

Chronic Illness to Remission: Navigating the New Normal

Guest: Candace Pierce DNP, MSN, RN, CNE, COI

Dr. Pierce is a nurse leader committed to ensuring nurses are well prepared and offered abundant opportunities and resources to enhance their skills acquisition and confidence at the bedside. With 15 years in nursing, she has worked at the bedside, in management, and in nursing education. She has demonstrated expertise and scholarship in innovation and design thinking in healthcare and education, and collaborative efforts within and outside of healthcare. Scholarship endeavors include funded grants, publications, and presentations. As a leader, Dr. Pierce strives to empower others to create and deploy ideas and embrace their professional roles as leaders, change agents, and problem solvers. In her position as the Sr. Course Development Manager for Elite, she works as a project engineer with subject matter experts to develop evidence-based best practices in continuing education for nurses and other healthcare professionals.

Host: Christy Jacks, BBA

Christy Jacks is the Marketing Manager for Nursing at Colibri Healthcare, where she is deeply committed to supporting the ongoing educational needs of nurses and healthcare professionals. With an extensive career that spans food and beverage sales, customer service, and running her own digital marketing company, Christy brings a wealth of experience to her role. Over the past four years, she has found immense satisfaction in advancing initiatives that prioritize nurses' needs. Originally from Pittsburgh, Christy has spent the last 20 years in St. Louis and now resides on the shore of North Carolina with her husband and four children.

Episode 1: Chronic Illness to Remission: Navigating the New Normal

Transcript

Candace Pierce: This is Dr. Candace Pierce with Elite Learning by Colibri Healthcare, and you are listening to our Elite Learning podcast where we share the most up-to-date education for healthcare professionals. For this podcast, we are going to go a little bit off of

So for those of you who've been listening to our podcasts, hopefully you remember our Invisible Agony series, or if you have not heard it yet, I really, really encourage you to go listen to the Invisible Agony series. In that series, my daughter and I, we really talk about her journey, our journey with CRPS,

complex regional pain syndrome. So first I want to say how much we've appreciated the uplifting comments, because yes, we actually do go through your comments on our podcasts and on our courses. And a comment that we often saw for the Invisible Agony podcast was requesting an update on her. Joining me today is Judah. And Judah, what news do you have to share?

JUDAH: I'm finally in remission.

PIERCE: Yes, so we are back to talk more about our journey through this chronic illness, but also, we're going to get to focus on what it looks like going from chronic to remission. And to help facilitate this discussion, joining us is Christy Jacks, our marketing manager for nursing. Christy, thank you for taking on this role for Judah and me to be able to share our story and hopefully it resonates with others.

Christy Jacks: Well, thank you so much, Candace, for the very welcoming welcome. And Judah, I am over the moon excited to talk to you. I think you are one amazing little girl. And I can't wait to find out about all of the things. So girls, let's just dive on in if you're ready. Judah? All right, girl. All right. Well, I'm going to start with Candace. Candace, tell me about the diagnosis your daughter received and your initial reaction to that diagnosis.

PIERCE: So the diagnosis she received, which we talk about in more depth in the Invisible Agony series, is CRPS, also known as Complex Regional Pain Syndrome. And this particular syndrome does not have a known cure. It does not really have a lot of treatment options as well, but it's also known as the suicide disease because the pain is so intense. It is rated, if you look at the pain scale, it is rated at the very top. The pain from CRPS is higher than amputation without anesthesia. It's higher than childbirth without anesthesia as well. It's a really horrifying diagnosis to get. And over time you can lose your functionality and go from hers was in her low extremity, which is normally where you're going to see CRPS. It usually happens after some type of, it could be a simple injury as a sprain, a strain, a fracture, a surgery. And it's where your neurological system resets itself to believe that you've had a traumatic injury to this extremity. It'll cut the blood flow off to that area. So it'll be cold and it'll change colors. And you'll see problems with hair growth in that area for lack of the blood and oxygen that it needs. It's a really horrifying diagnosis to get. And I really just, I already knew that this is where we were headed. So I think I had already started to resign myself to this is what was going to be. Getting the diagnosis wasn't as shocking to me because I think I had already started preparing myself.

JACKS: Wow. How did you manage your emotions during all of that, Candace? I mean, as a mother, I just...

PIERCE: I don't think, yeah, well, I don't think my emotions really kicked in until we were in the midst of it, where I was really, because at first I was like trying to figure out what was wrong with her. We were going to all those doctor's appointments and then finally we get that this is what it is. And so I already had a plan and I was already able to work with those physicians to get this plan started, to get treatment started, looking at options that were out there. And so my emotions really got the best of me when we started to not see her get better and we started to see her get worse. And I struggled and I will cry through this podcast as I already feel it coming on, but I struggled with being a mom in healthcare who's been to school for so long and I can't fix my own daughter. Like I can't, I can't fix it. And part of me feels like that's so selfish for me to be like, I can't fix my daughter. All these, diplomas and stuff are useless. I just need to throw them in the trash. But that's really where the most of my emotions sat was I can't fix her. What do I do? How do I, how do I keep going with this? This can't be her life forever.

JACKS: Goodness. How, yeah, I don't even know, Candace. I'm amazed by you as well. I mean, to be honest. Judah, I think you're the strongest person I've ever met. Can I just say that to you? You're one strong cookie. I feel like I might cry this whole time just throwing that out there with you. Candace, tell me about some of the first steps you took to support your child through this diagnosis and treatment.

PIERCE: So at first, when we got the diagnosis, Judah is, she likes to research stuff. She loves school. She loves to do research. And so I immediately said, do not Google this. Do not look this up. I wasn't ready for her to see it by herself. I wanted to be there to walk her through it. Of course she did. She Googled it at school. But I,

JACKS: And can you remind me how old she was when this all started too?

