

Self Identity and Finding Meaning Following Diagnosis

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[00:00:02] **Krissy Dilger:** Hello and welcome to the SRNA "Ask the Expert" podcast series. This episode is titled, "Self Identity and Finding Meaning Following Diagnosis." My name is Krissy Dilger, and I moderated this episode. SRNA is a nonprofit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our website at wearesrna.org.

[00:00:31] "Ask the Expert" is sponsored in part by Amgen; Alexion, AstraZeneca Rare Disease; and UCB. For this episode, we are pleased to be joined by Susan Wegener. Susan is a licensed clinical social worker and therapist in Austin, Texas. You can view her full bio in the podcast description.

[00:00:52] Hello and thank you so much for joining us today.

[00:00:56] **Susan Wegener:** Thank you for having me.

[00:01:00] **Krissy Dilger:** So, let's start off by talking about coping with a chronic diagnosis. How does a diagnosis affect someone long term?

[00:01:12] **Susan Wegener:** So, a diagnosis, I wanted to actually start just by giving one of my favorite quotes, and it's a Leonard Cohen song, and it's "The cracks are where the light gets in." And so, being diagnosed sometimes takes a very long time. Sometimes people have been to several physicians, and by the time people are diagnosed, there might almost be a relief just to know and to put a name so they can start treatment.

[00:01:47] But there is an emotional adjustment process that goes along with the diagnosis. And it's that same grieving process that Kübler-Ross talks about in one of her books, which is denial, anger, bargaining, depression, and acceptance. I know in the community there's a lot of talk about that grief and adjustment process is not linear, that at any point you can go back from anger to depression, and so it's a very fluid process.

[00:02:27] And it takes time. People will say, well, how long will it take for me to get to a place where I feel like I'm okay and I'm comfortable and I'm working on coping strategies and accommodations? And so, I usually say, somewhere up to two years. It could be even more. Because you're grieving the loss of yourself and several parts of who you are, but you're also learning and gaining ways to cope.

[00:03:02] **Krissy Dilger:** Yeah. I think that's really true for a lot of people who receive one of these diagnoses in our community. So, what does the adjustment process entail?

[00:03:17] **Susan Wegener:** So, like I was talking about it in terms of it following along the emotional piece, like, initially it starts out with denial, which is kind of disbelief that the condition has even happened. There's

kind of shock and "This isn't me," and "Maybe they read the MRI wrong," or "Maybe I should get a few more opinions," because it's hard to kind of wrap your head around all of that.

[00:03:51] But then moving through the next step is anger, and sometimes people, it's okay to get angry at the disease. And I think a lot of times that gets taken out on other entities or people, and it's misplaced. But it's important to feel that and move through that. And then the next step is kind of bargaining, which is kind of that, "I'll keep a perfect diet," or "I'll start exercising more if we could just kind of make this go away."

[00:04:28] And moving on from there is depression, which is where a lot of the grief sets in. And associated with that are a lot of losses. Just loss of your health, loss of, sometimes, relationships, sometimes jobs change. And so, from that one diagnosis, those are considered secondary losses. So, coping with each of those individually.

[00:05:08] It's a lot all at once, and it can feel overwhelming, but you are able to get to a place where things feel a little bit calmer, and you can manage better and lean into your support system. So, you just have to be patient.

[00:05:31] **Krissy Dilger:** Those are great sentiments to keep in mind, for sure. So, self identity and sense of self can also change following a rare neuroimmune diagnosis. Can you talk about identity, its importance, and the changes that may occur?

[00:05:51] **Susan Wegener:** Sure, and that's one of the losses, right? It's a very important and fundamental one. It also kind of depends on how old you are when you're diagnosed, where you are in your life. If you're moving forward in your career or you're working on building a family. And so, there are two different aspects to that.

[00:06:19] I want to define the self. The self is your character, your personality, your soul, the essence of who you are. Whereas your identity is who you show to the outside world or how the outside world sees you. So, I think there are changes in both of those, and a lot of times there are questions like, who am I?

