

S1:E4 "What the Heck is RSD?" Transcript

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Karen Costa:

Welcome to the ADHD gallery, a podcast about teaching, learning and living with ADHD. My name is Karen Costa, and I'll be your host and curator. This podcast is for the ADHDers of the world. People like me. Join me to venture through this gallery of ideas, curiosities, brain science, random hyperfocus interests, and reflections on what it's like to live with the gifts and many challenges of ADHD. Fellow dopamine hunters, let's be weird together. Stay connected at theADHDgallery.com. I'm aiming to be increasingly less active on social in the coming months, and maybe even years. So my website and email newsletter will be the best way to stay in touch.

Hello, everyone and welcome to episode four of the ADHD gallery. Come on in. My name is Karen Costa, and I'm your host and curator. Today's episode is called "What the heck is RSD?"

This is the episode on this list of episodes that I've been adding to for the past few months, this is the episode that I think I most wanted to avoid. So I figured it was time to face those fears. Get this over with. I'm going to be talking about RSD: rejection sensitive dysphoria today. This is something that I've struggled with, and it's also something I've learned a ton about in the past year. So let's dive in.

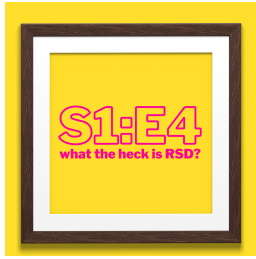
Alright, let's start with the big picture of RSD: rejection sensitive dysphoria. So I've mentioned to you all before that I often present to educators about how they can support folks, learners, with ADHD. And one of the things that I do, big picture, is that I introduce them to this idea. I see ADHD through what I call a strengths-based, challenge-aware mindset. I'm gonna say it again, I feel like it's, fiRSD thing, again, strengths-based, challenge-aware. So we always start with the strengths and we recognize the immense strengths of folks with ADHD. But we never forget that there are so many challenges that people with ADHD deal with on a daily basis. So I go through all these various strengths and challenges with them to illustrate how they can start to use this mindset in their lives and in their teaching.



When I come to RSD, one of the challenges of living with ADHD, before I explain it in detail, the first thing I do is ask folks, have you ever heard of RSD before? And the more that I do this workshop for people all over the country, for educators, and I'm really amazed, it is quite a thing to see that I would say about 99% of the educators that I work with have never heard of RSD. And let me be honest and clear here, before my diagnosis, I had never heard of it either. And again, I've mentioned to you I was diagnosed at age 40. I had never heard of RSD, and even several months into my diagnosis I had never heard of RSD. The psychologists that diagnosed me gave me zero information on RSD. The therapist I was seeing at the time, I don't think, let me just say no therapist I've ever seen has mentioned RSD. So this is not a criticism of the folks that I am presenting to and workshops with educators. This is just something that there's not a lot of awareness about. So I want you to keep that information in mind as I start to describe RSD a little bit more here.

It is a trait or what some call a collection of symptoms found in 99% of people with ADHD. I'm going to give you some good references to check out if you want to read more about RSD in the show notes. So again, this is something that basically every person with ADHD is experiencing to some extent. 1/3 of people with ADHD describe RSD as the most difficult aspect of living with ADHD, and believe me, RSD has some good competition, right? There's a lot of tough parts of living with ADHD. So a third of people are saying the RSD is the most difficult aspect of living with ADHD. So keep this in mind here, that again, in my travels in my observations, a lot of folks have never heard of RSD, and on the other hand, we're recognizing that this is incredibly common for people with ADHD. And it is incredibly difficult. So when I put those two things next to each other, I see a real area of opportunity.

The other thing I want to share is that when I do these workshops, I very typically get you know, questions at the end or comments or people email me afterwards or DM me, and I can honestly say one of the most common things that I hear from folks is Karen, thank you so much for telling us about RSD. I had no idea. That's something I'm dealing with and I never realized it before or that's something that I think one of my loved ones is dealing with or oh my gosh, some of the things I see with my students make so much more sense now. So it is really connecting with people that I'm sharing this; it's connecting with people that this is something folks are struggling with. And people are wondering why have I never heard of this before. So this is a real area of opportunity for us.