PIERCE: So she when we started this journey she was a nine when we got the actual diagnosis she was ten so CRPS is a Like you have to Make sure it's nothing else. It's a rule out diagnosis only there's no specific test or Exam that they do they rule out everything else that it could possibly be and when that's the only thing left on the paper then they say, all right, this is your diagnosis. So we had some time between when, and hers started from a fracture. It was so minute that it didn't even show up until we did an MRI. So she's had 11 x -rays, correct me if I'm wrong, Judah, 11 x -rays, two MRIs, and a CT scan. And her fracture actually didn't show up until we had an MRI. She's had multiple ER visits because the pain is so intense. I'm like cutting off splints because she is screaming like she's dying in pain. from let's see it happened in the summer of when she turned nine and she's a fall baby. So it happened. Let's see she her birthday is in October. So January when after she had turned 10 is when we got the official diagnosis. But by that time I'd already worked through like, if this is it, this is what we need to do, this is what we need to ask for. And so I already had the plans laid out for the physician and he immediately wrote the letter to get her into her first treatment program and really helped us get through

JACKS: Well, Judah, can you tell us, tell me how you felt when you first learned about your diagnosis?

JUDAH: When I first got the CRPS diagnosis, my first thought and the way he managed to explain it to me was just that he didn't know what was wrong with me. And that's how it just, it was something that was really scary to have this idea that they don't know what's wrong with me. I'm one in like a thousand of people who have ever had to experience something like this. And it happened to me of all people.

JACKS: What were some of the thoughts that ran through your mind, when this was going on, especially at the beginning?

JUDAH: At beginning it was more like trying to accept the fact that I had something like this because I'd known that there was pain going on. had felt it and I didn't understand. just the idea of having a name to put to it but also knowing that the doctors don't know what to do, it was scary.

JACKS Yeah, I'm sure. How about any specific moments or where you felt challenged or challenges that you faced? Do you remember something in specific?

JUDAH: I think some of the challenges that I faced was having to explain to people what was wrong with me or explain to people why I was acting, why I might be over here crying or trying not to cry. And you get a whole bunch of mixed reactions from people. You get people who get all sympathetic and you get people who try to ask questions to try to figure out exactly what it is. You have the people immediately looking for a solution, which I actually had one of my friends actually just try to like think is there a way

to fix this? And then you have the people who don't have the positive reactions and you have those who are telling you to pretend it isn't real. And it's based, so it's one of the issues of having the invisible disease because you're not going to tell a person in a wheelchair, pretend you can walk. But if I can't see anything's wrong with me, they're okay with telling me pretend it's not real.

JACKS Aww.

JACKS: Wow, how hard that must've been for you. I mean, you're going through everything and someone's trying to tell you to pretend it isn't real. mean, goodness gracious, girl. Again, you are one strong cookie. I'm proud of you.

PIERCE: And I will say, like when we started this journey, nobody set us down and walked us through what this was. No physician knew what to do. Everything that we found and that we did is because we researched it and found it ourselves. We didn't walk out with a treatment plan. We walked out with a diagnosis and no idea what to do next. So, we were really feeling our way through unknown territory.

JACKS: Well, Candace, that leads me to the next question then. What do you think of this diagnosis and of the treatment and everything that you guys went through? What was the most challenging aspects of your supporting Judah throughout this treatment?

PIERCE: So, last night as I was thinking about things for to this podcast, I came across something that I had written. And so I really want to share this that I had written about her because this was written after one of her worst nights. And it says,
“Judah, she's a fighter refusing to let CRPS define her life or hinder her dreams. We witnessed her strength as she works through the pain, often concealing it with a brave smile. But those who truly know her can discern the subtle signs that the pain is always present. And last night was particularly tough. After a long day, Judah went upstairs to take a bath, but little did we know she was struggling more than usual. While Blake and I tucked her younger sisters into bed, we decided to check in on her. There she was, sitting against her bed, curled up in a ball with her head in her lap, quietly crying. Our hearts broke for her and we immediately rushed to her side, holding her close as she poured out her pain. She confided that the things she used to enjoy like reading no longer provided solace or distraction from the relentless agony. What upset her even more was her inability to get up on her own. She didn't want to bother us and instead tried to cope by herself bracing against her bed. It was a poignant moment as Blake and I for the first time in years had to assist our oldest daughter in preparing for a bath. We helped her in and out, dressed her, and carefully tucked her into bed. As we lay beside her, Judah shared her struggles with faith and questioned why she couldn't feel God's presence in her darkest moments. Blake tenderly prayed over her and together we cried with our beloved daughter. It's not easy to reassure a 12 year old that everything will be all right when she knows that tomorrow, like the days before, will bring more stabbing, crushing, and burning pain. We remind her that she's not alone in her fight, even though she may endure the pain in solitude. She's not alone in the battle against CRPS. We plead with her to eat as the pain often steals her appetite and we encourage her to take off her shoes, because hers was in her leg, to maintain some level of functionality. We remind her to keep going because life doesn't stop for pain. This morning she's still in bed and it's the first time in two years with CRPS that she hasn't gotten up. But we won't lose Judah's determination has carried her this far and we believe it will continue to fuel her fight against the pain and we will be right by her side offering love, support, and unwavering faith that she will conquer this battle.”

And so, I think that that just really shows those challenging aspects of trying to support her because she is alone or she was alone in the pain... with the pain. We couldn't take that away.

JACKS: Hey Judah, what's your reaction to what your mom just read?

JUDAH: That moment in time is one of the few really, really clear memories of the years during the CRPS itself, because a lot of the CRPS is now fuzzy, or it's almost as if I'm viewing a lot of what happened in third person. But that moment when I just, I completely broke down has been one of the ones that has stayed clear. And it was one of the scariest moments of CRPS. I had been trying to get ready for bed. I needed to shower, I needed to change, I needed to do all that. And I stood at the edge of my bed and I dropped. And I hit the floor and I couldn't move. I couldn't bring myself to get up. I was physically exhausted. I was emotionally exhausted. And it scared me. And the hardest part of that was the fact I didn't want to bother my parents. It's one of the biggest challenges with a disease like this is at this point. It just felt like I was being a burden. And it felt like I was just continuing to stress them out. And I would feel really, really bad, even though I couldn't control the fact that I was in this pain. And so, I didn't call them. I didn't want to call them. I just wanted it to go away. And so that was one of the hardest nights and one of the hardest challenges of dealing with this disease.

