

Wynne Leon (00:00)

It is so nice to talk to you because I've just finished reading your incredible book, *Invisible Until I'm Not*, which is a wonderful collection of essays. And I want to read a little bit of the description from Amazon. This is not a book about overcoming chronic illness. It's a book about living truthfully inside it, about the grief that reshapes your future.

Kathryn M. B. Johnson (00:01)

Well hello.

Wynne Leon (00:27)

The caregiving that drains what little energy remains, and the slow, unglamorous work of resilience when the world expects strength, you cannot always give. I love that description because it it it kind of centers really what the purpose is, but reading your book, one of the things that struck me was the loss of identity that comes with chronic pain and ill illness.

Kathryn M. B. Johnson (00:36)

Yeah.

Does and it's not overnight. It's not overnight. I I was diagnosed when I was 32, and my children were still at home at that time. And I had so much to do and so much to take care of and was in a completely different season of my life. And I just really just pretty much pushed through it.

Wynne Leon (00:56)

Mm.

Right.

Mm.

Right.

Yeah.

Kathryn M. B. Johnson (01:23)

and tried to ignore it. But I was younger then. And you know, that was thirty some years ago. And

Wynne Leon (01:27)

Yeah.

And that's when

you were diagnosed with fibromyalgia?

Kathryn M. B. Johnson (01:34)

b

both fibromyalgia and degenerative disease. I had arthritis in my cervix. I just would cry if he'd say you shouldn't work anymore. I would cry because I like to work. And then he would let me go. And that actually got me through to the point where he actually

Wynne Leon (01:46)

Right.

Kathryn M. B. Johnson (01:58)

went out of the room, came back in, handed me a letter for my employer saying that I could not work anymore. This was my doctor. It was my favorite doctor.

Wynne Leon (02:07)

This was your doctor. Yeah.

Yeah,

yeah. that's the moment that you had some proof of what was slowing you down, right?

Kathryn M. B. Johnson (02:22)

Right. I went through all kinds of tests to rule everything else out. And what I liked about that time period, if you can like something, is the doctor that I had who was in the center of all of it. It wasn't all spread out like

Wynne Leon (02:33)

Yeah.

Kathryn M. B. Johnson (02:45)

Now where I have to go to an A specialist for absolutely every single symptom that I have. And everything used to come back into the central hub, which was my doctor, and he managed everything for me. And when he didn't have an answer, he would write a Bible verse on a prescription pad and give it to me.

Wynne Leon (03:00)

Yeah.

Mm.

Kathryn M. B. Johnson (03:14)

And for some reason that helped me more than medication.

Wynne Leon (03:19)

Yeah.

Mm. Mm-hmm. But as you've adjusted to this to the diagnosis, and and then you've had to come to terms with this change in identity.

Kathryn M. B. Johnson (03:27)

Mm-hmm.

Yeah, there's a lot of grief involved in that when you lose your identity. I always it was easy for me to make friends and keep friends and do things and then all of a sudden I was like completely shut off.

I just could not I could not go. I didn't know from one day to the next how I was gonna feel. And people don't operate on that that level. Yeah, the maybe it it gets old. So then I started writing again.

Wynne Leon (03:57)

Right.

Yeah. Right. The maybe I can come kinda.

Mm-hmm.

Yeah.

Mm-hmm. Mm-hmm. But one of the threads that I loved from your book was how writing helped you find yourself through it this, through the identity change, through the the grief of losing your mom after caregiving for her for so long. And one of the one of the quotes that I found touching, I I found in the foreword, I had been writing through my years of caregiving and illness.

But in those months after her passing, the words felt different. They became a way to keep myself company when the world had grown too thin.

Kathryn M. B. Johnson (04:54)

Yes, because nobody understands. There are people who do understand. I'm gonna take that back. Because they just don't know that other people feel that way. And that's part of the reason I wrote the book is coming to terms with the fact that it's okay to rest.

Wynne Leon (05:02)

Yeah.

Kathryn M. B. Johnson (05:18)

But the silence around me was deafening. And I found myself for weeks listening for mom to be calling me, just thinking she was in the other room, starting to have a conversation, then realizing she wasn't there to have that conversation with. Which that was hard. That was hard to get through. So

Wynne Leon (05:42)

Mm. Mm hmm. Yeah. And so writing became

another way of having a conversation, right?

Kathryn M. B. Johnson (05:50)

And then of course when mom moved in with me, I was had just started a column with almost an author dot com on disability. And I did that from like 2016 to 2018, I think. And I after mom came, I just did not have time. She's like it's like caring for an infant in a way.

Wynne Leon (06:07)

Mm.

Mm-hmm. Right?

Kathryn M. B. Johnson (06:20)

Plus I had Michael.

Wynne Leon (06:22)

Mm.

Kathryn M. B. Johnson (06:24)

And Michael came after my mom came. But I was really setting myself up.

Wynne Leon (06:30)

Right, right. ~

Kathryn M. B. Johnson (06:32)

Because

I just inside my head, I can do anything. I can do anything. But physically I do have limitations. And that's really hard for somebody like me. I must be a type A personality. I just

Wynne Leon (06:37)

Mm-hmm. Right.

