

InVisible InCourage with Nancy Sharp

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Transcription provided by Stacie Valle for Virtual VRI

Kellie Pokrifka: Hello everyone! Welcome back to Invisible Incourage. I am Kellie, and I have Kelly and Stacie with us today. I am pleased to present Nancy Sharp! Tell us how you are involved with invisible disabilities.

Nancy Sharp: I was originally introduced years ago when I attended an event with a colleague who had a sibling born blind. She knew I would be interested because I had premature twins with special challenges. It was a few years later when my twins were in high school and my daughter was in speech/debate at school and decided to take on her own invisible disability, which for her is mild cerebral palsy. I thought, you have to meet Wayne Connell, before I knew Jess Stainbrook was involved. It was such a great synergy to put my daughter in touch with this great association. It made her speech so much more substantial, but it also gave her an important community and skills and tools. It broadened her whole world. It has been an enriching experience for the whole family.

Kellie Pokrifka: That is so cool! What is it like being a caregiver to someone with invisible disabilities?

Nancy Sharp: Well, I have done a lot of caregiving, like any mother with children has. But it is interesting. My kids were born 19 years ago tomorrow and they were born at 30 weeks. That was extremely early. Rebecca came first, 2.5 lbs. and Casey followed 6 minutes later at 3 lb. and 2 ounces. When premature babies are born, and they are multiples, the chances for disabilities and challenges are greater than if you have a singleton baby born prematurely. It has been challenging and stressful. The whole notion of invisible disabilities is you don't

always see it and know what you are dealing with. Things are always a bit gray.

It isn't like it is black and white. And that has probably been one of the most important takeaways from my experience. You can't look at caregiving and disabilities in such black and white terms. It can take time for us to see what the challenges are and to see what we can do to support. Sometimes there is more than one right way to go about doing that. If you are a person that likes certainty that will be challenging. I am that kind of person and had to rewire myself.

Kellie Pokrifka: How do you go about doing that?

Nancy Sharp: You bang your head against the wall enough that eventually you realize "this isn't working." My son has ADHD and some processing stuff and he was always the one that was a bit more challenging on the surface because he had a lot of hyperactivity. It was very difficult for me, still is, because he is wired so differently. What I have come to learn is that I don't really know what it is like in his body and head. But when I started to realize also that I can't make decisions that are best for me, but that are best for him. Not based on what I think I might like. For him, that meant going to a school, Denver Academy, an incredible place for Casey and for many kids with all kinds of learning differences. He has found great acceptance and developed incredible friendships. It was a place he thrived. You want that for your kids. It wasn't working for him in other settings and it was a very painful realization for me to really come to terms with that. Once I did and he was in the end of 6th grade and things were coming undone, it was like a huge weight was lifted off me. I didn't have to hold it all on my shoulders. I could let him be where he needed to be.

It took me a bit longer to accept in the same way with Rebecca.

There are many misperceptions with cerebral palsy, but she has had several surgeries, tendon lengthening, Botox, and lots of therapy. It was very difficult for me. It wasn't until I began to be able to talk about it without the extra stress it was huge for me and for her. And I gave her the greatest gift I could, for her to accept all of who she was. I didn't know that until I began to really be open about it. Because, why not? She really then stepped into her light and became a speech and debate star. Really, her work advocating for people with invisible disabilities has been exemplary. This was the first year she qualified for state championships, and she also qualified for nationals. It will be done virtually. And she has earned All American status, which less than 2% of kids in the US get that.

So having her advocate for people with disabilities has really open up her whole world.

Kellie Pokrifka: Such a huge step. And being able to talk about it to your kids. Any advice for kids going through similar things? Like, I wish there was a manual.

Nancy Sharp: Unfortunately there isn't one. You could always Google "how to have a hard conversation with your Kids" but the meat of it is not to stuff it inside. Before you have hard conversations with your children, I think it is important to get to a place where you are calm and accepting. It took me a while. Had I been able to embrace my children's subtle disabilities soon than I was, I think I would have spared myself and them a lot of angst.

I think the second thing is to be matter of fact about it. Our disabilities don't define us. I believe that our abilities define us and that is what it means to be resilient. To understand that no matter the circumstances we have the ability to transcend the circumstances. To push beyond the challenge of adversity. That is what it means to

be resilient. When we encourage our children to understand that, yes, they have these disabilities but they aren't those things. For people who have cancer, you may feel overshadowed by that, but we are made of so many wonderful things and it is up to us and our caring caregivers to focus on the good.

Kellie Pokrifka: Feeling overshadowed is such a huge component. Do you have advice for how to get over and out of that shadow? How did you build the resilience?

Nancy Sharp: I had a lot of tough life experience. With my children it was challenging. I was looking at friends and their kids were reading books at age 3, or running a marathon at 5, and my kid was like no where near that.

Kellie Pokrifka: Comparison is tough.

Nancy Sharp: Yeah, you can't do that. It isn't healthy. You have to really make decisions best for your kids. So to build resilience first of all, it is something that is a skill. One that you can practice and develop over time. I want listeners to know that no one is born resilient. We have to learn this. I am a self-aware person and I have worked hard to develop and cultivate high emotional intelligence over the past several years. Also, because I am a professional speaker in this area, I have done extensive research in emotional intelligence and that feeds a lot of my work.

I am a lifelong learner and I am humble enough to know when something isn't working. It may take a while to make a change because I have to be able to see what that change is first. But I think resilience starts with a feeling. It isn't about the things happening outside of ourselves, like the pandemic for example. Everyone feels oppressed by that. But the resilience we need to summon comes from within. A

feeling we have that something isn't working in our lives. Right now we are having more time to reflect on what really matters and the choices we make in how we live. So many of us are reflecting and that can lead to resilience.