JACKS: Again, Judah, you're amazing. I just want to give you a big hug.

Candace, how do you balance providing care for your child through things like this and then managing other responsibilities?

PIERCE: This is a really tough two years and 10 months is how long we battled this before she went into remission. But during that time, actually, Blake deployed, my husband deployed. So I had gone back and gotten her into physical therapy because she was starting to lose more function. And so it was trying to get her to physical therapy twice a week, trying to get everybody to school, trying to get everybody to their activities, trying to provide comfort and love to the other girls too. Because every one of them feels loved differently. So I don't really know how I balanced all of that, to be honest. It was hard. But you're in a place where you don't have an option. You just have to do it. And so you do it. So that one's really hard for me to answer. I think most moms can attest you really don't know how you do it in the moments. You just, you do it because you don't have a choice.

JACKS: How about you, Judah? What are some of the hardest physical challenges you faced during treatment?

JUDAH: A lot of it was, a lot of the physical challenges itself were in reminding myself that I had to go through the treatment to get better. And it was also the fact that I had been through treatment before. It didn't work. And so it's dealing with trying to keep going while at the same time feeling like you've already been disappointed and wondering if it's even worth it to continue going if it's not doing anything. If it's not improving me, why should I keep doing it? And so there was a lot struggle within the fact of just having to go to physical therapy. I didn't want to go. I didn't want to go to treatment. I didn't want to get up in the morning and do it. At this point, it was just this fact it's not helping and nothing's getting better and it might never get better. And so that's one of the hardest parts about the treatment isn't even the treatment itself, but the fact that I have to choose to be in there and choose to do it.

JACKS: Yeah, there's a lot of mental strain that you're dealing with for this illness too, not just emotional. I mean, how did you get through that, Judah? Like, I mean, day to day, you know, like push yourself. I mean, you're a little girl, you know, like that's tough.

JUDAH: Yeah, I didn't have the healthiest coping strategies.

PIERCE: Well, Judah, I want to first interrupt you for a second because I wanted to clear up before you go into that is the first treatment program that we went into. Their goal was to teach her to accept the pain and live with it. Because if you look at CRPS, if you research it, they say there's no treatment, there's no cure. And so they're trying to say it's all in your head. And then they would tell us as parents that we weren't to acknowledge her pain. Yes! And so that's not a way to deal with this. So given that kind of backstory, Judah, I'll let you go ahead and finish what you were saying.

JACKS: My gosh. That changes things.

JUDAH: Yeah, it does. Yeah, no, my coping strategies through this were not healthy. The biggest one and really the only one I used was completely avoiding the pain itself or avoiding the reality. And so I'd spend a lot of my time reading books, using music, because music was a way to like leave where I was at the moment. I would in normal physical therapy treatment, a lot of my big distraction was I'd be reading while doing the exercises, which that's a skill in itself, in the fact I was able to do that. And I'd sass them, I'd talk back to them in a way that I wasn't being rude, but just like playing around. And it was just the way to keep the distraction off the pain because I didn't want to deal with it, I didn't want to live in the moment. And there was a big issue when we actually got to a treatment that worked where I would hide away in my headphones for a majority of the day and just have the music on because it was easier to distract myself from the pain than to actually live with it and try to work through it because that was the only way I knew how to deal with it because if I had kept focusing on the pain, I wouldn't have been able to continue. So while not the healthiest way to cope during it, it was really the only way I knew how that managed to somewhat work because none of the breathing exercises did anything and just I couldn't find anything else that

JACKS: I think you did the best you could, Judah. And it sounds pretty healthy to me. I can't imagine an adult going through what you went through and coping with it any better. So I think you did everything you possibly could. Now I want to hear about your remission. This is the, I can't wait to talk about this. So Candace, what was your reaction when you found out Judah was in remission?

PIERCE: So we are still new in remission at the time that we're recording this. So it's still fresh and you're excited and you're happy and ecstatic and you're all those words. But at the same time, in the beginning, you're like, is it real? Is it going to stay? Is it going to stick? And so it's an emotional roller coaster. I mean, this whole journey has been an emotional roller coaster. We have been fighting this from when she went into remission two years and 10 months from the time that she was an older nine-year-old and she's about to be 14, we have been battling this. so shock, my child is amazing and she beat an illness with no known cure per the CDC. So it has been a roller coaster. Looking back over that, I think you realize that there's some PTSD and all the things for everybody that we've been going through because that was our normal for so long. And so my reaction is like jumping up and down. my gosh, she got her life back. This is amazing. But there's also a roller coaster ride of emotions that come with it. It's so hard to explain.

JACKS: I mean, and how in that aspect too with Judah, how did you support her through this transition? I mean, again, like you said, it's a rollercoaster of emotion and Judah's probably thinking the same thing. Like, is this real? I've been dealing with this for so long. Like how, you know, what do you do as a parent?

PIERCE: I don't think anything changes from supporting her while she was going through it to now supporting her through remission. We are having to work together to find new normals. What does life look like now without pain without CRPS a shadow over her life and together we've had to figure out what are these new normals but we're also having to support her through things that came up from the illness where she locked herself away from the world and from reality. And we're having to pull her out of those things. So we're having to support her sometimes by pushing her out there, pushing her outside of her comfort zone to be like, hey, you got your life back, get out there and live it. You earned it back.

JACKS: Judah, how did you feel when you were told you were in remission?

JUDAH: It was one of the best things that's ever happened to me in my life. But it was also really strange because I had gone from living for like almost three years in this pain to suddenly just not having anything there. And so it was also just this weird strange sensation because there wasn't anything there anymore. And it was having to get back into the idea of I have a normal foot, I have a normal leg now, there is nothing wrong with it anymore. And it doesn't hurt. And so there was also a lot of having to figure out what is like normal pain now, because when you're feeling the all-encompassing pain, you really don't feel your normal pain. And then suddenly you're back in it and out of nowhere you're feeling like, it hurts to sit crisscross applesauce for long periods of time. Now, I didn't know. Yeah, it's having to get used to this new reality, but it's amazing because you've been fighting such heavy pain for so long and it's gone now. And it's like the feeling of feeling free at that

PIERCE: And I think Blake and I, every time she makes a noise, we're like, what? What is it? Everything okay? What's wrong? What's going on? And she's like, it's normal pain. And we're like, okay, okay. Are you sure?