Okay, so what is RSD exactly? So I've said to you it's a collection of symptoms or trait found in folks with ADHD. It does happen outside of ADHD. We're talking about ADHD here in The ADHD Gallery. So again, it stands for rejection sensitive dysphoria. And it is defined as extreme sensitivity to perceived criticism. That word perceived there is important. Okay, so sometimes folks like me, folks with RSD, you might be completely neutral with no intent to offer any type of criticism, but because of the way our system processes information, we perceive your neutral statement as criticism, okay? And we are extremely sensitive to it.

Folks with RSD often describe it using the word unbearable. Many people with ADHD will talk about RSD in terms of feeling physical symptoms. So this is really common that people who are experiencing RSD will describe it as physically painful. They're having what we would call somatic symptoms. So they'll say things, and I have said things like, it feels like my skin is on fire. Or it feels like my eyes are going to fall out of my head, or it feels like I'm going to implode or explode. We know one of the strengths of ADHDers is that we're very creative, right? So we have very creative descriptions for these physical feelings that we are absolutely having as a result of this sensitivity to perceived criticism.

Okay, RSD is considered to be neurological in nature. It is somehow related to, there's a lot of this somehow talk right? There's a lot of this maybe it's this maybe it's that out there in RSD and ADHD realm. So generally speaking, experts, folks like myself who both study ADHD and live with ADHD, talk about it as a type of emotional dysregulation that is, again, somehow connected to our unique brain chemistry. So we know folks with ADHD and people would probably disagree with me on this, but I'll say generally speaking, experts know that folks with ADHD have brains that are chemically, functionally, and structurally different than folks without ADHD.

We also know there is something really important, and we are learning more about this, going on with dopamine for folks with ADHD. Dopamine is the reward neurotransmitter. And as a reminder, a neurotransmitter is a chemical messenger who delivers messages around our brains. And it's the neurotransmitter that basically releases as the result of a reward. So when we do something good, that makes us feel pleasurable, or dopamine releases, and there's some sort of limitation there for folks with ADHD. They used to think we have less dopamine, a deficit, and now they're starting to consider that the chemicals in the brain that go around and clean up dopamine after it releases might be



too efficient, which is kind of, it's terrible. And again, quite painful and extremely difficult, but I also have to laugh at the idea that there's these chemicals in my brain that are like, Oh my gosh, there's dopamine. You're feeling too good. Let me help you by cleaning these up really quickly, right? So there's something going on in dopamine.

So all of these brain factors, we'll call them, somehow are resulting in this emotional dysregulation that is leading to RSD that is leading to this extreme sensitivity to perceived criticism. We also know that RSD seems to be more intense for women, and I'm sure there's obviously, if you know, folks actually studied women with ADHD as much as they should, we would know a lot more about what was going on there. Obviously, the way we're socialized has a lot of impact, I'm sure.

The other important thing to know about RSD is that it's very common. For folks who are experiencing it or have experienced it to avoid anything that might put them in a position where they are going to receive this perceived criticism. So you see a lot of talk of folks avoiding taking any kind of risks, putting themselves out there for fear of that pain that they will experience if they have to receive criticism. You'll often hear this described as playing small, you know, avoiding opportunities. Folks without RSD might look at somebody who's avoiding an obvious opportunity and say, What is wrong with that person? That doesn't make any sense? Why would they avoid that obvious opportunity? And for the person with RSD it makes absolute sense, right? Because that opportunity might expose us to a situation where we are going to receive criticism, and we are going to receive feedback. And we know that on the other side of that is pain. So we're not avoiding the opportunity. We're avoiding the pain that might come with it.

