

## **NF Stories Live- Meet Courtney**

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**Brandy:** Hi, everyone, and welcome to NF Stories Live, a show that shares people's journey of living with neurofibromatosis. I'm your host, Brandy and on today's episode, I'm excited to sit down and chat with Courtney. She's an amazing young woman who has been openly sharing her NF journey through her blog Courtney's Column since 2014. Welcome to the show, Courtney. Thanks for being here.

**Courtney:** Hi, thanks for having me.

**Brandy:** So I would love to start off by talking about this last year, everybody got hit with the pandemic, but on top of it, you decided to buy a house, get married all this whole time working on the front lines as a nurse. So could you share how all this was for you over this last year, how you coped, how maybe it was different for buying a house and getting married and and working on the front lines? What's that like during a pandemic?

**Courtney:** Sure. So really, the pandemic, as we all know, kind of hit March last year and we've had a good year to get used to it at work. So now it's kind of just seems like pretty normal, honestly, to put your mask on, put your eye protection on every day. I'm relatively sheltered in the fact I work, I'm a labor and delivery nurse, so we don't see a ton of covid where we're very lucky, whereas other units see quite a bit more. You can definitely tell kind of like the vibe of the unit changes when we do have covid or when we do have someone is covid positive on the unit, but we've been so lucky. It was really scary at first because there's so much uncertainty and nobody really knew how it's transmitted, who can get it, who can't get it, like where is it coming from? But kind of as things have evolved, it's just it's gotten easier. And now that a good chunk of our staff are vaccinated, it's definitely helped with the anxiety for sure. Yeah, I just got my second dose last week, so I'm done now. That's a bit of a relief to kind of have that done for sure. But we did buy a house. We were like, we were renting before. My husband and I, we were just engaged at the time we were renting. And we're like, you know what? When's a better time to do it? Our interest rates, I'm in Alberta, so our interest rates really, really low. So we thought it would be the perfect time to buy a house. We had no obligations left in our lease for renting, so we just decided to do it.

**Brandy:** Nice check all the boxes.

**Courtney:** So that was really exciting. Yeah, checked all the boxes. It was really scary to find a buyer, our first house. We moved like 20 minutes away from where I grew up. So it's nice and close to home and it's close to work for both of us. So that was a relief to.

**Brandy:** It worked out.

**Courtney:** And then, yeah, we also married. Yeah, we we had obviously started planning our wedding long before covid was a thing. I got engaged in 2019, so I was almost like our wedding was pretty much almost planned. And then in March of last year we got a phone call from our venue saying like you probably can't have the wedding that you wanted. What do you want to do? And we were getting married so we got married in September of last year. We kind of just waited a little bit to see because our restrictions in Alberta kept changing. I don't know what it was like in B.C., but it seemed like one day it was something and then the next day they changed it. And it was like back and forth being all kinds of I don't know. We went from having 10 people like our limits for a while was 10. And then when we got married, we got married outside so we could have had 100 people. But it was so hard to pick and choose, like who's coming, who can't come. So we ended up getting married with just 30 people. It was just immediate family and it was perfect. Honestly, whoever's out there who's maybe wedding got squashed from covid or if you're engaged, have a small wedding. It was so worth it. And it was the best day of my life. And I have to spend so much more time with my husband and is was just the people that mattered that were there. Right. It wasn't like, you know, your cousin that you've never met before or like someone you haven't seen in 20 years.

**Brandy:** It made more memories, more intimate.

**Courtney:** Yeah, totally. Yeah. And so we got married outside and then our my in-laws, we were lucky enough that we could use their property for our reception. And we just had a tent and we had dinner catered and. Danced all night, it was great.

**Brandy:** Wonderful.

**Courtney:** So that's kind of been 2020 was a very interesting year, but those are definitely the highlights.

**Brandy:** Yeah, the good part for sure. Did you have any challenges in 2020?

**Courtney:** Yeah, like health wise, for sure. I've behaved, my body behaved, it was great for the last couple of years, everything has been stable, just got like routine MRIs just to check in. I do have a brain tumour that we just keep an eye on. It hasn't grown since it was found almost. What was that, 13 years ago?

