Living with Sjögren's: How Do I Get My Life Back?

Shilpa Venkatachalam (00:00:00:15 - 00:00:44:16)
Welcome to The Sjö, pronounced “show,” a podcast series from the Global Healthy Living Foundation, created for anyone living with, caring for, or trying to understand Sjögren’s disease. Whether you're newly diagnosed, still searching for answers, or supporting someone who is, this series is here to help you feel less alone and more informed every step of the way. My name is Shilpa Venkatachalam, and I am GHLF’s Chief Patient Centered Research and Ethical Oversight Officer and the Principal Investigator of our PatientSpot Research Registry, and I’m delighted to be your host for this series.

Shilpa Venkatachalam (00:00:44:18 - 00:01:46:07)
In this second episode in the series, “How Do I Get My Life Back?” we're tackling a question that comes up again and again once the diagnosis dust settles, if it ever does settle: how do you actually live with Sjögren’s day-to-day? We'll go beyond the eyes and mouth to talk about dryness in places patients don't always feel comfortable discussing, and why something so often dismissed as minor can reshape daily routines. We’ll also dig into fatigue, not the kind of nap fixes but the kind that doesn't always show up on labs or scans, along with brain fog, headaches, and joint pain, and how these invisible symptoms can quietly affect work, relationship, and the things you love to do. So hopefully by the end of this episode, we hope you'll walk away with practical tips to manage these symptoms and the reminder that an invisible disease is still very real and still worth talking about.

Shilpa Venkatachalam (00:01:46:09 - 00:03:36:17)
With that, I'm delighted to introduce our guests. Today's first guest is Dr. Direnzo, an associate professor of clinical medicine in the Division of Rheumatology at the University of Pennsylvania, where she serves as Chief of Rheumatology at Penn Presbyterian Medical Center. She is a member of Penn Sjögren’s Center and directs the Penn Musculoskeletal Ultrasound Program. Dr. Direnzo’s clinical expertise spans Sjögren’s disease, rheumatoid arthritis, myositis, and scleroderma. Beyond her clinical practice, she also brings a holistic lens to patient care, incorporating exercise, anti-inflammatory diets, and mindfulness-based stress reduction alongside traditional treatments. She is here today to share her insight and expertise on what it takes to manage the daily impact of Sjögren’s. Very warm welcome to you, Dr. Direzno.

Shilpa Venkatachalam (00:03:36:19 - 00:04:39:09)
Our next guest is Melissa Taylor, known to her community as Autoimmune Auntie, an actress, content creator, and Sjögren’s patient based in North Carolina. Melissa started experiencing symptoms at just 20 years old, but it took four long years of being told it was just anxiety before she finally received her diagnosis. That journey came with its own kind of isolation, not just physically, but emotionally, as she found herself confronting fears about her health that many people around her could not relate to. Today, Melissa uses humor and honesty to make content about life with chronic illness, and she has become a powerful voice for something many patients feel but rarely hear said out loud: that invisible symptoms don't mean an invisible disease. As she puts it, just because it's less obvious from the outside doesn't mean it isn't severe. Please welcome Melissa Taylor. Melissa, lovely to have you again.

Melissa Taylor (00:04:39:09 - 00:04:41:12)
Yes, thank you so much.

Shilpa Venkatachalam (00:04:41:14 - 00:04:56:20)
So Melissa, actually let me start with you today. Tell us a little bit about what a typical day living with Sjögren's looks like for you. Are there symptoms that affect your routine from the moment you wake up? Carry us through your day.

Melissa Taylor (00:04:56:22 - 00:06:32:11)
Yeah, definitely. I really have to think about this question, because a lot of the things that I started doing happened subtly over time, and I do them kind of on autopilot. So sort of I realize the first thing I do when I wake up is I do a body scan to sort of check in how tired am I or how much does it feel like I have the flu or I have a hangover, even though I know I'm not sick and I know I didn't drink. And then the rest of my day is kind of determined from that moment. You know, am I going to relax more today, or do I have the energy to sort of go out and do the shopping or the laundry? So that's the first thing I do. The next thing I do is, I mean, my mouth is pretty dry when I wake up. Overnight, the dryness is a lot worse for me than during the day. So I usually sleep with, like, lozenges in. They're usually melted away by the time I wake up. So I really want to brush my teeth right away because it feels kind of gross in there. And I get some moisture on my tongue because my tongue will be all puffy and dry. My eyes, personally, they are dry, but my mouth is more my problem area. And then I base basically my whole diet around having Sjögren's too. So it plays an important role in pretty much every single decision that I make about my day and my life.

