" And even the person themselves isn't able to articulate or pinpoint, "Okay, this is a wrong motive." Versus, "Something's happening physiologically to me that feels very much out of my control and it's very much unwanted. I don't want to keep this. I desire that God would do something, but this feels very much connected with who I am." And it's hard to understand, so there's definitely a process. And so I'm wondering, has that changed through the years for you? And not just for you, but for your family?

Jennifer Ji-Hye Ko:

Yes and no. We have seen evidence of growing awareness. For instance, people used to come up to us and the focus would be on me and how I was feeling, and my husband would feel invisible. And after a few nudges people started engaging with him instead of engaging with me through him, and that was a win. And there have been other small changes. Our elders noticing and taking action, and so in our services, the worship leader says, "Stand, if you are able." Which is a small way to communicate, one, to people who aren't able to stand, we see you. And two, to the people who don't have to think twice about standing, hey the ability to stand is a privilege and not a given. Now there are many other additional practical changes that can be made with minimal cost and effort. And I think much of that work still needs to be done and is ongoing.

That being said, more than practical changes, I'd like to see social change from which the practical changes will flow. It's a shift in the church culture that allows disabled people to feel valued and celebrated members of the body of Christ. And that's not to say that no one will ever stare or say something insensitive, but that the hands and feet and mouth of the body would be doing their part in shaping and maintaining inclusive culture that will support us, the disabled and chronically ill, so that the full beauty of our strengths and spiritual gifts can flourish in a safe environment.

Crystal Keating:

Yeah, that's right. And Joni and Friends, our mission is to mobilize the church worldwide so that every person with a disability has a place in the body of Christ. And it's not just being a recipient of care and love, it's actually using your God-given gifts to serve, to be a part of the family. And so, even if you're listening today and you're thinking, "How do we change the culture of our church?" We have so many free resources on our website. In our [church training resource](#)



[section](#) we have booklets, we have videos, we have people who will help talk things through so just make use of our website. We'll put a link in our podcast page, but I love what you're saying that you want to place where the strengths and spiritual gifts can flourish in a safe environment. And so, Jennifer, if you had a platform to help the church better understand chronic illness and pain, what might you share with them?

Jennifer Ji-Hye Ko:

In my biblical counseling training, my pastor taught us to use this framework: loving, knowing, serving, speaking (or communicating to be inclusive), and training in righteousness. And I think of it as five strands that we can add in one by one, braiding them together so that they are constantly intertwined and interacting with one another.

First, we must come from a place of loving the person, and that love must reign over all of our thoughts and actions. And this love needs to be God-fueled, Holy Spirit-inspired, and others-motivated. It's agape love that seeks to serve, expecting nothing in return. And that will keep you thinking of what is best for others first, and not what you would prefer, or what you think is right in that moment, or what maturity level you feel a person should be at any given juncture. This step of loving, it's one that we all need to continually revisit in order to recenter and re-evaluate the source and motivation of our love.

And then once we have consciously acknowledged Christ-like love for the disabled person, we add to it the strength of knowing. In order to help someone, and in order to properly love someone in action, we need to know them. If you're a healthy and/or able-bodied person, you cannot fully know the nuances and subtleties of being a disabled minority. The closest you can come is to truly and actively be living life with someone who is disabled or chronically ill. This is more than seeing us on Sunday morning or at a weekly Bible study, this is getting involved in our day-to-day physical, mental, and spiritual life.

I would encourage people spending the most time in the step of knowing. Disabilities and chronic illnesses are so complicated that even when you think you understand, you don't understand. Even when I think I understand my own condition, I don't understand. I come to these other junctures where I'm like, "Oh no, I don't understand what's happening to me and in me." So people need to continually be observing, interacting, and asking good questions within a context and at a pace that is safe for the disabled or chronically ill person.

And there is a humility to this kind of work, acknowledging your own lack of understanding, acknowledging your rushing, or your impatience, and be willing to learn, even if it's awkward, or even if you put your foot in your mouth, which I have totally done. And it's part of the process and there's grace for that.

So then with the knowledge we've gained in growing love for the person, we add in the strand of serving. And oftentimes when people see a person with a chronic challenge, the first thing that comes to their mind in the matter of service is opening a door or giving a kind word or people often ask us, "How can I help?" Which the intent here is good, but this can be an overwhelming and oftentimes unanswerable question.