JACKS: Well, Judah, when you found out too, was there something that you were like, I can't wait to do this or I can't wait? Like, was there something that you were super stoked to do?

JUDAH: Sprinting. That was the one thing I had wanted to do with CRPS because I could not run or even push myself too fast or I would collapse. The fastest I could get was a jog. Even then it would end up with all -encompassing pain. So the fact that I could go a full sprint again, it was amazing. It was one of the best feelings I ever had.

JACKS: Do you think now you're going to do a little track and field? You're to be a runner now?

JUDAH: I don't know. It's kind of gotten to point where now that I can run, I just haven't since I've really gotten back. But it's something I sort of looked into because I used to be really, really fast. And I do want to build up back there to be fast again. But I also have to start putting the work in and start training to actually be able to do.

JACKS: Very mature of you, Judah.

PIERCE: I will say this little girl who is in this terrible pain that most of us cannot even imagine, she maintained straight A's all through her middle school years, because she had this all through middle

school at one of the top schools in the state of Florida, one of the hardest schools. And before we went to this clinic that we went to, and we spent four months and two weeks at this clinic for her to go through this treatment every day before she went into remission. She knew that she was going to have to push. So she started getting up early in the mornings and she was running through the pain. Cause she's like, I have to be stronger in order for this to work in order to go to this clinic and to hopefully be in remission. And so there were moments like what I read, but she, and that's why it was so abnormal with what I wrote where she's two years into this battle and she is not getting out of bed. She has fought. She has fought the entire.

Two years and 10 months to try to have a normal life, to live a normal life. And the people that were coming into the clinic when we went to where she was thankfully was able to go into remission, people were coming in with CRPS that were in wheelchairs, that were on crutches, on knee scooters, these people that were coming in. And so I would tell her through this whole journey, like, you've already done that hard work, you know, you learned how to walk again. You learned how to be barefoot again. You learned and maintained it and you worked hard to maintain it. And you know, we went to the clinic, not in a wheelchair and not on crutches like most of the people and most of the kids that showed up with what she had because she'd already put in that work. So she's just amazing.

JACKS: What an inspiration she was to those kids, I'm sure. Judah, what do you think, and Candace, you as well, what advice would you give to nurses who are supporting young patients and their families going through

JUDAH: I think I said this last time too, but it's the biggest thing is just to believe them and to help your kid feel like that or just help the patient if you're a nurse to know that they understand that you're going through pain. They might not know how it feels, but they're not going to ignore it and they're not going to tell you, it's made up because they understand you're not making this level of pain up. And it's just that idea of them accepting that you are in this pain and not trying to undermine you or try to tell you it's not real or to act like something else is causing it or something that's completely different is there.

JACKS: Acknowledging your pain. How about you,

PIERCE: Absolutely. Acknowledging the pain is huge. I would say when you have a patient who has a rare disorder like CRPS, some physicians can go their whole, some nurses can go their whole career and never see CRPS, don't even know what it is. Take the time to look into it, take the time to research it. But I also want to piggyback on what Judah said about acknowledging our pain. And CRPS by itself is known as the suicide disease because the pain is so intense and there's no known cure per se. People don't want to live in this terrible pain. And they see that as the only way out of it. And so what I would say is maybe we should reevaluate how we treat these patients.

Because we went to a clinic that is highly known, supposedly has a high success rate, the very first time when we first got our diagnosis, but a high rate, they say, helping CRPS to go away. But all they did was tell us to ignore the pain. And as parents, they told us to ignore the pain and all Judah wanted was for us to acknowledge, just acknowledge that she's in pain, acknowledge that, you know, this is happening and this is what's going on. And for her that, that really helped her to know that she wasn't alone rather than being made to feel like I'm making this up and nobody believes me. And, and I think that that really helped her to be able to deal a lot better with the pain. As a healthcare provider, I personally believe that we need to reevaluate how we treat these patients.

JACKS: I mean, yes, Candace, and I'm sure that would drive you a little bit crazy being in that position and someone telling you like, there is no pain, ignore the pain. Like again, as an adult, we wouldn't be able to deal with what you'd went through. Well, ladies.

PIERCE: Mm hmm. Right. Yes. And CRPS is in your head. So they are correct. But because it's nerve pain, it starts in our brains and it, you know, shoots it down. That's how it works. But to say that it's just in your head, that doesn't help.

JACKS: No, it really doesn't. Well, ladies, we are at the end of episode one. I would invite everybody to join us for episode two. And thank you for joining this one.

Episode 2: Chronic Illness to Remission: Navigating the New Normal

Transcript

JACKS: Well, welcome back, ladies. We're here for episode two of CRPS. And I wanted to just let everybody know, if you didn't see episode one, be sure to go back and watch it. In episode one, we talked about Judah's journey from diagnosis to remission, highlighting her physical, emotional, mental challenges that she and her mother faced along the way. In episode two, we are going to talk more about the patient's experience and provide insights, emphasizing the role of healthcare professionals in supporting patients throughout this journey. So ladies, if you're all set, we will dive right back on in.

PIERCE: I'm all set. Judah, how about you?

JUDAH: I'm good.

JACKS: Judah, you're the most important one, Judah, you all set? All right. So to both of you, how was the experience of managing an invisible illness where symptoms aren't always visible to others? How has that differed from managing a visible chronic illness where they are more apparent?

JUDAH: I'm good.

JUDAH: I used an analogy last episode saying you wouldn't tell somebody in a wheelchair to pretend they can walk. And I feel like that's one of the biggest differences with dealing with an invisible illness is the way people react to it. If they can't see something wrong with you, a lot of people are like, then there must be nothing wrong with you. It's the act of having to see that there's something physically wrong. And so you have the good side of people who are actually sympathetic and who actually want to help. You have the side of people who immediately look for something they can see. And if that has to be a doctor blaming my mom for doing something to me, or if that just has to be a person telling me to pretend it's not real, or that it's all in my head and I'm making it up.