Okay, this might be the hard part, a little bit about RSD and me, a little bit about my RSD experience. So as I mentioned before, I had never, never heard of RSD up until probably 18 months ago, probably about six months after I was diagnosed. No mental health professional had ever mentioned it to me. The folks who diagnosed me with ADHD never mentioned it to me. This was something that I learned on my own. I couldn't tell you where I first came across it. But obviously I was doing, I've mentioned big reader. I was doing a ton of reading and research on ADHD which brought me to RSD, and I was talking to a ton of folks who live with ADHD and listening to experts, medical doctors who also have ADHD and learning from them. And at some point there, I came across this. I had never heard of it before. So you know this, again, this is an area of opportunity for all of us that, I think we need to talk more about this. It's



widespread. It's really intense for folks with ADHD. And I think we need to get the word out. That's something that I'm working on. And the more I learned about it, if I had heard about it, and it didn't line up with anything I was experiencing, I probably would have set it aside. However, when I started learning about it, just you know, huge bells were going off in my head, oh my goodness. This is explaining to me, you know, that situation and that situation and that situation throughout my entire life. It explained so many things to me. I have a long history of feeling like I would just crumble in the face of any sort of feedback or criticism. Even like, just the slightest suggestion of hey, can you do it this way? It would result in me feeling like I was going to crumble.

So remember we talked about those, those physical feelings that RSD folks are experiencing. For me: a crumbling of my body and mind is how I have experienced RSD countless times in my life. When it comes to school, so formal school, where there is any type of feedback or grades, I would look at the grade and I would completely ignore the feedback. And I'm going to be kind of vulnerable here. I work in education. I'm probably not supposed to say this. I have taken courses as recently as a couple years ago. I didn't look at the feedback that my professors gave me. So I was doing a certificate up until a couple years ago. You know I've done many years of education, college, post college, When I get feedback, I just don't look at it unless I absolutely have to. You know sometimes there's like another assignment where you have to respond to the feedback you've been given. I avoid that if at all possible. I literally do not read feedback. And you might be experiencing some judgment of me right now that oh my gosh, I can't believe you do that. You need to figure that out. But I, you know, again, I just want to say, I am making, I have, oh even before I knew I had RSD, I was making decisions about what I needed to do to take care of myself. And I was avoiding something that I knew was going to cause me significant pain, and that I didn't have the appropriate support to process because up until 18 months ago I did not have the appropriate support to process those feelings. I get good grades, whatever that means anymore.

So let me also clarify, I can get 100 on an assignment. Let's say I'm looking online in the learning management system for a course, and I see 100 for an assignment, and I see feedback next to it. I do not read that feedback. Because that is how much it pains me to read feedback. Again, this is perceived criticism. So just even the possibility that there is going to be anything critical in that feedback, even if they're saying like, Oh my



gosh, this is wonderful. I just, I've gotten into such a habit of avoiding it that I won't even look at that.

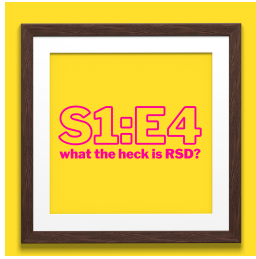
Another thing I'll share, I'm a writer, I've talked about the book that I've written. It is really, really difficult for me if anything that I've written has been published. I won't read it because if I see something that is, you know, a typo or mistake or something, I wish I'd said differently. It's excruciating for me, I crumble you know, those emails that you get where you're like, oh gosh, which direction is this email going? You know, you can see the little preview. I, again, RSD activation, so this has been a lifelong experience for me. I absolutely have the physical pain when I experience RSD; it will send me into a spiral. The bad cases, especially if you know, I'm having a bad ADHD day or a bad day in general. An RSD incident or activation can set me off for two to three days. You know, it can really turn my life upside down for a couple of days. And again, I'm going to talk about this in more detail in a minute. I am absolutely somebody who has avoided feedback, credit, perceived criticism, criticism, possible opportunities, because I was making decisions about what I needed to do to take care of myself. So if you are somebody who's in a position where you are working with folks who might you say, why are they avoiding that? We don't always know what people's motivations are. Sometimes I would argue probably all have the time. There's a really, really good reason for that and people are making decisions about what is best for them.