[00:06:45] Like, it kind of becomes almost an existential question about, am I still capable of doing certain things? Do I even consider myself as chronically ill? Because I know that's hard, you know, having a chronic diagnosis. I think sometimes it's easier to wrap your head around than saying I'm chronically ill.

[00:07:10] Other things like how will other people see me, I think a lot of times the diagnosis starts out as invisible. If there's a progression and things become more visible, if you're using a device, assisted device, or moving slower, or if it affects your cognition or your speech. Those changes are hard, and our ego gets involved in how we're seen when we're dealing with our own sense of self, but then how are other people seeing me as well.

[00:07:52] So, it's an important piece though, because there is hope around working through all of these issues. Again, I keep repeating; time, patience, and even self-compassion are really important.

[00:08:18] **Krissy Dilger:** Great. I think just knowing that if you're experiencing these things are not alone in those feelings. That kind of a shared experience can also be quite powerful. So, some people may deal with feelings of denial following their diagnosis. Can you talk about how denial affects self identity and adjustment?

[00:08:47] **Susan Wegener:** Sure. So, denial is, I always feel like in a way it can be protective. When we talk about healthy denial, which is not allowing yourself to go all the way to the worst-case scenario, right? Kind of being able to stay in the present moment, and not that you're not acknowledging the future or your

condition, but that there's a protective layer that has enough hope, that will allow you to continue to function emotionally, physically.

[00:09:22] But then also, on the other side of that, I think some people go the opposite extreme where it's like, I didn't hear anything the doctor said. I'm going to keep pushing my body as hard as I can and prove to everyone that I can keep it all going and take on more responsibility, and then end up in overload.

[00:09:45] So, I always talk about the circle is the self, and there's a little tiny circle in that big circle that is the diagnosis. And so, by not being able to say that I have this diagnosis, you're denying a piece of yourself, which is really important because you're a whole person.

[00:10:11] Again, like, I was talking about your character, your personality, who you are is still the same. That part of you, that essence has not changed. So, finding ways to incorporate that into your life and conversations with other people, I think, is really important.

[00:10:37] **Krissy Dilger:** Can you just speak to maybe some of the coping strategies that you talk about with your clients for dealing with a shift in self identity or sense of self following diagnosis?

[00:10:53] **Susan Wegener:** Sure. So, one of the really important things that I work on is trying to reinforce strengths and values. I think that kind of helps people to realize that those parts of themselves are still there and to use that, the inner strength and the values.

[00:11:15] Just to give a reference, there's a wonderful exercise in *Dare to Lead* by Brené Brown that's a two-page values exercise. There are a hundred words. Look at those and decide which are the most important to you and resonate with you and then move forward in your life using those as kind of a guide.

[00:11:41] Another important thing is working on not comparing yourself to who you were prior, because there's a lot of lamenting, which is part of the loss, but if you continue to compare, it just creates more grief and more negative thinking.

[00:12:04] And so, that's why being able -- and I think you can acknowledge who you were and work through the grief and then continue to keep thinking, okay, well, who am I now? How can I move forward? What's left for this to help teach me and guide me? So, I think that's another important one.

[00:12:34] And then working on separating out the parts of the old self. There might be pieces that are still there, but like, if you'd been an athlete or a dancer or a runner, that mindset, that "go, go, go" might still be there for you in your mind but your body may not be able to continue at that level, but there are other things that you can do, which is the accommodation piece.

[00:13:09] So, I think trying to figure those things out, whether that's with a physical therapist or a counselor. I had one last; I wrote these down so I wouldn't forget them. The other thing is -- most important is that we have the power to choose how we see ourselves and who we want to be.

[00:13:36] I think we forget that sometimes. That at the end of the day, you get up every morning and get to choose, am I going to have strength today or I'm just going to hide away from the world? So, I think working on just choosing yourself every day is really important.

[00:14:02] **Krissy Dilger:** Those were wonderful strategies. Some people may struggle with finding meaning or purpose following their diagnosis. Can you talk about this issue and how you've seen it manifest in clients?

[00:14:23] **Susan Wegener:** Definitely. It's really important, and I kind of have mentioned it over time and now I feel like I talk about it more. And I also think that asking that question, so what I usually ask is, what has the diagnosis taught you? Or, how have you changed in ways that you never thought were possible?