PIERCE: Yeah, she's talking about, are you talking about one of the ER visits where the doctor came in and was like, where's her splint? And I said, you didn't put her in a splint. So in the beginning of our journey, we didn't know that it was CRPS yet, but we had kind of had an idea, but we were with just a

regular orthopedic clinic on base, on a military base. And we were just moving to Florida at this time and she was screaming in pain. I'm like, I don't know what's going on. So, in the very beginning we went to the ER probably what three or four different times trying to find what is happening? This is not normal. This is not a sprain. Why is she screaming like she's dying?

And so, we're you know, one of the orthopedics that we hadn't even seen this particular one, but he comes down from the clinic because he was on call and His first words out of his mouth are "well, where's her splint?" so my words back to him were, "you didn't put her in a splint." So he leaves the room and sends somebody down to put her in a splint, which I did end up cutting off a couple of like probably 24 hours later, because she's still screaming in pain. And I'm like, this is not, this is not working. So, I would say in the beginning, it was really hard because most people with CRPS will tell you that they have gone to the emergency room multiple times, and eventually you start, I'm sure people start questioning you like, why are they back? What is going on with this?

And no, there's really something wrong and we don't know what this is. And I don't know if anybody has seen the, there's a show that Judah and I finally did sit down and watch it. It was on Netflix and it was about a little girl with CRPS and her family and how the hospital treated the family and the mother and took their little girl away and tried to accuse them of something that wasn't true because she had an invisible illness. She had CRPS. And so it's really hard in the beginning. So my biggest advice is to make sure that you educate yourself and be prepared and be ready. Have those notes, what you've done, what you haven't done, but you also have to find those physicians that are going to fight with you. And we had a really amazing pediatric orthopedic who just really wanted to fix her. And he knew that something was wrong. And I remember him just sitting on the side of the bed being like, I've done everything I can do. There is nothing for me to fix. And he's the one that helped us get to our first treatment center.

But I think that's what's really hard. When somebody has a break or somebody has something visible, it's seen, it's known. People know what to do about that. People are really uncomfortable when you have an invisible illness. I mean, friends are uncomfortable, you know, out in public, it's uncomfortable. Or you have people who say, well, she was just running. Well, yeah, she can run and she can walk. But they don't understand the pain. They don't understand the disease. They've never looked into it, but they just see her and they're like, she's fine. But if you really know her, like I said, in that note, like if you really know her, you see those subtle signs that she's not fine. She is just trying to continue to live and not let CRPS win in those moments. And I think that's what's the hardest.

JACKS: Absolutely. And you mentioned something that leads me to my next question, Candace, and about other people's perceptions or misunderstandings of the illness. And how did that affect you and your family, particularly in social or public settings? And Judah, you did talk a little bit about this in episode one, where you said like you would be crying and like, your friends would try and help you. Can you tell us a little bit more about, do know what I'm referring back to? How you were saying like, your friend would try to help you. Like they didn't understand what was wrong with you?

JUDAH: Sorry, I lost that for a second.

JACKS: That's okay. No, you're good.

JUDAH: Yeah, there's been multiple instances where things like that can occur. I feel like a lot of it was in middle school. We went through middle school where the people you meet in sixth grade, you're going to know for the rest of your three years in middle school. And so you live in a high middle school where

everyone's going to know your name at that point. And I feel like one of the biggest things was like walking in there like on a cast and stuff and then having a physical thing. A lot of people notice that because I'm walking in a cast and a knee scooter like walking around. But like when the cast is off, even the people that I have told the CRPS about, a lot of them forget it exists or forget that I have an issue now that they don't see anything wrong. And like there's a few kids who will remember and those are going to be more your like closest friends. But even then half the time they're not actually seeing you're in pain because you've either gotten too good at hiding it or they can't read you as well unless it's a really bad day and you're actively showing it. So, it was definitely a lot harder in the friend department and it got to the point where I didn't want to bring up the fact I had CRPS or any of that around kids at school and I wanted to separate that from my school life which was hard when it was like always hurting. But I didn't want to wear things that would show that I had something wrong with me to school. I didn't want to leave the room and use like the 504 plan that I had in place for stuff like that because then it gave attention to the fact there was something wrong with me. I'd already experienced enough with people looking at me weirdly after it or treating me differently or just forgetting to exist in the first place. Which really hurts when you realize people you've told have completely forgotten about it and you still end up getting kicked in the

JACKS: How about for you, Candace, too? Like, how did it affect you and your family, you know, in social settings? Like, do have any stories?

PIERCE: Well, I think for us it would limit how much we went out because we didn't want to take her somewhere and she's struggling and you know, in a lot of pain. But when we would go out, she would take a book, she would have something to try to distract her and she would remove herself as it got worse, as the pain continued to get worse because it got to a point where we were like, we have to do something. Like this is not getting better, it is getting worse and we have to find something else. We started researching and there was a clinic that has, like they specialize in CRPS and they won't say that you're cured, they will say that you're in remission and they fight with you and for you.

But because it is so non-traditional, insurance doesn't cover it, which is crazy. But yeah, it's more of just, it's invisible. So, people don't understand, people don't believe you. People see the opposite of what you describe because they don't know her. We stopped traveling because it was so hard, and we love to travel and being a military family, your parents live, you know, far away and so you have to drive and we just, it was so hard on her and she would struggle for days after we would get somewhere that it was just, it wasn't worth it anymore. So, we really became more home-bound so to say, like choosing to not make her go out in those places and really restrict, know, it kind of restricts what you can do as a family and where you can go. And even with family, mean, family is the same way. Like my parents were amazing as far as coming and seeing what Judah was going through and being a part of what Judah was going through. Because if you don't see it, you don't understand it and you don't know it. And so, when we say things like, hey, we're not traveling anymore, then, we can't get to you because it is so hard for her in the car. But like I said, if you don't see it, you don't know it. So when you go out in public, when you're with your friends, if they don't see it, they don't understand. And it's hard to have a connection when you don't understand what they're going through.

JACKS: Sure. Well, now that you're adjusting to life and remission for both of you and your family, can you describe the emotional journey you've experienced for you as a parent from the initial diagnosis to hearing about her remission?