Shilpa Venkatachalam (00:06:32:13 - 00:07:24:22)
Thanks, Melissa. And actually, a lot of the things that you were talking about, the fatigue, you know, this doing the body scan sounds very familiar to me. I live with rheumatoid arthritis. And Dr. Direnzo, you know, we hear this very often from the community of patients living with Sjögren's, dryness in places people may not expect, including the eyes, mouth, nose, and the genital areas, sometimes making it really hard for patients to talk about. And many people think of dryness as a relatively minor symptom. They're not thinking this is, you know, going to affect several things in my life. But for patients with Sjögren's, it can have a, obviously, a significant impact on daily life, as we've just heard. Could you talk a little bit about what some of the challenges are that dryness can create, and how can patients work with their care team to find relief?

Dr. Dana Direnzo 00:07:25:00 - 00:08:37:05)
Yes. That's a great question and a question that comes up multiple times a day throughout my day working with Sjögren's patients. So dryness can impact everything. It could impact every organ system. So, let's say, you had mentioned oral dryness, dry mouth. But certainly for a lot of people, it could also impact your eyes, quite severely. So we think of those from the get-go, but also we're thinking largely about gland function. And glands are everywhere throughout our body. So people will mention to me, you know, I feel like I don't sweat as much as I used to, or I tend to now have sweat in odd distributions that I'm not accustomed to. I get reports of dry skin, hair quality changing. You could talk about anything in this context, but I used to, I had this conversation the one time about hair conditioners. It's like, "I went through five different types of

hair conditioners because I feel like my hair was so dry, and I just really don't understand. Can we just think about that a little bit?"

Dr. Dana Direnzo 00:08:37:07 - 00:09:36:02)
Also genital dryness. We don't, you know, oftentimes want to bring that up, but I would actually encourage any patients, I know you're asking me from the position of known Sjögren's, but your rheumatologist, your doctors are expecting you to start asking about those questions. So I think the most important thing is to know that it could occur anywhere. And bringing it up is expected. We want to help you. We want to know about that. And we should be able to talk about these things. The challenge is, are there available resources or tangible things to give you for those dryness, and sometimes you have to brainstorm and be creative about that. And that is a lot of what is in drug development right now, and that we would look to seek different solutions to in the future. But no aspect, big or small, should ever be brushed over. You should be prepared to talk to your doctor and bring it up with your doctor about joining us in different aspects.

Dr. Dana Direnzo 00:09:36:04 - 00:10:40:23)
So you asked what are the challenges and impacts? I think it would be connecting, you, say if it's coming from the perspective of the rheumatologist, connecting you to the right resource. So if you have Sjögren's disease, a lot of times we want to manage your care as a team. So you should be teaming up with an eye doctor so we can kind of really optimize as best as we can through different types of ocular exams, right? Me as a rheumatologist in clinic, I'm not going to get too far when I'm just using my little lens in the clinic opposed to what the eye doctor can tell you with their fancy equipment. And I'll use those terms, fancy equipment. But there's a lot of available ocular drops and different types of solutions and even procedures that could be helpful to you. And then the other thing that I encourage all patients with Sjögren's disease to be geared up with is either a dentist or oral medicine provider. And there's different, different variations of that.

Dr. Dana Direnzo 00:10:40:23 - 00:11:37:16)
So we traditionally just think, "Oh, well, I usually just go to the dentist for, you know, teeth cleaning. You know, what are they going to be telling me?" But bring it up. Bring up "I have a diagnosis of Sjögren's where I have dry mouth and it's really symptomatic for me. You know, what are the ways that I should be managing preventatively from tooth decay and some of the complications?" So there's special type of toothpaste you could get into. There's different types of cleanings they could be doing. And oftentimes we encourage you to go more frequently to the dentist than every six months, even three months if you're able to. And then finally, I'll say on top of that, you can partner with gynecology, who might be unfamiliar with disease, as well as dermatologists and then a list of other specialists. But I don't want to belabor this question. But yes, dryness can impact anything. Nothing is too small or too large. And we are expecting you to bring it up.