One of the questions I always begin with, the first foundational question that is a part of the resilience framework I developed, and the first question is where do I feel challenged, or stuck or frustrated. If we can't answer that honestly then we don't have the tools to become resilient. We have to understand what is holding us back to apply the tools to help us move forward. Resilience is about integrating the lessons and the losses.

Kellie Pokrifka: Tell us more about your work.

Nancy Sharp: I have been a professional speaker for a number of years, which I love. Right now the world is changing and people are not booking live speakers, but I am doing a lot of work online. The second part to my business is writing. I came to speaking through writing. I wrote a memoir and it got a lot of attention and it sparked interest in my personal story of loss and resilience. That story begins and hinges on May 20, 2001. 19 years ago from tomorrow. That is what the entire book hinges on. I have gone on to write a few different books and have been a book coach. I have a Master in Fine Arts and am a certified instructor in Guided Autobiographies. I recently created a whole new platform for my work called "Tell your resilience story" and I am excited about it because it dovetails perfectly with the training I do with live audiences. But the platform is about helping people to own their mark in the world. To identify their life stories and to put it on paper. Whether for themselves, or a book, or a legacy for their family, or a Memoir - it doesn't matter. No writing experience necessary.

I like to serve others and that is what gets me out of bed every day. Helping people be at their full potential in life. So through the written and spoken word I make meaning of my life.

Kellie Pokrifka: That is so important, especially if dealing with chronic illness or pain. It is a struggle to put what you are going through into words. You want to but it is hard to do.

Nancy Sharp: I really just love to work with people. There are different options to do so and I think it is really important. I feel like the world will be a better place if we all could own what makes us unique and to celebrate our differences and abilities. Just to be involved with people in touch with ourselves.

Interestingly, the work I am doing is not just about being so self-evolved. That is a part of it but also about building empathy. The more self aware we are the better we are able to cultivate empathy with people. With family members, friends, business communities, and others. This is all part of resilience. There is individual resilience and collective resilience. Collective is something that is just as important. We don't live in a silo. We live in communities of our choosing and the Invisible Disabilities association is a great community. All you do supports the notion of collective resilience.

Kellie Pokrifka: I haven't heard of Collective Resilliance before. It sounds powerful.

Nancy Sharp: It is. Something that was really studied after 9/11 and lots of research about how communities can come together to heal and fortify. I integrate that too because when working with groups it is important. It helps people realize the link between how their resilience can also support a more collective resilience in their

communities.

Kellie Pokrifka: How did you get into public speaking?

Nancy Sharp: I got into it because my book, "Both Sides Now" just provided a lot of opportunities to do that. People started to reach out. It won the Colorado Book Aware for creative non fiction, and it got people interested. When I first started speaking the story was about loss. My twins' dad, Brett, died of a brain tumor when the twins were 2.5 years old. A lot of caregiving was going on there. It wasn't an invisible disability. You can't hide brain cancer. But a lot of people started asking me to tell my story and that was how it started.

I talked a lot about loss at first but then we have to pay attention to the way life goes on and I realized I was done talking about grief and loss in the way I had. Not that you "get over it" it is always a part of you. Tomorrow is my children's 19th birthday and I remember that day like it was yesterday, with their dad. But resilience is the bigger part of the story. The what now? The what next?

It is ironic that when we are able to hold that in a bigger piece of the story we better honor the memories of our loved ones. We serve those who we love better by living fully.

Kellie Pokrifka: You also wrote a children's book?

Nancy Sharp: I did! "The Sky is Everywhere" that originated from my twins after their dad died. I wanted to do something to give back to communities and families and children that are experiencing grief, loss and trauma. It is used in hospital settings and camps. I like it when it reaches someone who needs it.

Kellie Pokrifka: That is incredible. You have been through so much

and you really define survivor. You are so brave and a positive outlook.

Nancy Sharp: Well thank you. I have worked hard at that. That is also the role of a parent. But I want to live my life and be productive. I want to be someone that uses the things that happen to me and to help others move forward. Everyone has stories and hard things in life. No one gets away with living in a pristine garden. We all help each other and do what we can. This is how I make meaning and serve.

Kellie Pokrifka: And what about on the days you aren't feeling powerful. On your toughest days and darkest hours, what gives you the courage to get through?

Nancy Sharp: I didn't feel quite that badly the other day, but I did have a day like that and I was just tapped out. I was depleted and had nothing left to give. I was snappy and feeling fitful within myself. I sat myself down and said, "you're going to sit and put pen to paper to stop the swirling thoughts in the head." And that was important and grounding. Writing is a good strategy that helps me. The other thing I do is meditate. Centering and stilling my mind. Then I ask myself, "what do I need today?" and I think that is something that everyone can do. What do I need to make myself feel better today? If we wait for someone else to miraculously appear we might be waiting a long time. We have to realize that is misplaced energy. We have to be intelligent and self aware enough to know it is our responsibility to nourish ourselves. And it is up to us to know what we need.

Kellie Pokrifka: Not always easy but always important.

Nancy Sharp: And I mean small things. We could all use a vacation, but what can we do in the interim?

Kellie Pokrifka: Great answer. Is there anything else to say to the

invisible disabilities community?

Nancy Sharp: Keep pushing forward and being positive. I feel like one of the lessons to be integrated is the loss of freedom from COVID-19. Things we took for granted that were simple and life has changed. But maybe one of the lessons is that we are communicating in different ways and reflecting more openly and honestly about how we are feeling and what really matters. I think that is hugely important to this community to share their stories in ways that bring the world closer together.

Kellie Pokrifka: I love that.

Thank you so much for coming on today. We can follow your work in the comments of this and have links out to your stuff. If you can answer some comments from people that will be wonderful.

On Thursday we are having a special memorial day Invisible Encourage, so come back for that.

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