Okay, I want to talk for a minute about what I see as the difference between labeling and naming. So this is, I don't even want to say controversial. It's just a topic that folks have different experiences and opinions and, you know, certainly we have different values in life. So we come to that question of the value we place on a diagnosis of ADHD from different angles. And now we're adding this possibly what some might perceive as a label, RSD. So here's how I define a label. A label makes me feel small. It feels like it's reducing me down to that one word or phrase. So if somebody is labeling me with ADHD, it feels like they're implying that that is all that I am. Or if somebody's labeling me with RSD it feels like they're, you know, oh, that's just her RSD, that explains everything about her right? They are ignoring the totality of my experiences, the totality of my strengths and challenges. So a label makes me feel small. A name, however, a name for me feels really powerful. It feels like it's opening up possibilities. And name connects me to information and to communities of support. And this has been very true of coming to terms of my ADHD diagnosis. When I first got diagnosed, again, March 2020. Global pandemic. It was a really intense experience for probably like a year,



again, combined with the pandemic, at its, you know, at its absolute worst when we didn't know as much as we know now. It was a really stressful and intense experience. And there were moments when I would just get so frustrated and say, forget this, forget this label. And I did feel like it was a label that had kind of been placed on me. But, you know, over the past year I've really worked through that some and I now think of ADHD as a name. And it's one of many names that describes my experiences. And I am able to reject it as a label and accept it as a name at the same time. Both of those can be true for me, and I'm willing to accept it as a name. Because the name ADHD has connected me to so much information that has helped me be healthier and happier. And the name ADHD connects me to communities of support with my fellow ADHDers who I love, who I feel so happy and safe with and weird and wonderful. And if I didn't have that name, I feel like I wouldn't have found those connections. So just like that name of ADHD, learning about RSD has also been really helpful for me because it allows me to name this experience I'm having, of how I feel in anticipation of feedback, or how I feel when I've gotten feedback and three days later, I feel like I'm still spiraling about it, and the name of RSD has also helped me to learn how to honor my needs. So I have learned through that name of RSD, I have learned that, you know, like, this is the reality of how my brain works, but I also feel like there's really fundamentally nothing wrong with me here, right? Like, my brain is behaving quite logically for how it's built and how it operates. And it's perceiving this criticism and, you know, probably, you know, my dopamine cleanup crew was too efficient. So it's not there to buffer me against this criticism. So it's just like, a very logical, normal reaction for me. And I'm okay with that. You know, it just, it's like, oh, okay, this is RSD happening. So just that process of knowing what's going on in my brain, and putting a name to it takes so much of the intensity of of the RSD symptoms. Whereas before, I would say, like, oh my gosh, what's wrong with me? Why am I reacting this way? This anxiety is this perfectionism, blah, blah, blah, is it this or that or this or that? None of which was really the root of it. And for me, the proof is in the pudding. Because when I started to name it as RSD and think through it and feel through it, the intensity absolutely lessened, which to me is a sign that I'm on the right track here by naming it RSD.

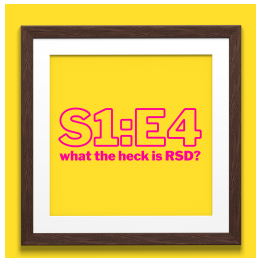
So just that, you know, knowing what's going on is so helpful for me. I've also learned that I can change the way that I engage with other people around feedback, and like, I want to say this nicely, I like, don't have to engage with your feedback all the time. Sometimes I might if there is something that I need on the other side of it, or one on the other side of it or value on the other side of it. But I don't need to take your feedback just



because you want to offer it to me. I'm able to say I am somebody who has RSD, and this person wants to provide me feedback and the costs of it outweigh the benefits. So I'm going to choose to disengage, and I can do that in a direct and kind way. But I just am very more, you know, am much more considerate of myself and my needs and who I take feedback from. I can really weigh everything that's going on. I can weigh what I want and what I need. Maybe I need this paycheck, right? And this person is on the, you know, the first thing that gives me my paycheck, and they say I need to give you this feedback. So I can make that choice. Okay, yeah, I do want to get that paycheck. So I'm going to accept that feedback and I'm going to process it. And in other situations, I'm going to say no, that's okay. I'm not going to activate my RSD.