Shilpa Venkatachalam (00:11:37:18 - 00:12:17:12)
Lovely. I mean, you provided a lot of useful information right there. So it's a care team we're talking about. It's a constellation of different specialties. And it's important to sort of, you know, not decide for yourself what's worth telling a doctor and what's not. And so, you know, one of the things we do at the Global Healthy Living Foundation and, Dr. Direzno, you mentioned this, patient-reported outcomes. You know, track your symptoms so that you can keep note of your

symptoms. Journal them. We have an app called PatientSpot that can be used by people living with these diseases so that you can communicate better with your doctor.

Shilpa Venkatachalam (00:12:17:14 - 00:13:02:01)
I want to come back to you, Melissa, because Dr. Direzno actually pointed out some very interesting things about this everyday lived experience, right, of living with dryness and the other symptoms, fatigue, etc. Can you talk a little bit, Melissa, about how living with dryness has changed your daily routines? So, you know, Dr. Direnzo mentioned you could get special toothpaste, or you could go and see the doctor or the dentist or the eye doctor, etc. But what are the activities that you've enjoyed typically that have been in some ways affected by your diagnosis? And what do you wish others understood about the impact of this disease?

Melissa Taylor (00:13:02:03 - 00:14:18:11)
Oh man. Yeah. Dr. Direnzo mentioned so many good things, and I was thinking about, like, the special toothpaste. I use a special toothpaste that has hydroxyapatite in it. And I do still struggle with some form of embarrassment around these conversations sometimes, even with my care team. For example, like, my teeth. I always get compliments at the dentist. “Your teeth are so nice. You know, they're looking really good.” However, I have been embarrassed to tell them sometimes it feels like I can feel a piece of my teeth crumbling. It feels like sand in between my teeth. And even though I've had Sjögren’s for over like ten years now, I've still been embarrassed to say, “Yeah, they look nice now, but I can feel them kind of. And I know that they’re, it feels like they're disintegrating in real time.” I don't know what where that kind of embarrassment comes from, but I think it's kind of everybody's worst fear, right? We've all had the teeth falling out dream. And as Sjögren’s patients, we’re kind of living it in slow motion. So I think that it is important to bring those things up, and I will the next time I'm at the dentist.

Melissa Taylor (00:14:18:13 - 00:15:52:16)
The activities that it's changed for me, I was really someone who would get ready to go for my day in, like, half an hour. I was not a big planner of, you know, what I'm going to wear, doing my hair, all of that. I was very much like, “Okay, the day has started. I'm going to get up. I'm going to go to the gym. I'm going to hang out with my friends. I'm going to, basically, just do whatever I want, go to work.” And now activities are based more around “I expect to not feel very well tomorrow. So I'm going to get a good night's sleep. And I'm going to just plan my day based on what can I do?” Which oftentimes doesn't involve going to the gym anymore because I can't keep up with what I had done previously. I can't go to CrossFit every day anymore. What I can do is walk with my dogs or walk on my treadmill, lift light weights. But I used to be very, very, very active. I would go indoor rock climbing. I was at CrossFit every day. I ran a 10K pretty shortly before my diagnosis. So I am not nearly as active as I used to be. And even some small things kind of have changed. Like, my husband bought a convertible. We’ll go out in it, but it is, like, so drying, both mouth and eyes. And so I just, yeah, it can be very uncomfortable to do even something small and fun.

Shilpa Venkatachalam (00:15:52:18 - 00:16:59:03)
Yeah. Sorry to hear that. It sounds really challenging, Melissa, and thank you for sharing. You know what a lot of people, we just talked about it, it might be embarrassing to share certain things. But thank you for so generously sharing so that other people who are listening might

think, “Hold on a minute, I experience this too,” and then talk to their doctor about it. Dr. Direnzo, coming back to you, you know, as Melissa was talking, I was thinking about there's dryness, but there's much more than dryness. And, you know, because these are systemic diseases, there's a constellation of other, symptoms like fatigue and brain fog, and, you know, this feeling that I'm not really feeling good, joint pain. These are not things that are really visible, right, in bloodwork or scans. So how would you advise patients cope with these symptoms when they start interfering with work, relationships, or even the daily activities that Melissa was alluding to?