PIERCE: Such aa emotional roller coaster. You know, you go from like just wanting to scream, like just want this to go away to being excited that she got her life back and you know that she's enjoying life again. It's really hard to process it. And I will say when you adjust from this chronic illness like this is how life was. So this is how life and you're by yourself, it's hard to process. And as a healthcare provider, there's nobody there to help you process that. Like I couldn't go out and get and meet with a psychiatrist or a mental health provider because they're all booked. Because when remission happens, remission happens. So there's no help with processing. And I think it takes time to really chew on that. You're excited.

Don't get me wrong. Like I am so excited, but it's a lot of it's a huge emotional roller coaster to process. And I remember being at the clinic that we were just at where she went into remission. I was talking about some of the things that were going on and she a mom who's going through this too. She said you can only heal one thing at a time. I was, you are so right because when you are going through something like this as a parent, your stress levels are through the roof. Like you are constantly researching. How can I fix her? What can I do for her? Checking in on them. Being all that you can be for them, encouraging her not to let this like when not to let this take over her life. And then you go to and so it's just it's a lot. It's a huge transition. It's a good transition. But emotionally, it's a lot. I wasn't prepared for what it would be like to go from. Yeah, it's a lot.

Your emotions are all over the place, but then you get to also focus on healing yourself taking deep breaths and getting your cortisol levels down and your stress levels down and eating healthy and being present instead of surviving. And I think that's one of the biggest things that I have learned that I wish that I had latched onto was during that two years and 10 months, I felt like we were really just surviving. We weren't thriving, you know, we were surviving and that was our life. And what I should have been doing is figuring out how to presently live, how to live in the present rather than just, yeah, rather than just trying to figure out how to survive through this day. Because even though that was hard, one of the hardest things I've ever gone through, it was still life. Life doesn't stop. I think that's my biggest lesson that I took from this.

JACKS: It's hard to do that in the moment though, and what's amazing about this story is that not only did Judah get her life back, but I feel like you did as you mentioned, it's just, it's a beautiful story, Judah. I'm so happy for you. Candace, how has your life changed for your family since receiving the remission diagnosis?

PIERCE: Trying to figure out our new normal, being able to travel and what we can do. And I think that's our biggest thing is we were a family that loved to travel, weren't we, Judah? And so...

JACKS: Where was the first place you guys are going To go?

PIERCE: So, we went and saw some friends in Montgomery. She's going to go to Aviation Challenge Camp. And this time she gets to go pain free. She got a scholarship to go. So, she's going to that and she's getting to do all these things that she has always wanted to do pain free.

JACKS: Cool!

PIERCE: We live by the beach, so we get to go to the beach, and she can run on the sand. And I think we went to the beach the first weekend we got home, didn't we? We ran on the sand. When we were told she was in remission, one of the things our family loves to do is go on the boat. And we hadn't really

been able to enjoy the boat because the vibrations and stuff from the boat were just so hurtful for Judah. And so, we put her, we put the boat in that weekend, and she got up on water skis like first time out in the water. so, we put her to the test to make sure like this is remission and it is sticking. And so, but we're able to do these things that we love to do as a family, but we couldn't really spend a lot of time because number one, we didn't want to leave Judah by herself. And, you know, we wanted to do things we could do as a family, but we wanted her to be able to enjoy life again. And that's really the biggest thing that has changed is Judah gets to enjoy life

JACKS: So, talking about adjustments then, I mean, there are any other or really big adjustments besides like not traveling and not really going out as much that you feel like you had to make as a parent.

PIERCE: I would say as a parent with three kids, when you have one who has something chronic, it's hard to not just be focused on her. And I wouldn't say forget your other children because you don't forget them. It's just that the time and energy that is spent taking care of a chronically ill child takes away from your other children. And so, for me, it was how do I make sure that I'm giving my other daughters what they need? How am I meeting the needs of Judah? But I'm also making sure I'm meeting the needs of everybody else in our house. And that's really hard because even as a parent with a child with a chronic illness, you're tired of emotional exhaustion. No, I don't have the pain that she has, but you have that emotional exhaustion, that mental exhaustion of trying to fix it. How can I fix it? And you carry that. And that is hard, that is hard.

JACKS: Absolutely. How about you, Judah? Let's talk about how you adjusted to life after living with a chronic condition and then suddenly not having it.

JUDAH: Yeah, I really adjusted to living with it by just learning to separate myself from the world using books or music and to really just avoid it. And the other adjustment ended up keeping it hidden or separate from school as well. And so having to adjust to that and having to adjust to still having to get up in the morning even while dealing with this pain. Actually, right after we ended up getting CRPS, we ended up moving and so before we got our diagnosis, it was CRPS, we were in the process of moving to Florida. So, I ended up starting in a brand-new place with a disease we still really knew nothing about that was continuing to get worse a whole lot more. And so, you're having to address a completely new environment where you know like really absolutely nobody at the same time dealing with something you know absolutely nothing about at the moment. And it was definitely a hard adjustment and it wasn't something I was prepared for. And it's what it led to a stage of introvertedness in my life where I basically cut myself off from everybody. And so, while I didn't know a lot of people at school, there were very few I could and could still legitimately call friends.

JACKS: Judah, is there a challenging part of the transition from having a chronic illness to being in remission? Was there something challenging about making that swap back that you could talk about?

JUDAH: It's, I described this a little bit earlier, but it's now having to get used to normal pain because I'll get random normal pains at some of the most randomest times. And I'm over here like, what the heck is happening? And so it's getting used to that because normal pains happen every day for some reason. And now I'm having to refigure those out because I've completely forgotten what it's like to even feel, not have constant pain, let alone feel normal pain for once. So it was definitely a big, big challenge with that. And I feel like the other challenge is having to remind myself there's nothing wrong with me anymore. Because there's always that big fear it's going to come back or that if I do something, if I like injury again, it's going to restress it to the point it'll I'll have to deal with this all over again. And I don't

think I'd be able to handle having to deal with another three years of my life being taken up by so much pain. And it's definitely some of the biggest challenges coming back. And I think one of the other challenges/ The idea of remembering how I'm supposed to act without pain, because I mean, I closed myself off for a while, and it's having to reopen back up and re-experience what the world is like without pain.

