



## Take Control of Back Pain

Hosts: Rebecca Gillett, MS OTR/L and Julie Eller

**Guest Speakers: Rita Roy, MD, MS and Jed Finley, Patient Advocate**

Nearly 16 million Americans live with persistent or chronic back pain, and a staggering 80% of people in the U.S. will experience low back pain in their lifetimes. It's no wonder then that back pain is the 6<sup>th</sup> most costly health condition in the U.S. as well as a major leading cause of depression and anxiety. In this episode, we explore the social, emotional and physical impacts of chronic back pain as well as various strategies to help relieve arthritis-related back pain. Additionally, we discuss the importance of building a strong support network and how giving back can help improve quality of life with chronic pain.

Our guests include two patient advocates living with chronic back pain, Rita Roy, MD, MS, CEO of the National Spine Health Foundation, and Jed Finley, a special education teacher and founder of the Facebook-based support group "Living With Ankylosing Spondylitis."

Rita Roy, MD, MS is a physician and entrepreneur of emerging technology for health care communication and education. She is the CEO of the National Spine Health Foundation, where she brings her expertise to help drive the mission of improving spinal health care through patient education, research and patient advocacy.

Jed Finley is a special education teacher who works with children with autism and autism spectrum disorders. He is a support group leader for the St. Louis chapter of the Spondylitis Association of America and founder of the Facebook-based support group, "Living With Ankylosing Spondylitis," which boasts over 26,000 followers and continues to grow by a few hundred every week.

### **Additional Arthritis Foundation resources:**

Check out all of the programs and resources for the Arthritis Foundation's September Pain Awareness Month at [arthritis.org/realpain](https://arthritis.org/realpain)

Join our [Live Yes! Arthritis Network today](#) to make connections and get information and resources to help you manage your pain.

Back Pain Causes and Treatments: <https://www.arthritis.org/diseases/back-pain>

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Osteoarthritis of the Back/Spine: <https://www.arthritis.org/health-wellness/about-arthritis/understanding-arthritis/back-oa>

Axial Spondyloarthritis/Ankylosing Spondylitis: <https://www.arthritis.org/diseases/ankylosing-spondylitis>

10 Tips for Easing Back Pain: <https://www.arthritis.org/health-wellness/healthy-living/managing-pain/pain-relief-solutions/10-tips-for-easing-back-pain>

QUIZ – Test Your Axial Spondyloarthritis Knowledge: <https://www.arthritis.org/diseases/more-about/when-back-pain-means-you-have-axspa>

Find guest speaker and patient advocate Jed Finley's [Facebook Group - Living With Ankylosing Spondylitis](#)

National Spine Health Foundation: <https://spinehealth.org/>

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## Take Control of Back Pain Episode #21 – September 8, 2020

### PODCAST OPEN:

Welcome to the Live Yes! With Arthritis podcast, from the Arthritis Foundation. You may have arthritis, but it doesn't have you. Here, you'll learn things that can help you improve your life and turn No into Yes. This podcast is part of the Live Yes! Arthritis Network — a growing community of people like you who really care about conquering arthritis once and for all. Our hosts are arthritis patients Rebecca and Julie, and they are asking the questions you want answers to. Listen in.

**Rebecca Gillett:** Welcome to the Live Yes! With Arthritis podcast. I'm Rebecca, an occupational therapist living with rheumatoid arthritis (RA) and osteoarthritis (OA).

**Julie Eller:** And I'm Julie, a JA patient who's passionate about making sure all patients have a voice.

### MUSIC BRIDGE

#### Rebecca:

Thanks for joining us today on this episode of the podcast. September is [Pain Awareness Month](#) and if there's anyone who understands pain, it's all of us who live with the pain of arthritis. One of the things we're focusing on is back pain and arthritis. It's something that millions of people suffer from, and I'm definitely one of them. No two cases of arthritis-related back pain are exactly the same. I had my first cervical fusion surgery when I was only 31 due to degenerative disc disease and osteoarthritis in my spine. I've had two more surgeries since then on my neck, so it really affects people of all ages Julie.

#### Julie:

Yes, that's definitely true. My first encounter with back pain was when I was in elementary school and it would interrupt my ability to sleep, interrupt my ability to sit in class all day. And we know that's not the only presentation of back pain in our community. Back pain from arthritis can have several causes. There's degenerative, wear-and-tear spinal OA and then there's back pain caused by inflammatory kinds of arthritis, like psoriatic arthritis and axial spondyloarthritis, also known as AxSpA. Most people in our community are really familiar with ankylosing spondylitis (AS), a type of AxSpA which can lead to spinal fusion, usually if left untreated. The other type is non-radiographic AxSpA. It has the same symptoms as AS, but spine changes don't show up on X-rays, which can be really frustrating from the patient perspective in getting a diagnosis, finding the right treatment and so on.