Dr. Dana Direnzo 00:16:59:05 - 00:18:07:00)
Yes. That is a tricky question. But before we get to what we're going to term the invisible, I do want to touch back on something that Melissa said, because I think that's really important to get out in the open and address. I try to bring it up in my patient visits. But that's this embarrassment that you were alluding to. You know, like, “It's hard for me to bring up talking about my teeth, my oral care, even my eyes.” Particularly if you might be a patient with a lot of redness to your eyes or puffiness to your eyes. But we should be able to talk about on what we could term body image. And that definitely is something that could be impacted by Sjögren’s disease. And you shouldn't be embarrassed about bringing this up. So a lot of times I could impact mental health. And you might be going to the doctor. And yes, we put on the forefront, what are your labs doing? Even what is going on in the inside, these questions that you're going to start asking me about, like quality of life and fatigue and dryness and pain and everything like that. But we should also be able to talk about body image because it really impacts mental health.

Dr. Dana Direnzo 00:18:07:00 - 00:18:56:12)
So if you externally don't feel like you're feeling your best, you should be able to talk about that in a communicate with your doctor. And sometimes it's good to get this out in the open. So I don't think that should be a source of embarrassment whatsoever. And we're here to help. And that's particularly why I was bringing up, you know, sometimes having a team approach, a good dentist or oral medicine and certainly a good eye care team to help with those issues. Because we should be able to say, like, “Hey, my eyes have been really, really puffy, and I feel like people are noticing that at work. What can I do?” or “It's really impacting me because I'm trying to keep it inside and I'm trying to, you know, like, wear eyeglasses to cover it up.” If you're a person who needs corrective lenses or something like that. Or my teeth, you were saying that you feel embarrassed about even bringing that up. So that should not be the case.

Dr. Dana Direnzo 00:18:56:14 - 00:19:54:15)
And so I wanted to pause on that before we move on to some of the more invisible signs and symptoms. So my biggest advice to a patient, because it could feel pretty nebulous. So the number one thing that I have patients come in and say, and then it'll probably take five appointments or more to kind of unpack is “I generally don't feel well” or “I feel terrible. Help me.” Well, we have to pinpoint what is making you feel terrible. And that oftentimes comes back to a constellation of things. And a lot of times that might be something like fatigue, that might be something like pain. But even saying “I'm in pain,” that's really difficult. So the more specific you can think about what is going on in your body, the more helpful your healthcare practitioner could be. So when you're, for example, thinking about fatigue, there's a whole different host of

ways and means that you could be fatigued. Are we talking about mental fatigue? And let's think about that.

Dr. Dana Direnzo 00:19:54:15 - 00:21:05:18)
And we might come up on this later in the conversation, but, you know, in the beginning, in the morning, I might have clear thoughts. And then I get this comment, actually, quite frequently, "By the end of the day, I turn into a pumpkin. I cannot think. I cannot get my thoughts together." And I will actually have patients who will change around their work schedule to accommodate when they feel like they're thinking best. So that that might be mental fatigue. There might be physical fatigue. It might be that "By the end of the day, I physically feel that I cannot move on. I have to rest. I fall asleep early" and so forth. There might be "I might not get, by the end of the day, I feel tired in my body, but I am not able to exercise or do things the same duration." So I might feel the same amount of energy throughout the day, but the duration of things I could do, things might be shortened. So fatigue is this huge, huge domain, construct, whatever we want to call it. But we have to make it more specific so we could tangibly work on things. So it's hard to say, "Let's work on my fatigue." I need to know how your fatigue is impacting you so we could get to it.

Dr. Dana Direnzo 00:21:05:20 - 00:21:41:08)
And then the same thing with pain. So pain, quite nebulous. I'm having, you know, pain in joints. I'm having pain in muscles. I'm having eye pain. You know, there's so many different ways and locations that pain can impact you. Is it pain that's very intense, is it dull, you know, like what is the quality of your pain? So if we can make some of these nebulous, very overwhelming type of symptoms more specific, they then can become more tangible to tackle and manage. So that would be my biggest advice when we're starting to get into some of these invisible signs and symptoms, if you will.