JACKS: So that leads me to my next question for you, Judah. Has your daily routine changed since being in remission? Have you added more things in?

JUDAH: This was something that I actually worried about a lot when I was in treatment, well my final treatment before remission. And it's kind one those things when you're like expecting remission to create this huge change and suddenly everything's going to be different. But now when you come back, it's the same house, it's the same people, it's the same room that you've lived in for the past three years with the pain. It's the same area, it's the same town, it's the same people you've spent your entire three years of this around. But you come back and while the routine is the same, it's also different because now I'm not struggling to put shoes on in the morning because it hurts. I'm not struggling to pull myself out of bed because I know the minute I leave this bed, the pain's coming back full force. It's no longer having to worry about this pain stabbing me or causing me to almost fall, decide to give out on me randomly while walking down the stairs. It's like it defies all your expectations and the ways of what you're expecting to happen and the ways of what you're not expecting to happen. But it's also something wonderful and it's really an amazing

PIERCE: She sat beside me in the pool one day and she was just sitting dangling her legs in the water and before she could not have done anything like that at all. And she said, I have to remind myself that I can do this and it's not going to hurt. it's just something that sticks in my mind is her sitting beside me with her feet in the water. Seems simple to most parents, like, my kids do that all the time, the pain from the allodynia that CRPS causes, she couldn't even handle the air blowing over her leg, much less water.

JACKS: My goodness. Yeah, just something you take for granted or just don't even think about. Judah, were there any challenges that you faced while adjusting to post-life treatment that sticks out to

JUDA: I think it is kind of weird not having the same routine that I had while during treatment because like treatment you kind of fall into this routine of what you're doing and how you're working toward it and you're coming back here you don't have that same routine anymore because now you're just trying to figure out how to live life because I've had like a treatment routine since we really got this diagnosis since from when I started my first treatment to just going through basic physical therapy to just coming back and starting this brand new treatment that ultimately put me in and so it's like a loss of comfort in the idea you have a set routine, but it's also you're gaining the comfort of knowing that it's not coming back and that you just defeated something that's been with you for

PIERCE: think one of the biggest challenges for both of us, and Judah, I'll let you piggyback on this, is we were at a place that we just left where she actually went into remission, but there were so many people who had CRPS and who were dealing with this of all ages and from all over the world. She actually learned how to do the Rubik's Cube by, was he from Ireland? He was from Ireland and he had CRPS in his arm. He couldn't even move his arm.

JUDAH: He was from Ireland.

PIERCE: arm and he pulled out a Rubik's Cube and said, hey, I did my dissertation on the algorithms for a Rubik's Cube and he taught her how to do a Rubik's Cube. saying all of that to say like we had a support group. We loved each other. We worked with each other. We cried with each other in the parking lot of the clinic. We went to dinners together. We knew what each other was going through and supported each other through all these challenges. And you go into remission and it almost feels like you're ripped away from this community that you developed and go home and you're going home to people who haven't been what you through what you've been through and who don't understand what you've been through. And you miss that community that you had at the clinic where all of these people understood. They just understood. And I think that's one of the biggest challenges for us coming home and getting back into our normal, normal routine of living.

JACKS: Right, right. So Candace, that's actually what I wanted to talk to both of you about next was the emotional and social aspects of having a chronic illness, how it affects you now that you're in remission and what you might not have anticipated during treatment. that maybe you may have just answered that question with the community that you surrounded yourself with.

PIERCE: Yes, absolutely. The community was such a big part, I think, of even going into remission. But I'll say that when I walked into the clinic, because she was there for four weeks, four months and two weeks, and we had no idea when she was going to leave. And so we did some split like Blake stayed with her the first bit. My parents went up for a couple of weeks and then I was there for over 10 weeks with her. And so, I really got to know these people that were going through these same things, moms of children who are going through it. And the support is just huge. And it's something you don't have in the beginning. We didn't have it when we were at home. We didn't have that until we got made it to this clinic. And I think that that's part of the hardest because you don't really have somebody emotionally and socially to help you navigate through your feelings or even just to hold you and say, it's okay to feel this way. And so you doubt yourself, is it okay for me to feel this way? I don't know, I've never lived this before. And I just didn't anticipate how hard it was to come home. And the thing is, is that we've stayed in contact with, she still is in contact with a lot of the children. There's a lot of kids at this clinic and she's still in contact with them. And I'm in contact with a lot of the parents, and the people themselves who have gone through it. And they all say the same thing. I wasn't ready to leave my community. I didn't know what it was going to be like to leave my community. And I desperately miss that community because you bond over such a traumatic, rare disorder that most people don't even understand. And it's probably not something while you're there and you're hearing this wonderful news about your daughter or your child that you would even think like you're going to be feeling like this later. You know, you're just so happy. And then it's just, like you said, you're ripped from a situation where you are supported and everybody understands to going back to normal. And yeah, it's just something that you wouldn't expect. Judah, how has your perception of yourself changed now that you're in remission? How do you feel about yourself?

JUDAH: This one was a bit of a harder one because it kind of during it, I kind of have differentiated myself between three different periods of like in the beginning being this extroverted younger kid who just wanted to make friends with everybody who she met, even if she never asked their names, to becoming such a closed off away from the world, avoiding it like really most social interaction that wasn't people at school and kind of hiding away from it, to having to come back from that and figure out who I was because, and who I'm supposed to be because I don't have the same fearless nature of walking up to everybody and saying hi as I did when I was a lot younger because I've seen the other side of people a lot more and I've seen the people who don't act who don't act nice or who really don't really care about or who are just looking for reasons to place blame on you or just trying to tell you to forget about pain that

you have. And it gives me a much more cynical view on people now. Because now I'm like overhearing like other girls my age all complaining about the fact they got dirt on a lululemon skirt when they're at summer camp. And I'm over here just like getting frustrated because I'm just happy I'm able to wear normal clothes without worrying about pain. And over here complaining when they chose to wear that skirt to an outdoor summer camp. And so it's definitely made it a lot harder because I just, you start seeing a lot of the flaws in the way a lot of other kids my age think. And now I'm just kind of like, it's scary to go out there and make friends, but I'm also learning that I need to like interact with people who aren't my family because I've ended up having like a fully charged social battery now but nobody to spend it on. And so, like, I'm getting lonely because I realize closing myself off is not that much of a good thing because now I'm like over here, like, I have nobody to talk to anymore. So it's definitely a lot harder with the perception of self.