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**Rebecca:**

Yes, and today we're lucky to have two amazing guests to share their stories about living with arthritis-related back pain, as well as strategies to combat pain and stiffness. They'll also share some of the incredible things they're doing to support the community of people who live with back pain. It's so helpful to get to talk with some patient leaders who understand the need and offer support to those who are experiencing chronic back pain.

But before you introduce our guests, Julie, we want to remind our listeners that every type of arthritis-related back pain is different. So always check with your doctor or a health care professional before trying a new therapy or strategy to alleviate your back pain.

**Julie:**

Yes, that's always going to be our top advice: Check with your doctor! Today we're going to have two guests on our show: Rita Roy, who is the CEO of the National Spine Health Foundation, where she brings her expertise to help drive the mission of improving spinal health care through patient education, research and patient advocacy. She'll be joined by Jed Finley, an ankylosing spondylitis patient advocate, and the founder and administrator of a really cool Facebook support group called Living With Ankylosing Spondylitis. Both patient leaders have done amazing work to build community in the back pain space, and to really make sure that patients who live with chronic back pain know how to get the care and support that they need.

Welcome to the podcast Rita and Jed. To kick us off let's have each of you tell us a little bit about yourselves. Rita, do you want to start?

**Dr. Rita Roy:**

Sure. Thank you. First, I want to thank our colleagues at the Arthritis Foundation for inviting me on to this podcast today. This is an incredible opportunity for the National Spine Health Foundation to collaborate with the Arthritis Foundation, and it makes a lot of sense for us to do that. I am the CEO of the National Spine Health Foundation, but maybe more importantly, I am a spinal champion. I had a spinal fusion three years ago and I have never felt better. So I am passionate about my job, not only as this being a career that I love — patient advocacy and medical research — but also as a patient who feels so compelled to create an organization that is advocating for the voice of patients in spinal health care. We all know how common back pain is and arthritis of the spine is a leading cause of degeneration in the spine.

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And so, we ought to be friends; the Arthritis Foundation and the Spine Health Foundation have a lot to talk about together.

**Rebecca:**

Oh, we're so glad to have you. Jed, tell us your story.

**Jed Finley:**

Hi. Well, thanks so much. It's really great to be here. My name is Jed Finley. I am ankylosing spondylitis patient and advocate. I was diagnosed with AS when I was 12 years old. I started a support group on Facebook called Living With Ankylosing Spondylitis, which now has a little lower 26,000 members. I'm also a support group leader for the Spondylitis Association of America for their St. Louis chapter. I'm a writer, I'm a blogger. I'm trying to be a podcaster. Uh, but, uh ...

**Rebecca:**

Well you are now.

**Jed:**

Yes, that's true.

**Julie:**

Yeah, it's official (laughs).

**Jed:**

I like doing advocacy. I like representing the patients. Ankylosing spondylitis is such a lesser known disease. People call it a rare disease. It's not a rare disease, it's just not very well heard of. I want to be the voice for ankylosing spondylitis, to spread the word, let people know what it is and hopefully educate people on what it is, what it does, and how it can be treated.

**Julie:**

Do you mind telling us what ankylosing spondylitis means and what that diagnosis is?

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**Jed:**

Sure. Ankylosing spondylitis is an autoinflammatory disease. It mainly affects the spine and causes — over time — the spine and the vertebrae to fuse together. Uh, however, it can also affect the major joints of the shoulders, hips, knees and then also peripheral joints in the hands and the feet. It's an all-encompassing, kind of arthritic condition. It's degenerative. When you get it, it's best to treat it quickly cause the longer you have it untreated, the harder it is to treat. So, yeah, it's kind of a pain in the back.

**Julie:**

(Laughter.)

**Rebecca:**

(Laughter.) There's no two ways around it.

**Jed:**

Sorry for the bad joke. That was terrible. I apologize.

**Julie:**

No, it was great. I'm going to have to use that one. That's fantastic (laughs).

**Rebecca:**

Dr. Roy, can you touch on some of the different types and how prevalent back pain is in the U.S.?