Shilpa Venkatachalam (00:21:41:10 - 00:22:23:18)
Wow. You said so many things that now I'm beginning to digest. And I love how you break down fatigue into mental fatigue, physical fatigue, fatigue at the end of the day, you know. And, Melissa, I want to come back to you about this because when I talk about fatigue or pain from my RA, you know, there is a mental health toll because then you feel like, "Oh, I'm complaining again. I wonder what people might think of me." You know, these are things that come up over and over again. So have you learned or have you changed how you communicate what you need to other people? How do you navigate that?

Melissa Taylor (00:22:23:20 - 00:23:15:21)
Absolutely, yeah. And this is actually a newer thing in my life. Because for a long time my journey was sort of to, for lack of a better term, gaslight myself. I thought, like, I'm just being lazy. I'm not trying hard enough. I should be capable of this. There was a lot of "I should" kind of going around in my brain. And I have been in therapy, and it's helped a lot. It's helped me to name what I'm feeling. Because if I am not aware or not communicating to the people in my life what's actually going on internally, how are they going to know? Because I've figured out what's obvious to me is not obvious to someone who's not living in my body. So for a long time I assumed that it was obvious. And it turns out it wasn't.

Melissa Taylor (00:23:15:22 - 00:23:56:20)
So I've learned to better communicate fatigue, brain fog, what those things actually feel like and what it means when I say them. Like, okay, I have brain fog. Well, what does that mean? Well, I was at the grocery store earlier today, and for a moment I didn't remember where I was. And I'm 33 years old. Or I left the car running in the garage for four hours because I didn't automatically take the keys out. That's brain fog. But when you just say these kind of like Dr. Direnzo was saying, these nebulous sort of terms, okay, so fatigue equals tired. No, it doesn't equal tired because you can rest away tired. You can't rest away the fatigue that I'm feeling.
Shilpa Venkatachalam (00:23:56:22 - 00:24:52:18)
Wow, yeah. So Melissa, actually I'm learning a lot from you and Dr. Direzno in this episode, you know, in terms of the communication. So we've talked a lot about the physical symptoms and in some ways, you know, physical symptoms, not always, but there is something that can be done about it. I think what we are also wanting to understand here is the connection between, Dr. Direzno you touched upon this, the connection between chronic illness and mental health. Is there some way for people who are listening in here to know when they should start considering seeking additional support? That could be through, you know, talk therapy or mental health support. But how do we know when we should start? Is there some kind of yardstick we should be following?

Dr. Dana Direnzo 00:24:52:20 - 00:25:47:10)
I think everyone needs mental health care. I think that's an important part of anyone's care plan, whether or not they have a chronic illness or not. So I think the threshold where you might seek external care might be maybe more so what the question is, and I would actually encourage anyone to journal or like think about how their thoughts, their emotions, their feelings are interfering with their day-to-day. So I would argue that if any point in the week you have had a down moment because of your health, which then manifests in the thoughts you're having and you feel like you are not, you know, optimally functioning or engaging with others the way that you want to be, that is the moment that you should seek some external care.

Dr. Dana Direnzo 00:25:47:10 - 00:26:49:03)
And it could come in a variety of different forms. So when I start talking about that with patients, it's got to be something you feel comfortable with. So not everyone feels comfortable talking about their mental health. And Melissa, you kind of touched on that before. You thought others were understanding what you were going through. So then sometimes it could be helpful just talking through on how that could be interfering with your day-to-day for someone else to kind of report back to the others in your life how it's impacting you. So I tell patients sometimes it's just helpful to have like a session or two to just process with an unbiased party, all the things that you've been experiencing, to then be able to communicate back to someone else on how you've been feeling. So journaling that, testing it out on another party, and I say that because sometimes it is hard to get connected with mental health providers, it shouldn't be, but sometimes it is and that's a reality, is one way to do it.