**Brandy:** Wow nice

**Courtney:** So we just keep an eye on it. Yeah, we got really lucky. And so it was actually kind of right after my wedding that I started having some problems. I had some weird problems with some bleeding. I do have some hormonal issues. So we were wondering maybe if like some of the hormonal fluctuations were causing some abnormal bleeding. And so whatever they are like let's just send you for an ultrasound,

**Brandy:** Normal routine.

**Courtney:** Cool I've had lots of those and anyone who's had NF has probably had an ultrasound before. And so I wasn't really expecting anything to come out of it. And then I got a phone call like 2 days later from my doctor's office and they're like, hey, can you come see your family doctor tomorrow? And anyone who's ever had a problem come up knows that they call you when there's an issue.

**Brandy:** Yeah.

**Courtney:** So I went in the next day and I was like shaking in my boots in my chair.

**Brandy:** I bet

**Courtney:** and it's hard to sometimes being a nurse and then being a patient because you almost know too much.

**Brandy:** Yeah what's that like?

**Courtney:** It's really hard sometimes because as a nurse, especially as a labor and delivery nurse and anywhere is like you work critical care, you always hope for the best, but prepare for the worst. Because you always have to be on your toes because you have babies. I mean, you know that things can change at the drop of a hat and you have to be ready. So you're always prepared for that. I'm always prepared for things to go wrong at work. And so I've unfortunately kind of adopted that into my whole health is that I'm just always ready for something bad to happen, whether or not that's a good coping skills.

**Brandy:** Are you more prepared than when it comes up?

**Courtney:** I think so, because most of the time everything comes back fine and then I'm like, oh, well. It's good, we're all good, but when it doesn't come back okay I'm like, well, at least I've prepared for it.

**Brandy:** Yeah, exactly.

**Courtney:** So, yeah, they they handed me my ultrasound report and they're like, well, they thought I maybe had endometriosis,

**Brandy:** OK,

**Courtney:** Which I wasn't super convinced that that's what I had just with all my hormone problems, it wasn't a very probable diagnosis. They're like, well, just go for an MRI, see what you can find. Cool so I had an MRI in January of this year and then I got another phone call like 2 days after from my family doctor again. And he's like, hey, so they actually found a 5, almost 5 cm by almost 5 cm by 5 cm mass that wasn't there in July when I had a CT scan of my abdomen. And they weren't really sure what it was based off the ultrasound or based off the MRI. They thought it could be a neurofibroma,

but they don't I don't know what everyone else has faced, but I find it really hard to find a doctor who is knowledgeable, who has treated someone with NF before.

**Brandy:** Yeah is has been a commonality.

**Courtney:** So they said it was either, I know from like symposium's and whatnot. It's a widespread problem. They said either neurofibroma or it was a possibility that it was ovarian neoplasm, which can be either benign or malignant form of a tumour.

**Brandy:** OK,

**Courtney:** So that was scary to hear that, that I might have cancer. So I'm lucky enough. Like I said, I worked labor and delivery. So I know all the gynecologists in Red Deer in the Red Deer area where I live.

**Brandy:** Who you know right?

**Courtney:** So I called in a professional favor, its who you know, I was just chatting with one of the doctors and he's like, I'll see you as a patient. No worries. And so I waited my appropriate appointment time. I did wait. He didn't see me that day. And long story short, we still don't know what it is and it is being surgically removed at the end of the week.

**Brandy:** Oh, wow.

**Courtney:** So and yeah. Like, what's today? Tuesday. Friday I'm having surgery.

**Brandy:** Oh wow

**Courtney:** Then they'll biopsy it, they'll figure out what it is. I was sent for bloodwork and the tumour markers that they sent off came back negative, which means it's likely. Yeah. Probable that it's benign, which is awesome.

**Brandy:** That's really good news.

**Courtney:** So We'll see.

**Brandy:** So what does this mean for you, like future wise as a woman? Are you still going to be able to have children? Is that something that you planned to do?