**Dr. Roy:**

That is really the important question to ask. It's really staggering. You know, on a personal level, 100 million Americans are affected every year from neck or back pain. That's approximately one-third of the United States population. We say it's you or someone you know is suffering with a neck or back condition. From a health care cost standpoint, the No. 1 reason for doctor visits for physical pain is back pain. It's the second highest reason why people visit their doctors after the common cold. When we look at the total economic burden of the cost of treating back pain, the U.S. Bone and Joint Initiative reports numbers from \$315 billion annually, as an annual

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cost to the economy. So, it's a \$300 billion cost of treatment, which actually doesn't even include chiropractic care, physical therapy or alternative treatments. That's just the impact to treating neck or back pain. And when we look at the larger economic impact ... 264 million lost workdays. It's one of the most common reasons why people miss work, it's due to back pain. No. 1 cause of job-related disability in the United States. It costs companies an estimated \$250 billion in lost productivity.

What are the causes of neck and back pain? One of the leading causes of neck and back pain is arthritis. Degenerative conditions in the spine are part of the aging process and wear and tear of the spine leads to arthritic conditions that causes back pain. One of the often overlooked complications of back pain is depression. People with chronic back pain are four times more likely to carry a diagnosis of clinical major depression.

So, when we start talking about the impact of neck and back pain, there's a personal impact, there's a health care economics impact and there's a larger economic impact and burden to our society. It's really a very big problem.

**Julie:**

It's always really, really impressive when we hear the burden of arthritis, the burden of back pain and chronic neck issue. And Jed, I wonder if you could share a little bit with us about how ankylosing spondylitis back pain has impacted your life.

**Jed:**

Prior to my diagnosis, and then I mean shortly after it, I was an athlete, I was a runner, I played hockey, I played football. And eventually I definitely had to give up hockey, I definitely had to give a football. But I kept on running and I was able to keep that going, you know, for another 10 years after my diagnosis. And then one day, I'm out in the middle of a five-mile or a 10-mile run, I'm halfway through and I decided to stop. And just like Forrest Gump, my running days were over. It was, uh, you know, it's really caught up to me. And I thought mind over matter, that's the way I'm going to beat this. You know, AS is a very ... it's a very strong, powerful disease, and mind over matter, it's not quite enough.

I'm a special education teacher and I used to work in an autism center with little kids. And I used to get down on the floor with them and play with them. Eventually that got really difficult. I had to go to my supervisor and say, "Look, I can't sit on the floor anymore, because once I

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go down, I'm not getting back up again." But on the other end though, you know, it allows me to open up new avenues where I can be more of a writer, where I can do podcasts. Where I can do whatever it is I can do. It forces you to find your comfort level and then molds your life to fit that comfort level. Had I not had to give up all these physical things, maybe I never would have started writing, you know, who knows? So, I like to think that it changes life, but it can also change things for the better.

**Rebecca:**

I couldn't agree with you more on that Jed. I also, as an OT, worked in early intervention with kids and sat on the floor, and worked with them and crawled and jumped. But after my last cervical spinal fusions — I had two surgeries in one — I couldn't go back to it. It was really hard. I did, I tried. We share a similar path, and I think so many people out there do. You have to adjust your lifestyle. You have to put your health first. Sometimes, not everybody can do that. And so it's hard to find that balance. So, that brings me to a question for you Dr. Roy: What are some of the most effective treatments for arthritis-related back pain?

**Dr. Roy:**

So, that's a great question Rebecca. And there are lots of ways to approach answering that question. I want to be careful about not giving any one particular person medical advice in this podcast, but just want to say that there are general approaches to treatment of arthritis in the back. And I encourage anybody who thinks that they may have this condition to talk about it with their health care provider.

What we say in spinal health care is that we try to start with the most reasonable and minimally invasive approach to treating conditions. You start with anti-inflammatory medications, and then we sort of move down the path of treatment. So, treatment is one thing. So, we look at non-steroidal treatments. There are injections that can happen, and then ultimately, the sort of the last step in all of that is potentially surgery. Arthritis of the spine tends to focus in what we call the facet joints of the spine. So, if you were to look at somebody's back, from their back, you have these little bony protrusions that come off the vertebrae into the back. And sort of where those vertebrae stack up against each other, it creates joints we call facet joints. And that's really where arthritis tends to set in. You can do very targeted injections if medications like non-steroidal medications are not helping.

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But the other area to think about in treatment of arthritis in the spine is, physical therapy. Physical therapy is so important and so critical to stabilizing and strengthening your spine. And the way that is done is through core strengthening activity. Many physical therapists in the spine practice will say you actually have three cores; you don't just have one core. We tend to think of the core as our abdominal muscles, and yup, that's a core. You also have a core that supports your neck. You've got core muscles that are supporting our thoracic or the chest part of our spine. So those kinds of activities and exercises are really, really important. And at the end of the day, if there's one thing that we tell people, if there's one thing you do to take care of your spine, it's just move. Walk around your house, walk around your apartment, walk around your block, walk in a park. Get steps in. It is perhaps the single most important thing you can do to maintain flexibility and strength of your spine. During times like the COVID time this year, when people have been more homebound or working from home or learning from home, it's really easy to just sit all day. That's true if you're in a desk job anywhere at any time. So the idea of raising the awareness of "just move," it's probably one of the single most important things people can do to take care of their backs, and also to prevent conditions from flaring up in their back.