[00:14:53] I do think that that question takes a while to get to. It's not something all of a sudden you can kind of just have a magic wand and be adjusted and know what your future looks like and all of that. So, I do think that that is something that takes time to develop and to kind of think about how your life has changed in a positive way.

[00:15:25] And so, part of that process, and that's where the values come in. The values and the strengths are you kind of have to turn into yourself inward and be in a more reflective mode. And journaling is a great way to kind of start doing that and just kind of seeing where your journey with your illness has taken you and then assessing what's come out of that for you.

[00:15:58] **Krissy Dilger:** So, you mentioned journaling can help just turning inward. Are there other coping strategies that you coached your clients to do to kind of help them find meaning and purpose following their diagnosis?

[00:16:20] **Susan Wegener:** There are, and I can give you maybe some examples of that. So, one of the ones was I focus sometimes on relationships and the value of relationships and how healthy they are. And so, working to be able to set boundaries and explain your illness to family, colleagues, loved ones, so that they understand that you may have limitations. And I know it's hard for some people to be open and honest about that.

[00:17:10] But sometimes people end up, kind of their support system changes a bit, and so they learn to find groups of people, which is where a support group comes in. And I'll talk about that in a little bit. But finding friends and even a partner, or if you're single, who are healthy and who understand and are patient and are kind of your partner in your health.

[00:17:45] I know friends are a little bit different than an intimate partner but finding people who understand and will take time if you have to cancel, or if you're not able to be there 100%. So, I think that's really important. One of the reasons that journaling helps is I have people do self-care journal, like, what they were able to do today, if they were able to, like, if they swim, get in the pool.

[00:18:22] Even if it's just once a week, I think finding, again, turning inward towards self-care and finding ways also to nurture yourself, which may seem foreign initially, because I think a lot of people are externally driven. But I think it helps too, and then give yourself credit for what you have done moving forward. So, it's kind of like a positive reinforcement.

[00:18:55] I can do one more. Also, priorities too. That's a really important one is sometimes we have this to-do list, and we have this thought in our head, I have to do this, this has to get done. Maybe you used to be able to run, like, four or five errands in a row. And so, being realistic about that and really looking at what's possible, how do I pace myself, how do I rest in between, and is it really that important that this gets done today?

[00:19:36] A lot of times the priority turns to making, carving time to just rest after you've had an active day. It doesn't mean that you can't go out and do things, but it just means that you still are integrating that into your life.

[00:19:58] **Krissy Dilger:** Great. How did you, I guess, get started on this topic of finding meaning in a tough diagnosis or in suffering, as a therapist?

[00:20:15] **Susan Wegener:** So, I read a wonderful article that was titled "How to Find Meaning in Suffering," and it was in Scientific American. There was a wonderful researcher who's done research in positive psychology, and she was talking about a term, which is post-traumatic growth. I'll kind of describe a little bit about the article.

[00:20:41] She started out with talking about finding meaning in suffering. So, people who had been through, like, the shooting at Sandy Hook or Las Vegas or some of these mass casualties, Uvalde, and how people had, kind of they were looking at the aftermath of that and how they had been able to kind of work on finding meaning and turning things around.

[00:21:08] They also found that those families felt more connected to each other. And that's kind of how this started, I think, for the author and that suffering can actually bring people together. And I was just thinking we see support groups are exactly that example, that bringing a group of people together with the same neuroimmune diagnosis helps them.

[00:21:43] There's already a level of comfort the minute you walk into the room because instead of explaining your illness, you just say, wow, I'm really having spasticity today and the person next to you is like, oh, I get that, or cramps in my legs. And so, there's this common bond that you have. I think as we know support groups decrease isolation, which inevitably decreases depression as well. So, they're very beneficial.

[00:22:18] One of the other things -- so, processing hardships are another, well, that's kind of what we talked about with the support groups. The same research also says that suffering can create more compassion for other people. I do think that we find that to be true, at least I do in my practice, that in your whole life you never would have thought that you would have gone through a medical illness, especially people that are diagnosed younger, in their 20s, in their 30s.