**Courtney:** I've always really wanted children like ever since I was a child, my parents can attest to that I always had dolls and I always, always very maternal. I mean, I picked a labor and delivery as a career for a reason, like I love babies. My endocrinologist has assured me my biggest concern of removing I might need to have an ovary removed, kind of depending on where this tumour is. They think it's attached to the ovary, but they're not sure. They think maybe part of it might be attached to my uterus. They don't know. So endocrinology wise, hormone wise, they think I'm stable enough since I'm on some drug replacement for that. And then I was assured that my fertility shouldn't be affected.

**Brandy:** OK,

**Courtney:** Despite the fact that their take probably taking out one entire ovary.

**Brandy:** Wow that's awesome.

**Courtney:** But Tara;s, actually, I watched Tara's interview, the one that was posted last week, and all of that really resonated with me. My husband and I are definitely interested in genetic testing of an embryo. I'm much like Tara. I'm also a first generation person who has NF so. Yeah, if we're able to do that in the future, that might work better, too, if I'm working with one functional ovary. So, yeah, so we will see my surgeon, go ahead.

**Brandy:** So would you carry the child or would you consider surrogacy?

**Courtney:** I would love to carry a child on my own. Definitely. Of course, I just got married. So everyone's like babies when are you having babies? It seems like it's like ticktock, Like my in-laws really want another grandchild and my nephews. My sister in law's kids keep asking, they are like babies. When are you having babies?

**Brandy:** What about your parents?

**Courtney:** I would love to. Oh, yeah, definitely, my mom definitely is very ready. I think my dad's like still you're still my little girl is not ready for that yet.

**Brandy:** Yeah, yeah.

**Courtney:** Just a little bit. You're 27.

**Brandy:** I think it's time, Dad.

**Courtney:** I think it's time. Clock's ticking. So, yeah, well, I'd love to, but I'm also very aware that there's risks, so. That's a conversation once this whole surgery is done with and we know what this mass is, that's kind of our next topic to tackle.

**Brandy:** How have you been coping with this amount that you have dealt with in the last year and now with this? Don't know what it is inside being removed. How have you coped with all that? How do you keep your you're so happy and uplifted. How do you keep that going?

**Courtney:** It can be really hard to go, like I said earlier, to go back and forth from nurse to patient. Good days and bad days. I've definitely cried about it, I've had lots of emotions. My husband has heard me talk about it lots. My friends have been really great and my family's been there for me to talk about it. But ultimately, the one thing that I've always kind of stood by is no matter how much I want it to change and how much I want it to be different, how much I don't want this necessarily to be part of my story, it is and no amount of wishing or hoping or praying it away will make it go away. So at the end of the day, I just have to take it and go with it because it's the cards I've been dealt with and. I can't really stop my life just because of it, so.

**Brandy:** Keep living anyways

**Courtney:** keep going. Yeah, and I mean, it's going to be what it will be, and I've got great support behind me if it is what we don't want it to be, if it is malignant and cancer.

But there is a really high likelihood that it isn't. And it's just a little blip in my radar and soon enough that it'll just be another story to tell. So.

**Brandy:** Wow. Wow. Your so inspiring. So would you say your family is your biggest support? Or would you say you have others that have supported you?

**Courtney:** You know, I really struggled for a really long time if anyone's ever read my blog. I struggled for a really long time with accepting my condition and kind of accepting that I was different in a sense. It wasn't until I was in my grade 12 year of high school that I kind of finally came clean and told my friends what I was going through because no one had any idea and up until that point, it was solely my parents and my family that were my support system because I wouldn't let anybody else in. And after that it slowly grew and my friends became a huge support system. And then reaching out to the NF community itself has been huge for me just to see. Like, I'll never forget my first conference in Alberta. I was sitting in a room in Calgary and I was just looking around being like, wow, all of these people have somewhat of an idea of what I'm going through. And that was really life changing for me. And that's when I got to meet Reggie Bibbs there, which was so cool.

**Brandy:** Yeah, totally.

**Courtney:** He's like my NF idol, my idol. I just I love Reggie with my whole heart. So he really, meeting him really changed a lot for me. And he's been a huge support as well. So, yeah, it's just you got to look for your support in lots of different avenues because each person that you meet will give you something different.