Un

unwilling to accept your limitations. So you brought up Michael, who is your great grandson, right? And you took him in when he was nine months old. And as you said, you were taking care of your mom. You have chronic illness. and he calls you mom you describe your relation. It's such a beautiful relationship. But you know, you've had to reset what you can do.

Kathryn M. B. Johnson (06:56)  
Yeah.

Wynne Leon (07:14)  
you know, in a day, but your courage to step up still shines through. I mean, it's just amazing. ~ tell tell us a story about how Michael came to live with you.

Kathryn M. B. Johnson (07:21)  
Well

Michael, his mother is my granddaughter.

And she was staying with us, living with us, when she and her boyfriend, when she was pregnant with Michael. So after she had him, they were here a good six months living here with Michael, which my mom hogged all the time.

Wynne Leon (07:51)  
Mm-hmm. ~

Kathryn M. B. Johnson (07:53)  
My mother just thought the sun rose and set on Michael and he thought the same about her. And they decided one day that they were gonna leave and come to find out they really didn't have any place to go. I guess they didn't like the rules. Because there were rules. You know, when you have family living with you, you have to have rules for sure. And

Wynne Leon (07:59)  
Mm.

Mm.

Kathryn M. B. Johnson (08:19)  
They didn't have any place to go and they had parked in his mother's driveway in a car that was missing the windshield in the back. And Michael was in the back seat of the car, in a car seat. And his mother called social services.

Wynne Leon (08:29)  
my goodness.

Kathryn M. B. Johnson (08:39)

And for let's see, that was when he was six months old, so like the next three months, he was with his aunt on his dad's side. And I got to see him once a week. And then she told me one day

Wynne Leon (08:52)

Okay.

Kathryn M. B. Johnson (08:57)

that she didn't think that she could handle another child because she had three of her own. And that she was gonna take him back to social services. And I said, No, I'm taking him, so I'll meet you there. And that's how I got Michael. Then I went to court, of course, and kind of made it a little bit more permanent, but ~ he's not adopted. He's just permanently in my custody.

Wynne Leon (09:08)

Right. Right. Yeah.

Yeah. Wow.

Mm mm. But that's Yeah. Right. And he calls you mom and you have this beautiful relationship he sees you. He holds the door open for you. He you know he's

Kathryn M. B. Johnson (09:25)

And he thinks I'm his mom.

at after

school, I try to walk f as far as I can down the hill. Now I used to not be able to get past my mailbox. But he'll say, stop and wait for me. And then he comes up the hill and gets my hand and holds my hand all the way up to the door.

Wynne Leon (09:41)

Yeah.

Mm.

Yeah.

~

Kathryn M. B. Johnson (10:00)

We'll pass a chair in the yard and he'll say, Do you need to sit down? He he's my baby. I just don't know what I would do without him now.

Wynne Leon (10:06)

Mm.

Right.

Right,

right. I think you said before we started recording, you're you're a natural caregiver and you know, your chronic illness, all that you've been through, it that doesn't stop that. So you just figure a way to make room for love, right?

Kathryn M. B. Johnson (10:26)

That's

what my parents taught me is a a lot of what they taught me was endurance, how to love somebody. And I you know, sometimes I think with everything that I went through, would I even do it again if I had to do it over? And I'd do it in a heartbeat.

Wynne Leon (10:30)

Yeah.

Yeah.

Mm.

Yeah.

Yeah. You write and I love this this line. The proudest moments come when he looks past what I still carry and sees the good inside me. That kind of seeing fills me with warmth and acceptance.

Kathryn M. B. Johnson (11:04)

Yes, sir. Yes, I'm telling ya.

Wynne Leon (11:06)

Mhm. Mhm.

those kids, they just grab us by the heart, don't they?

Kathryn M. B. Johnson (11:13)

Yes. I'm just glad he's not here right now though. Because he loves Zoom meetings. he always wants to be a star in them. And I there's nothing really I can do when he's here because he just will barge his way right on in.

Wynne Leon (11:16)

Well ~

Mm,

Right.

Well, I'm sure he'll be a star in his own right. So you have a lot of experience with the medical system, doctors that are dismissive, the unfortunate course of action that happened with your mom's kidney stones that led to you know, ultimately to her death. For for doctors that you that read your book, what do you hope they take away from it?

Kathryn M. B. Johnson (11:56)

well I hope they remember that patients are actually experts in their own bodies for one thing.

And I hope they maybe will try to listen and not be so dismissive for instance, with my fibromyalgia, if I have aches or pains and I actually call the doctor because of it, it's immediately called fibromyalgia. No tests.

No checking. And I go to the doctor now and I feel like I'm on some sort of a conveyor belt. You know, you got fifteen minutes. Everybody's got their 15 minute slot. And I've gotten to the point now where until I find a good rheumatologist, I just keep my aches and pains to myself, which is not the healthiest thing to do, because you never know.

Wynne Leon (12:37)

Right.

Yeah. I mean I think one of the lines that I I took away from your book was that being dismissed hurts almost as much as the illness itself.

But it's that being seen that really matters. as much as as the the aches and and the treatment, right?