Dr. Dana Direnzo 00:26:49:03 - 00:27:49:11)
The other way is there's a lot of, and Global Healthy Living Foundation does that, you have a lot of resources online to connect you to different types of programing with regards to mental health. Mindfulness is one aspect. We might talk about that in a little bit. But there's a lot of different

online self-directed programs to touch base and for you yourself process what you've been feeling. Because the reality is, and we always talk about it, which is so goofy to me, we always talk about mental health siloed from your physical health. But that's not the case. We're one person, we're one body, and they all go hand in hand very closely. And especially in the setting of Sjögren's disease, which has a lot of neurologic manifestation and probably background pathophys, is we need to think about your mental health just as equally as your physical health. So we need to engage with both and think about both. So, yes, it's never too early, mental health care is always a good thing, and I encourage it for every single patient.

Shilpa Venkatachalam (00:27:49:13 - 00:28:22:14)
Great message there. Mental health is for everyone and there are different ways to access resources, support resources. Melissa, coming back to you. Based on what Dr. Direzno just said, has there been anything that has helped you, small practical things that you might do every day that makes living with the disease a little bit easier? Or even things like tracking your symptoms, paying closer attention to patterns. Is there anything you could share with the audience?

Melissa Taylor (00:28:22:16 - 00:29:28:08)
Yeah, I absolutely notice that when I am not feeling well physically, my mental health also goes down. So, there's definitely a connection there. My first clues usually when I'm getting sick, if I'm catching something, are that I start to feel more anxiety a few days beforehand and then I know "Oh, I'm about to get sick. And I probably got sick because I went out to this birthday party and everyone was sick." But yeah, I use a vagus nerve stimulator. I think it does help as long as I'm consistent with it, and I'm not always, but when I am consistent with it, I find it helpful. The other thing I did is I got a standing desk and a walking pad in my office, because it's not always easy to get out and go walk outside. We live on a hill. You know, it's just not the easiest to walk outside. So I got a walking pad to make sure I'm still getting in a walk every day, no matter what.

Melissa Taylor (00:29:28:10 - 00:30:38:21)
Other mental health tools, my therapist is specifically, she specifically works with chronic illness patients. So she has an understanding of, a better understanding of sort of what our experience is like. So she can speak to me on that level that not everyone can. And I think that that has been really helpful. And also leaning into the community of chronic illness patients, it's sort of like, it helps me feel more grounded in my experience to have that community and that connection with people I don't really have to explain. For a long time, it felt sort of like there was this disconnect between who I am and who I'm being perceived to be, because the fatigue looks like laziness from the outside, and the brain fog looks like incompetence from the outside. And so I'm feeling this kind of disconnect between who I know myself to be, but who I can feel I'm being perceived as. And it's a really weird kind of place to live in.

Shilpa Venkatachalam (00:30:38:23 - 00:30:58:21)
Yeah. That was so well said is, you know, you sort of recognize yourself in a certain way, but then your body is not allowing you to do the things that you associate yourself with, the things you enjoy doing, etc. So, you know, these are some of the really important things. Yeah.
Dr. Dana Direnzo 00:30:59:00 - 00:32:00:13)

Shilpa, can I actually piggyback on that because I think that's really important what you just said, Melissa. So, I am an enormous fan of group mental health sessions, groups. So there's all different varieties. There's group, like cognitive behavioral therapy, there's mindfulness, stress reduction. And there's different types of support groups, even, that don't necessarily have a mental health practitioner providing them. But I think it's really good and cathartic to talk about the symptoms that you're experiencing because that also allows you to process. And you kind of alluded to now a second time about this construct of who you are, your identity. So your physical identity and now you're talking about your mental health, your identity of how you're identifying yourself from within. And it's very helpful because it can be isolating and lonely to have a chronic disease, especially when you're sorting things out.

Dr. Dana Direnzo 00:32:00:15 - 00:32:43:22)
Now, thank goodness, there's a lot of highlight and news coming out about Sjögren's disease. But before then, you know, I was like fielding a lot of these same exact stories in my clinic. It's like, "No one knows what this is. No one believes me. Like, I don't know if I should believe myself." And the answer is yes, you should, and this is your lived experience. So if you have access, and you would be surprised because sometimes I get like, "No, I live, you know, in a rural area, like there's not going to be anything around." Actually, there's a lot of things around in a lot of places if you go looking. And then certainly there's online support things. And I know there's links actually throughout, again, Global Healthy Living Foundation and so forth.