I can also check in with myself. I have good ADHD days. I have bad ADHD days. I have, like all humans, good days and bad days. So maybe I'm having a good day. And I say to myself, Okay, I think this person's feedback might be valuable. I'm going to accept it. Right? Um, it's definitely going to do some RSD activation, but I feel like I'm in a good place to process it. Whereas other days, I'm having a tough day. I'm gonna say you know what, not today, right? Maybe not ever, but definitely not today. Or maybe in a couple days when I'm feeling better. And I've also learned through this RSD process to allow myself, you know, to access resources. So one of the things I do, let's say I'm interviewed, and my name shows up in a publication somewhere with quotes. That's a huge RSD trigger for me, I cannot read anything that I've said that's been put into print or anything that I've written. So I've gotten really good at like, texting a friend or a loved one or family member and saying, hey, I was interviewed for this publication. Can you look it over and tell me how I sound? I wouldn't have done that two years ago, I would have been too embarrassed. And I will be very forthright, and I know who I can ask and who I can't ask. And sometimes, you know, they're usually, oh, you've done a great, you talked a little bit about this, and just them kind of like, leaning me into it. Maybe I'll take a look at it. Maybe I won't, but I know now that I have all these choices about what I can do to honor myself and to recognize the reality of how I perceive it, the reality of RSD in my brain, and I've got lots of choices about how I can move through that.

Okay, I want to talk a little bit about giving feedback to people with RSD. So when I present to educators, this is a really common question that I get. They're so interested to learn about RSD. And then almost always, somebody says, okay, Karen, you just said that it's excruciating and physically painful for people with RSD to receive criticism or feedback. So what are we supposed to do? Because part of my job is to give



feedback to people. So I'm going to share a few thoughts with you today on how to give feedback to people with RSD. The first suggestion I have is, maybe don't? Maybe people don't need your feedback. In 12 Step programs, I've been a part of a 12 step space on and off for the past several years. There's a concept called crosstalk, and in 12 Step programs, we do not crosstalk; we share our stories. Everybody listens. Nobody says a word. It's amazing. By the way, it's truly life changing. You share your story, you share whatever you need to share in your meeting. And everybody listens. And when you're done talking, they say thank you or thank you for sharing. Or sometimes they say keep coming back. And we love slogans in 12 Step programs. And that's it. Nobody says, you know, I'm really glad you brought that up, here's what I think you need to do. Or nobody says, I really can't believe you made that decision. I really think you should have done this right. No one says a word really other than thank you. So if you are providing feedback in these meetings, that's considered crosstalk and is not allowed, really clear on that.

So I've often thought about what the world would look like if we maybe have more no crosstalk policies out there. There is this idea that everybody is just dying for your feedback and your advice, and that's not true. Sometimes people just need to be held and heard and supported. They just need you to listen. So you don't always have to give people your feedback. Maybe consider that the person that you are talking to or engaging with or learning with or teaching with, doesn't need your feedback. It's a possibility. So let's start there. Just don't do it.

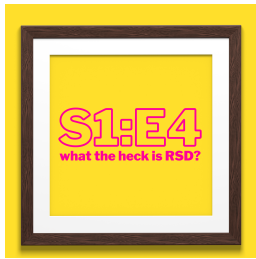
The second thing I'll share is that if you are in a position where you feel that you need to give feedback for your job, you feel that it is appropriate in the situation, think about the timing, and make sure you are communicating with people. So we often kind of foist feedback on people without paying any attention to timing and without communicating with them about whether they're in a place to receive the feedback. I know this isn't always feasible for educators. Folks are very busy. Folks have a lot of limitations working in education. I understand that. But there are perhaps spaces and times when you can be a little bit more flexible about how you give feedback. So maybe you want to shift the timing, maybe feedback can wait for a day. Maybe you want to check in with the people you're giving feedback to to see if they're ready to receive that feedback. So timing and communication.