Kathryn M. B. Johnson (13:22)

Right. And that emotional cost is really big for somebody that hurts all the time and you can't really it's so hard to explain. They want to know, does it burn? Does it sting? Does it do this? Does it do that? Well in fact it does all of those things. It does all of those things.

Wynne Leon (13:40)

Right.

Kathryn M. B. Johnson (13:44)

So how would you describe it? Excruciating.

Wynne Leon (13:47)

Yeah. Right. And one of the reasons you wrote the book is

to bear witness that, you don't have to suffer. In silence.

Kathryn M. B. Johnson (13:54)

it's it's possible

to pull yourself out even though you hurt on the inside like I'm I hurt right now in my back and and you know just sitting here to do this it takes effort which at some point I will pay for I know I will but

Wynne Leon (13:59)

Yeah.

Right.

Kathryn M. B. Johnson (14:21)

I'm so excited to be talking about my book.

Wynne Leon (14:23)

Yeah. Mm-hmm.

Right. I'm so glad that you showed that. one of the beautiful threads that shines through all of your essays is love and the way we do extend ourselves because of it. you have this great story of caregiving for your mom and she asked for a sweater and you you went to get it for her and and she noticed 'cause you had to pause. Can you tell that story?

Kathryn M. B. Johnson (14:50)

Well, the sweater, it's funny because I that's just like one of many, many times that that actually happened. My mom was cold natured. So she liked wearing sweatpants and jeans even in the summertime. I'd just get sweaty looking at her. But she I I used to buy her sweaters. Pretty sweaters.

Wynne Leon (14:57)

Of course.

Ha ha ha

Mm-hmm.

Yeah.

Kathryn M. B. Johnson (15:18)  
that she could wear and she loved that.

Wynne Leon (15:22)  
Mm.

Kathryn M. B. Johnson (15:22)  
I bought her a black and gray and pink striped sweater. And she just absolutely adored it.

Wynne Leon (15:30)  
Yeah. Yeah. And so you Right. And she asked you to reach for it and it was on the top shelf. And you go to reach for it.

Kathryn M. B. Johnson (15:32)  
Because they get frail.

And it was it was hard. It was hard to get that down. You just do it. You just do it. But I could feel it. And you know, the one of the sad things for me though is with the fibromyalgia, I'll I have so much guilt now that I wasn't a hundred percent.

Wynne Leon (15:45)  
Mm, mm. Yeah. Yeah.

Right.

Mm.

Kathryn M. B. Johnson (16:09)  
For her when she needed me because of fibromyalgia. And that's one of the reasons I wrote the book, was to come to terms with the fact that rest is not laziness, and that if I couldn't take care of myself, I wouldn't have anything to give to her. And I never operated that way in my entire life. It was just give, give, give, give, give.

Wynne Leon (16:12)  
Well Yeah. Mm-hmm.

Right.

Yeah.

Right. But she saw you. I mean that's what's amazing. It that why I think why I love the sweater story is she saw you have to pause after getting that sweater and she you know,

she just she still took care of you in the way that she could, which was not only in seeing you and in and just saying, Just sit. Yeah, just sit. Yeah.

Kathryn M. B. Johnson (16:52)

Take it easy. Just have a seat, sit and

I miss that. Just sitting, saying nothing, watching Hallmark movies on TV.

Wynne Leon (16:58)

Mm-hmm. Right? With your mama.

Yeah.

Right.

Kathryn M. B. Johnson (17:08)

Just the it's the quiet, let's be together.

Wynne Leon (17:11)

Yeah.

Yeah. Right. and that's the wonderful part of the story is that, you know, I think she saw that you were taking care of her even through your pain and and and and yeah.

Kathryn M. B. Johnson (17:27)

We had our little tiffs.

We would have our tiffs. She would want something like right now and it wasn't possible. And I would get it, but it would have to be on my ability to get it. But I would do it all over again.

Wynne Leon (17:35)

Mm-hmm. Right.

Yeah.

Yeah.

Kathryn M. B. Johnson (17:49)

I would do it for longer. You know, I would do it for longer.

Wynne Leon (17:51)

Yeah, right.

Mhm. Right. It was so sad to lose her and one of the things that your essays do is bring back that s we are caregiving often in in

our own conditions that aren't perfect and we're still doing the best that we can based on love. And and your mom knew that and you gave that to her willingly.

Kathryn M. B. Johnson (18:13)  
Right.

I was there when when she passed and not many people can say that. And so when I was born we were together, and when she passed away we were together, and I have pictures of her all over this room because this was supposed to be her room. I have her organ in the room.

Wynne Leon (18:23)  
Yeah.

Right.

Kathryn M. B. Johnson (18:49)  
Which was the last gift my dad bought for before he passed away.

Wynne Leon (18:54)  
Yeah, yeah. Well, your book is beautiful. Thank you so much for taking the time to to talk about it, to be present for everybody that suffers through chronic illness and still wants to show up and try things and be there for others. Mm-hmm. Beautiful, beautiful message. Thank you, Kathryn.

Kathryn M. B. Johnson (19:11)  
You're not alone.

You're welcome.