Dr. Dana Direnzo 00:32:43:22 - 00:33:33:12)
But I would encourage anyone who's having any of these thoughts to join support groups. And even better as sometimes like in person or online group sessions particularly centered around the stresses that can arise from having a chronic illness and in particular rheumatic disease. And certainly it's a little bit harder to find maybe a Sjögren's specific one, but they do exist. I know they exist. And then sometimes it's helpful, and you had brought up anxiety before, but different anxiety centers and mental health clinics do provide a lot of these things because it is an adjustment in terms of thinking about all these aspects as related to your health and then how you identify and interact with that. So I just want to put in a plug for group therapy because I'm a big fan.

Shilpa Venkatachalam (00:33:33:14 - 00:34:51:10)
Lovely, lovely and very important for our patient community to know, especially as they're listening. You know, the sense of really articulating, both of you, the resounding message was articulating understanding your body, understanding your mind, articulating it, communicating it so that you can get the right kinds of support as best as possible. And it's something why we also keep talking about, and Dr. Direnzo, I know you're a big advocate for, patient-reported outcomes because some information comes directly only from the lived experience. There is some information you cannot get and glean from bloodwork and scans and imaging. It's about how far can I walk? Can I take my dog for, you know, a walk? Can I go to that skiing trip that I've been planning with my family? Those are the things that matter to patients. So communicating that, you know, and journaling about those things so that together with your clinician you can make a, you know, set out goals to achieve that are aligned for both clinician and patients are really important. And that's why I keep repeating, you know, for the patient community, we do have the

resources at GHLF. So please reach out if there's anything that you would like to learn more about.

Shilpa Venkatachalam (00:34:51:12 - 00:35:22:00)
As we wrap up this absolutely amazing conversation, I want to ask you, a lot of people who we've spoken to and encounter in the patient community will often feel like the disease, Sjögren's, has taken over their life. And they feel sort of out of control. So when someone with Sjögren's is asking, "Well, how do I get my life back?" for both of you, what would you want them to hear? And let's start with you, Melissa.

Melissa Taylor (00:35:22:02 - 00:36:19:10)
It is such a journey. I will just say, it took a long time for me to accept that I had an illness. It is something that I railed against very hard. I did not want to believe that I would have something that would impact me for the rest of my life. And we talk about, you know, it was four years of symptoms, two years of me pushing really hard at "No, something is wrong." And when I was first trying to get a diagnosis for Sjögren's, it was still a syndrome. I was being told that it cannot cause neurological symptoms. It will only cause dry eye, dry mouth. And so I think for me, part of my struggle was really believing that the doctors are telling me the right information and that everything else I'm experiencing must be stress. I must be just really stressed out about all this.

Melissa Taylor (00:36:19:10 - 00:37:22:14)
And so a huge part of it for me has been sort of the new emerging information coming out about Sjögren's because it is matching more with my lived experience as time goes on. And that feels really good and vindicating for me. And for a while it did feel like Sjögren's had taken over my life. As far as managing symptoms, it was my daily life. There was no guidebook. No one told me, "All right, you have Sjögren's. Here is what you need to do exactly to manage it." It was more like, "You have Sjögren's. Good news, it's not a big deal. You'll just have dry eye, dry mouth. It's going to be okay." I really wanted to believe that. That's the version that I wish were true. But I could have really used sort of like a holistic approach, like Dr. Direnzo has sort of. It is a mind-body connection. Your whole body is connected. And that just makes sense to me.

Shilpa Venkatachalam (00:37:22:16 - 00:37:38:14)
Yeah. Dr. Direnzo, what would you say about that? Your message about the fact that this is both mind and body, holistic approach is a very powerful message for people listening in for us living with these diseases. What could you add to that?