The other thing I want you to think about is that feedback never stands alone. It is always part of these larger communities that we have created. So if I'm in a welcoming, supportive community, and somebody gives me feedback, whether it's critical, neutral, positive, whatever the case may be, I'm going to receive it as part of that larger, welcoming, supportive community. And if I'm in a really stressful, intimidating community, I probably wouldn't be there. But if I had to be there, if I had to be I would receive that feedback very differently. So if you are somebody who's in a position where you are giving feedback to others, whether that's students or colleagues or employees, think about the broader community and you know, if you haven't done a great job there, it's going to be more difficult for people with RSD and for all people to receive that feedback. So think about how you can create conditions. I love that phrase, how can we create conditions where people feel like they can talk to you about how they receive feedback, or they feel that they can communicate their needs, or they feel that they are a little more open to how they can receive feedback that is going to be based on the larger community?

I mentioned this before, but I'd love for folks to realize that when people or learners avoid submitting work or engaging or taking risks, that doesn't mean that we are lazy or that we don't care. It might be because we are experiencing or have experienced ours. I don't even think, I don't even really believe that people are lazy or don't care, ever. I think people are always making the best choices they can for their own well being. But this is a really common thing that I think educators or people in positions of power or employers assume; we assume that somebody didn't turn something in on time and therefore they are XYZ right? We start labeling them. We start reducing them and making them small. And really that person's doing what they need to take care of their needs.

So another one of the things you can do is send an email or video, letting people know or letting students know, you know, it's normal to be anxious. Give them some words of encouragement. If they're feeling scared about submitting this, just check in with them, right, just be human, be supportive. Again, we talked before about creating a supportive community. Be a little bit proactive and recognize, hey, this might be a scary thing or this might be bringing up feelings for you, and let people know they can reach out to you and tell you about what they're experiencing. I do that often in courses I teach, and I very often have students who will email me back and say, Karen, I know this assignment is due in two days. I have to be honest with you. I am petrified, right or



terrified. They will use really vivid words to describe how they're feeling. I am so scared that I'm going to fail. I'm so scared that I'm going to screw up. I don't want to let you down. I don't want to let myself down. And they've just put an immense amount of pressure on themselves. Whether or not they have RSD, that's an opportunity for me to say, hey, you're going to do great. Do your best; your best is good enough. And often just one kind word or phrase is enough to nudge them forward and get them to the other side where they can submit that assignment. But again, I've got to be proactive and let folks know that I'm available. And open to having that conversation with them.

The next suggestion is that when you are giving feedback, if you've decided that that is appropriate to do, do so without judgment. So even if somebody has completely bombed an assignment or a task or completely misinterpreted it, whatever the case may be, I can offer feedback without believing or trying to communicate that I am better than them because they bombed that assignment or misunderstood that assignment or didn't do on that assignment. Like that does not mean that I'm better than them. Right? I would actually argue that if I was going to be a jerk and be judgmental, and get on my high horse in the feedback that I give them, that I would actually not be better than them at all. Okay, but what I'm saying here is detach from any idea that somebody's not submitting assignments or not doing this some sort of character statement. Right? You don't know what's going on behind the scenes. I have absolutely, again, I have education coming out of the wazoo. I have absolutely, you know, avoided things or ignored things or had other types of, done other types of behaviors that might have looked illogical to you from the outside that made sense to me, and that were absolutely what I needed to do to avoid pain and to take care of myself. So just detach from any assumptions you're making. Keep it simple when giving the feedback, stick to the facts of what that person needs to do, what they can act on in order to improve. Notice some positives, but again, keep it simple and stick to the facts.

And last but not least, keep RSD in the back of your mind now that you've learned about it. It is one of many possibilities to explain behaviors that might seem confusing to you. Whether or not RSD is what's in play, the awareness of it, and how people experience it, and the neurobiological conditions that are going on in our brains. Hopefully that will remind you to just be more gentle when giving feedback, and I don't think that is the worst thing if we all are a little bit more gentle and loving and caring in how we provide feedback to each other.



Okay, everyone. That is a wrap for Episode Four. Thank you so much for making the time to listen today. I know that you have a lot of choices about what to give your attention to. And it's an honor that you choose me in the ADHD gallery. Your support means the world to me, please rate the podcast share with your friends and colleagues. And of course, make sure to sign up for my email list by visiting theADHDgallery.com Thank you friends.