JACKS: And I think that makes total sense. And I agree with you, you know, this happened to you and now you see the world in a different way and that's okay, you know? I love that you think that the Lululemon dirty skirt is not a big deal. That's the way everybody should feel. The last question that we'll talk about, and this is for both of you, is what has it been like to reintegrate into activities and routines that you missed out on during your illness, sorry. And are there any social situations that are more difficult or just different in general?

JUDAH: I think it's been actually kind of easy to get back into activities or even to start trying new activities because I'm no longer worried it's going to cause, it's just going to act up or cause pain and so it's a little bit more of that fearless of I can try all these new things because I've spent the last three years having to hide away from everything and now I know it's no longer going to hurt me. Besides from me maybe tripping and falling and the occasional like skin -year -knee type. I feel like while those activities have been easy, social situations have not gotten easier. If anything, it's like coming back from being behind a wall and realizing how awkward you are around people, even though you want to be around them. I don't understand how to read social cues anymore, or I don't even think I ever did, because I was just the extrovert talking about everything. And so being older as a teen and going into high school, as mom said, teens are usually not super nice to people who don't act a certain way or don't look a certain way now. And so it's definitely a lot harder to go out there and try to put myself on the line because you understand how a lot of people might react to you because you are a bit awkward. You're a bit really loud talker. Like mom has to tell me to quiet down when I'm not even realizing I'm being loud because I get so excited I start yelling without realizing. And so it's like that but also trying to put myself out there because I really, really want new friends now. But a lot of teens either don't know how to hold a conversation or will not be willing to hold a conversation with me. And so it's definitely a lot harder with social situations because coming back from just hiding away and becoming an extrovert again is a lot harder.

PIERCE: Well, and a lot of people got to know her when we moved here as an introvert because she did lock herself away and she put a wall up. And so now she's having to overcome those kids that did try in the beginning to be a friend to her. And it's not that she wasn't friendly with them. It's just that she locked herself away. And so, she's seeing the repercussions of those choices that she made when she was going through this illness and also how teenager know and preteens don't understand what she was going through and why she locked herself away and so they don't know You know how to react now so She's definitely going to have a lot of a lot of growing this year as she walks into high school But she's walking into high school pain -free. So in remission We did come home with some things when you were talking about routines. So she has some. We brought home some medical equipment that she has to do. So she has to do vagal nerve stimulation twice a day. And then she does a microcurrent machine twice a

week. And we go back in six months to, for, she'll redo all of her treatments for that whole week. And so, yeah, I know she's super excited about that.

But before we go, Christy, I did want to ask this last question of Judah. So Judah, when you're looking over your journey from when we received your diagnosis of CRPS to today, when you're living life in remission, what message or advice would you like to leave with, say, our listeners, especially seeing as most of them are going to be nurses and other healthcare professionals? So those people who are really supporting patients like you and families like ours who are going through similar experiences.

JUDAH: I think one of the biggest things as like the nurses is especially at our where I became went into remission we had such a big community and it wasn't just among the patients it was among the doctors and the nurses who were working there because they actively worked with the patients you could tell they wanted to get to know you and they wanted to help you and they were willing to push you they would joke around with you they would playfully insult you if you insulted them back. You could crack jokes, you could tell them about what you're doing, they'd ask what you were doing. You get to learn about their own family and they learn about you and it's one of those deeper connections because you don't have to go through that experience to be able to develop a connection with these people or other people who are going through these disease. But you have to be willing to listen and care for them. And I think that was one of the hardest things because going through all the different treatments I did, you meet people who are basically just there, who are stuck in the mindset of, you're going to have to live with this forever, learn to deal with it. And so they're going to treat you snappily. They're going to treat you if you start crying or going over it, they're not going to be too kind about it because you have to get over and learn to deal with it in the real world. And so you meet people like that and some of them might have good intentions, but things like that can hurt more than they help. And then you meet people who really want to, who like enjoy hanging out with you, but they don't know how to fix this type of thing. They can't quite do anything, but you have the people who are willing to try. They're willing to try to push you in physical therapy and stuff. Then you meet the people who actually know what they're doing and are really there to connect with you. And so even if you don't know what you're doing, if you don't know much about it, try to connect, become friends, work for your patient because when you just stand there and just watch them or treat them as a case study but don't actually do your own research to try to help them and connect with them. It hurts more than it helps.

PIERCE: Absolutely. And what I would say to this is going through something like this when, as I said before, when you look at CRPS, they say that there's no known cure and insurances only pay for your band -aid treatments, physical therapy, cognitive behavioral therapy, ketamine drips, opioids, spinal cord implants, and all of those things only treat as a band -aid. she had her whole life, Judah has her whole life ahead of her, and those were options that we didn't want for her, but that's all the insurance will cover. So we had to look outside of the box and look for how we could treat the root cause, which was the nervous system. And we spent upwards of \$75 ,000 in order for her to be sitting here on this podcast to say that she is in remission and insurance has paid none of it. So, if you're a healthcare provider who has sway with, you know, healthcare policies government, we have to do better with requiring our insurances and requiring our federal government organizations to look at what actually works to treat root causes. Because every child and every adult that is suffering from something like this deserves to also be able to have treatment that will put them in remission that has been shown where the evidence shows that it works rather than continuing to push paying for only band -aids.

JACKS: Well, ladies, I want to thank you both for being here. And Judah, I'm over the moon happy for you and for your remission diagnosis. And I just want to let all of our podcast listeners know, you know, there

is this is a full series and we did have a series prior to this about six months ago that I encourage you to listen into as well, as well as to explore many of the courses that we have available on elitelearning.com, help you grow in your careers and earn CEs. Thank you so much.