Dr. Dana Direnzo 00:37:38:16 - 00:38:42:03)
So first I would piggyback that. Melissa, unfortunately I hear your same sentiments all the time. So I certainly believe your story when you say, you know, it was a couple years to get a diagnosis. And I think I've heard the story enough that I get stressed out about it. You know, like that's stressful to be experiencing all these things. You're just trying to figure things out. You're just trying to get the right information. You're hoping that the people you're going to are telling you the right information. But what I actually start with is I do genuinely think that it can be okay if you're partnering with someone you trust and you have a good working relationship with. So I would stress that your job as a patient is really to be interviewing a doctor that you're going

to be working with over the course of a lifetime. I mean, maybe not a lifetime, things happen, but you are trying to find someone who could be your partner.

Dr. Dana Direnzo 00:38:42:05 - 00:39:40:20)
And then on the equal footing, when I am thinking about my patients, I am trying to push them into being my partner. So you also don't want me to be talking at you and telling you x, y, z things, right? So you're going to get the most out of your working relationship, and I call it a working relationship, when you're finding someone who believes what you're saying. And then you, on behalf of the patient, are presenting information that is very specific or as specific as it can be. So I'm going to reframe the question because I actually laughed when you sent me this email because I was like, man, how do I kind of correct even the Global Healthy Living Foundation from wording this question because I don't want my patients sending this question to me. So it is okay to be overwhelmed and say, "How do I get my life back?" But then just imagine on the role of the doctor, I got a doozy of a question. I don't know what's wrong, so if you can't tell me what's wrong, I don't know how to help you fix things or partner with you to fix things.

Dr. Dana Direnzo 00:39:40:22 - 00:40:42:06)
So when you are a patient, I would say, number one, you got to think to yourself, what are the biggest barriers in my day-to-day? What is the most impactful thing that I want to work on in order to feel like I'm at a better place? So I usually encourage people to bring maybe 2, 3 things to the appointment, or big goals that they have. So, for example, for you, it might be your energy levels and your fatigue. And then I would encourage you to think specifically like what part of your day, like, are you really feeling low, low energy, and specifically how, your mental health, your physical health, are you losing stamina, is it just a matter of x, y, z things? So how can you pick apart the problem that you feel like is the most impactful? Because then that's going to be how you could partner to think and brainstorm. And it might be medications or might not be medications. Like how can you partner together to very specifically make action and plan?

Dr. Dana Direnzo 00:40:42:08 - 00:41:22:04)
And we have to be as specific as we can to make an action plan together. So that's what I encourage, everyone kind of think, because unfortunately, rheumatology appointments take a long time to get. So you have, making a joke, but you have some time to think about what are the things that I need, you know, I need to be changed or what are the things I need to be figured out? And the more specific you get, the better answer you might get back. And it is a working relationship.

Shilpa Venkatachalam (00:41:22:06 - 00:42:18:11)
. So I think that's a really powerful message. And the other thing that both of you alluded to is different things matter to different people based on where they are in their life, their disease journey, what they want to do in life. And so communicating that to your doctor so that you can, you know, do the things you enjoy the best in the best way that you can is really important. So I really love this notion of the partnership, but also, you know, communicating so that care can be tailored to your needs, to your priorities, to your specific goals. And what a powerful message to end on as we come to the end of this wonderful conversation.

Shilpa Venkatachalam (00:42:18:11 - 00:43:09:19)

I really want to thank you both. You know, this episode for me felt like it was, first of all, very comforting. But it was almost like a handholding each other through the journey. And we hope that everyone's journey through their disease is a handholding between the clinician or the care team and the patient. So thank you very much for joining us today and for sharing your expertise on Sjögren's disease from what it takes to get to a diagnosis, to the day-to-day realities of caring for patients living with this condition. You know, conversations like this one are really important for helping our community feel seen, understood, and better equipped to advocate for themselves. We're truly grateful for your time and for your insight.

Shilpa Venkatachalam (00:43:09:19 - 00:43:49:10)
And to everyone listening, thank you for tuning in. If today's episode resonated with you, we invite you to explore more resources on Sjögren's disease and self-advocacy, and to listen to our next episode of The Sjö. Subscribe to The Sjö or visit creakyjoints.org for the latest information and news about living better with Sjögren's disease. This podcast was made possible with support from Novartis. If you like what you heard, be sure to rate our podcasts, write a positive review, and spread the word by sharing with your family and friends. It will help more people like you find us.