Oftentimes these momentary acts of service vary in motive and do not have the same longevity as the person's condition or circumstances. However, informed by the knowledge we've gained in love, our service is more genuine, it's willingly long-suffering, and better informed. It's here that people are more likely to pick up on the fact that oftentimes the service that is most needed is the ministry of presence without expectation of a change in circumstances, to be a long-suffering witness. This is a way to display sincerity and love and service.



And another way is to become aware of your ability privilege, which is the constructing of environments around non-negotiable attributes that not everyone might possess, and the different ways that that privilege manifests into harm both globally and in each individual local church. The church body would do well to educate generally about the disabled minority group. The church building, procedures, and programs like childcare need to be accessible to everyone. And not simply ADA compliant because while those regulations are good, they are sometimes insufficient and couldn't possibly apply to all the specifics of each location and community.

Crystal Keating:

It's true.

Jennifer Ji-Hye Ko:

And so all of this is best informed by the disabled people in your midst, hearing what they need. And from other trusted sources, like I've been enjoying Michael S. Beates book, [Disability and the Gospel](#).

Crystal Keating:

Yes, that's a great one.

Jennifer Ji-Hye Ko:

Yeah. Which I would submit as mandatory reading in seminary. The framework does go on to add the strands of the communicating the truth in love and training in righteousness, but I would stop here because our tendency as human beings is to be quick to speak, to be quick to train. And even wise and trustworthy people can say ignorant and hurtful things that might have been helpful if spoken to an abled person. I would strongly encourage people to really lean into loving, knowing, and serving because if we are doing these three well, communicating the truth will come naturally. Able people might find that they are being trained in righteousness themselves simply by being involved in the life of a disabled person, which my husband will tell you, it's humbling.

More than anything right now, disabled and chronically ill people need to feel seen and heard, valued, celebrated, and safe, lifted to be seated, as Psalm 8 says, "A little lower than the angels, crowned with glory and honor." And lingering in loving, knowing, and serving can accomplish this so that God is glorified to and through the body of Christ, which will allow the church to be as complete as possible this side of heaven.

Crystal Keating:

That's so good. I love that you really stayed on knowing. We've heard enough stories of churches who are doing great ministry be asked, "What's it like for a person with a disability in your church?" And I think the responses are like, "Well, we don't necessarily have people with disabilities in our church." And it's like, "Well, why not?" It's that question of, "Why don't we? But then if we do have people with disabilities in our church, what do they need?"

Well, they can go to the experts and find out, but what better thing to go to the people themselves, the family themselves, and ask? Get to know them, explore, and maybe the family doesn't know themselves, and it's a great time to learn from each other to start that conversation. And I know that you and your husband have really worked hard to humbly be



open like that. And I know you're involved in your church so what is your own role within your church community today?

Jennifer Ji-Hye Ko:

Oh, right now it's complicated. I haven't really been able to be part of the church in a traditional way for a couple of years. Everyday stimuli like sights and background noise or the band's rhythm section being just out of sync or the smallest social slight has the ability to do real damage. And while some of these things could be remedied with equity and accessibility, some can't. How do you make church service safe and accessible for the teen who repeatedly clicks his pen to self-soothe, and also the person who is on a sensory neurological level, overwhelmed by the clicking pen.

Crystal Keating:

Right.

Jennifer Ji-Hye Ko:

I don't envy the people who need to make these creative decisions.

Crystal Keating:

No.

Jennifer Ji-Hye Ko:

In the past, I have served many different ways from Sunday morning welcome team, to facilitating prayer meetings, community groups, and Bible studies, and writing for the church blog, and serving in our counseling ministry. I had the opportunity to get creative in how I deployed my gifts. Paul says in 1 Corinthians 12 that there are varieties of gifts, but it is the same God who empowers them all in everyone.

We touched on it earlier, people who have chronic challenges and/or disabilities have gifts that we desire to use, and we may need to do that in an unconventional way, to get creative and color outside the lines of tradition both for the benefit of a church, as well as for our own safety.

The cover of [Joni's 2021 Planner](#) reminds me of that. All these colors and different shapes and patterns, sizes, and chroma coming from different places, not in a rigid order, but flowing freely, yet still headed in the same direction.