**Brandy:** That's wonderful advice. Is that why you started the blog? Is that you were hoping to reach out to other people like you had been inspired?

**Courtney:** Yeah, that was a big part of it, I remember before I was really comfortable with talking to people about kind of what I'd been through, I really searched the Internet for someone that I felt like I could relate to because I just wanted to feel like someone else understood what I was going through since none of my family had NF I was like, you don't know what it's like. I can't talk to you about it. So I searched the Internet high and low and really couldn't find anything of anyone kind of in my age group or anything

like that. So I was like, here's my opportunity. And so that's kind of where I started. I can't believe that was 2014. I just feel like it was that long ago.

**Brandy:** Yeah, I know. When I went back, I'm like, wow, it's like it's still going because I've only recently caught on to your blog. Yeah, That's good. Have you met people through your blog? Have people reached out to you?

**Courtney:** People have reached out for sure. I've had comments left kind of on the public forum, but then I have had people email me or I've had people through Facebook that are like, hey, my friend saw this and who's aunt shared it and cousin shared it. And this resonated with me or hey, I have NF as well. Let's connect. So that's been really cool to make those connections with people. And my whole thing behind the blog was even if it just helped one person, in the end it was worth just worth it to share my story. And it's kind of started as more of an information blog. And then it slowly morphed into, like, this is my story and this is what I've been through. Its kind of cathartic for me to.

**Brandy:** Yeah, I was just going to say, has it helped you.

**Courtney:** To write it?

**Brandy:** Yeah, to work through everything.

**Courtney:** Yeah, for sure. And if anyone has ever read it, you can tell I kind of write with some humor sometimes, too. Yeah. Slightly to make it a little bit less like, oh dear, this is what's going on. But it's also a good coping mechanism for me too sometimes is just to throw a little bit of humor in it. But yes, definitely writing has been a big part of accepting and trying to move forward with everything for sure.

**Brandy:** Is there any words of wisdom like I said you've been sharing since 2014? You've been through numerous things. Is there anything that like growing up with it and being alone? Is there anything you could talk out to the younger generation, what it's like living with NF any wise words that you would like to share?

**Courtney:** You know, I think the biggest thing for me and if I could go back to my younger self and say, like, take my shoulders and shake myself and be like, it's OK. Like

people, when I remember I posted on Facebook, I posted like a note on Facebook a long, long time ago in my grade 12 year. Hey, this is my story. This is what I've been through. This is who I am. And the amount of outpouring of love and support and people being like, Hey, girl, I've got you, was really humbling and really inspiring to me. And I think my biggest thing for people who are younger or who are going through a hard time is just reach out to people, because as unsupportive as some people are, that's just very few and far between. And the majority of people will welcome you with open arms and be there to support you and love you. And if they're not going to do that, then why do you have them in your life? That was a big thing my mom always said if they don't love you for this part of you, then what's the point? Because this is part of your story, right? It's not who you are. I'm not defined by my diagnosis. And I've always been very adamant that I'm not defined by my diagnosis. But it's kind of what makes me who I am and I'm the person that I am because of the trials and tribulations that I've been through. And if you don't like it, then. That's fine. I don't need you in my life, so there's lots of people that will love and support you regardless, and I think that's just the biggest thing for young younger people to know is that there's lots of really great people up there,

**Brandy:** Find them and hold on to them.

**Courtney:** Yes, hold them close, my childhood best friend. She's been my very best friend since the first grade. She is still my best friend. She was my maid of honor. And her husband is my husband's cousin, so.

**Brandy:** Wow.

**Courtney:** Yes.

**Brandy:** Small world.

**Courtney:** Yeah. So you just hold those people close because they'll love you endlessly.

**Brandy:** That's wonderful. Thank you so much Courtney for talking to me today. And I hope in the near future we will be able to hold a symposium and all get together again.

And we'll continue to follow you in Courtney's column and I hope the best for you for your upcoming surgery. And thank you again. Bye.

**Courtney:** Thank you. It's nice to talk to you. Bye.