[00:22:56] And that you just kind of stop and slow down and see things in a different light. And sometimes people don't want to slow down, but our bodies definitely slow us down. So, I've definitely seen that, and that's something really good that comes out of this.

[00:23:16] The third aspect of post-traumatic growth is greater life appreciation. And the fourth is that kind of existential conversation that I talked about earlier, that questioning, who am I, what do I really want to be doing, what's important, what do I want to leave, what mark do I want to leave on the world, and whatever that is. And the last one is finding new possibilities. And so, finding different ways to do that.

[00:23:53] When I talk about leaving your mark on the world, that could be spending time with your grandchildren and nurturing them and teaching them about your family, your history, and creating good human beings out in the world. So, it doesn't have to be something fancy, like, starting a company. So, I think you have to think in your own life, in your own way how can you affect change.

[00:24:30] **Krissy Dilger:** Do you have any other coping strategies for finding meaning in suffering?

[00:24:42] **Susan Wegener:** I do. I know we've talked through this video about some ways have come through the conversation, but I just want to kind of reiterate that finding stillness. I had recently taken a CEU course on our nervous system and how we don't really take time. The clinician was Deb Dana. She's an LCSW.

[00:25:11] We don't take the time to be still, and that having a diagnosis inevitably slows you down. And whether that's the initial diagnosis, if you ended up in the hospital or if you're having an exacerbation or if there's a progression, but stillness is so important and it's in those moments of stillness that we find clarity.

[00:25:42] And so, I talk a lot about meditation with clients or even just breathing, taking a moment to take three deep breaths and just reset everything. It's hard and I think you have to kind of ease into it because some people just don't feel comfortable. They need to be on the go and moving or their brain won't slow down.

[00:26:13] But I think that's what I've seen as people have been able to, and it doesn't slow you down meaning that you just stop functioning, it just means that you take time to quiet your mind and your body, and it's restorative. So, that and also finding ways to be self-compassionate.

[00:26:40] Kristin Neff, she's a psychologist that has this wonderful book called "Mindfulness Self-Compassion." I think we are our own worst critic a lot of the time, and our self-esteem is one affected by that. And also, I think once there's a diagnosis, the self-esteem can be further affected, especially if there are changes in your physical appearance or in your cognitive ability or your speech.

[00:27:17] And so, trying to find a way to just give yourself some grace, like, "I am doing the best that I can in this moment." So, I sometimes have people do little mantras, like, "I'm going to be okay" or "I'm enough, it's enough." Just small things that they hear and that will remind them, okay, it's not your fault, your body is just not cooperating right now.

[00:27:59] And trying to keep the intensity of emotion, whether that's frustration with self. Because at the end of the day, we are the only one that can tell ourselves, that can give ourselves grace and self-love. I guess that's the word I was looking for. And there's one more.

[00:28:31] The last one is that another way to find meaning is that we talk about mental flexibility, which is the ability to see things in gray versus black-and-white thinking, the all-or-nothing approach. And so, I think that dealing with a diagnosis helps to kind of stretch that mindset and that in a way you have to constantly think outside of the box because you're planning ahead.

[00:29:12] Your mind is kind of always thinking about the next step, or if I go here, is it going to be accessible? How long am I going to be standing? So, I think that in a way it creates a way of thinking or creative thinking to figure out, to handle solutions, I guess.

[00:29:37] So, solution-focused thinking. And I think that's a huge gift because if there's more rigid thinking, there's more frustration, but if you can kind of let things move according to their own pace, it's a lot easier on you. So, thank you.

[00:30:04] **Krissy Dilger:** Awesome. Thank you so much and we are so grateful that you came and talked to us today. And I know a lot of people in our community will be able to benefit from the ideas that you brought up and the strategies you laid out for coping.

[00:30:23] **Susan Wegener:** Well, thank you so much. I feel grateful, and your organization does such a wonderful job of supporting the community. So, thank you for letting me be a part of it today.

[00:30:37] **Krissy Dilger:** Great. Well, thank you so much.

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