Crystal Keating:

That's good.

Jennifer Ji-Hye Ko:

The body of Christ is a motley crew of people from all walks of life headed toward the Father in different and unique ways, which displays the diverse beauty and creativity of God. And man, I want to highlight that.

So I suppose my role more recently has been to help broaden the community's perspective of what the body of Christ could be, and how the complex diversity of the disabled community can reveal the complex and diverse beauty of God that He uniquely displays through us. There is a



richness there that has largely gone untapped that I would love to see shared and celebrated. The richness of hard-fought love, the breadth of hard-fought joy, the intimacy of hard-fought fellowship with Christ, the hard-fought sacrifice of forgiveness and reconciliation, and the displays of God's glory and goodness through the hard-fought working out of our salvation in intensely difficult, acute, chronic, long-suffering circumstances.

It is uncomfortable grace, and it is wildly breathtakingly resplendent. And a beauty that people facing chronic challenges have the opportunity to experience chronically every minute of every day as our conditions have us cleaving to the Father. And a unique beauty that the rest of the church body has the opportunity to experience with us as they lean in with loving, knowing, and serving disabled and chronically ill people in their midst.

Crystal Keating:

That is so right. We do need to do it together. I heard Dr. John Swinton talk about mental health and the church, and he was talking about coming to church, and many of us sing these joyful songs. And you have a brother or sister battling that day with the chronic illness or a mental illness, and they're not able to rise and shine as maybe everyone else is. And so, how powerful it is to sit with a person in that, and to lament with them in that moment.

And then there will be a day when they can rise and shine, and that's a great day, and another day to sit. But to have a safe place where God is working in and through all of us, no matter our challenges. And I just think I need to re-say this again because this was so good that you want to help broaden the community's perspective of what the body of Christ could be, how it can reveal the complex and diverse beauty of God that he uniquely displays through us, and so embracing all parts of the body.

Jennifer, you are an amazing, amazing poet. Your waters run deep, my friend. And last time you left us with a poem. So as we close our time together, I'm wondering, would you like to share another poem with us today?

Jennifer Ji-Hye Ko:

Yes, I would. This one is called *Clip My Wings*, and it is a glimpse into the struggle and faith of someone, chronically fellowshiping with Christ in his suffering.

When i cry out,  
“Lord, let me die,”  
please remind me, Father,  
You clipped my wings so i may fly.

i don't need legs to dance,  
or hips to sway,  
nor notes from my lips,  
to brighten my day.

Just a song in my heart,  
my Lord on my mind,  
though a realm apart,  
i'm not far behind.

Just a lifetime away.



When i can hold on no longer,  
i fall on my face,  
to worship my God,  
in this holy place.

There is nowhere like it,  
i hope you will see,  
that Christ carries on,  
when there's nothing left of me.

i hide in this place,  
though dreary and cold,  
curled up with my Master,  
yes, Him from of old.

When i don't know what to do,  
what to say or where to go,  
i know i'll stand firm,  
no matter how the wind may blow.

Still, as my bones  
are covered with skin,  
here is my soul  
encased therein.

My hair may turn white,  
with wrinkles on my face,  
but i pray with all my might,  
i won't grow old in this place.

My soul has grown wings,  
because of my King,  
yet unable to fly,  
a bird on a string.

Sooner rather than later,  
i pray to depart,  
all of Him for all of me,  
to be nearer His heart.

Yet, when i cry out,  
"Lord, let me die,"  
please remind me, Father,  
You clipped my wings so i may fly.

Crystal Keating:  
That was beautiful.



Jennifer Ji-Hye Ko:

Thank you.

Crystal Keating:

"Sooner rather than later, I pray to depart, all of me to be near his heart."

Jennifer Ji-Hye Ko:

Yes.

Crystal Keating:

And that's our prayer for everyone listening today that God would draw you nearer to His heart, that churches would grow in their understanding and their ability to welcome and embrace people with various seasons of life. And Jennifer, thank you so much for coming back on the podcast today to share about your experience with the church and what God's doing in and through you to really bring awareness about displaying God in all His complexities through the body of Christ.

Jennifer Ji-Hye Ko:

Yes, thank you so much for having me again, Crystal.

Crystal Keating:

Mm-hmm. God bless you.

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