**Julie:**

Just move, that's right, that's right. And it can be hard when you're in chronic pain to figure out how to move joyfully and what that looks like for you and how to kind of get that motivation.

**Dr. Roy:**

One of the best ways that you can overcome that pain is to move. Now, some people may need to talk to a physical therapist or talk to their health care provider to make sure that they're doing correct movement. But for the majority of us out there, you wake up, you're stiff, or you're feeling stiff or tense during the day ... the best thing you can do is move. And to your point, it seems counterintuitive and yet, it is the best way to, in many cases, to overcome that pain.

**Julie:**

Jed shared his story just before about how, at some point, he realized that the 10-mile run was not going to be the thing for him. Jed, I wonder, have you found movement that feels good in your experience?

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**Jed:**

You know, I'll confess, my movement has been really lacking lately. But, that's OK. during my school day, I still, I transfer from class to class, so I still get to move from one end of the hallway to the other end of the hallway. I do probably a lot of unnecessary walking. I probably could stagger my day to a way where I don't have to move as much. But I kind of like going from one end of the hallway all the way to the other. Which again, that does force me to move. A while ago I got into long-distance walking. I got a fitness app that would tell me what my goal was and how far off and how much faster I had to walk. And you know, I got five miles in an hour and I was trying to break 10 miles in two hours and I came so close. That runner in me, that competitive mind, you know? I still like to push myself further. And yes, I will hurt afterwards. I would much rather hurt from something that I did than hurt just because I'm existing. Because the fact that I wake up in the morning in pain and I eat breakfast in pain and I go to lunch in pain, and I just live my entire days in pain, it just brings me down, you know? It's such a hard way to live. So, when you go out for a five-mile walk, or however long you walk, and you come back and your legs hurt, that's a good pain, you know? I got this because I pushed through something. I've done physical therapy and that was fantastic. I had a great PT, who his college roommate had AS, so he actually knew what it was and limitations of it, and you know, what I wouldn't be able to do. The other thing we worked on with him was, uh, I, along with being stiff as a board, I'm also hyper flexible in a couple of joints, so we worked on strengthening those joints.

**Rebecca:**

Well, I like how you said that. You know, I feel the same way. You wake up and you have pain and you didn't do anything; you just woke up. But I like to walk and hike, too. And if I'm hurting a little bit while I'm walking or after a hike, to me, at least I've moved my body. We've had a listener once send us a comment saying, that it's hard for her to hear people keep saying that you need to move and you need to keep exercising. That the exercise does make her hurt more. How do you balance out the good pain versus the pain, that you know is AS-related?

**Jed:**

During my distance walking time, when I was kind of pushing myself, the need to go further, the need to beat my time, eventually though that pain did catch up, and I did take a long time off from walking. The ankylosing spondylitis body is always in a state of distress. I'm

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constantly in a state of fight or flight. My immune system is attacking, it's saying, "No, no, no, this is bad. Let's go after that spine. Oh, who needs cartilage anyway?" (Laughing) But, when you push your body, when you exercise, when you do like any kind of strenuous lifting, like the house I'm in right now. I helped renovate it last year, put down new floors and whatnot, which is something I enjoy doing. But crawling around on the ground; not great for an AS body. So yeah that ... it really took a toll on me. Eventually the body has a way of saying I don't like this. The inflammation does catch up. It's such a fine line to walk and everyone's line is completely different. You need to know yourself, you need to know your limitations, you need to know what you can do. And then work within that. And then if you can push a little bit further, fantastic! You need to kind of find your comfort zone and work in that, and make the best out of what you have been given.

**Julie:**

Yeah. And I'll add to that. And give yourself credit for the movement that you have had.

**Jed:**

Exactly, mm-hmm.

**MUSIC BRIDGE**

**PAIN AWARENESS MONTH PROMO:**

September is Pain Awareness Month – and the Arthritis Foundation is offering special programs and activities to bring arthritis pain out of the shadows. We're shining a light on how the disease affects real people who are in real pain – to make real progress. See what's happening and learn more at [arthritis.org/real\\_pain](https://arthritis.org/real_pain).

**Rebecca:**

Rita, are there any practical at-home treatments that you would recommend to people who are having arthritis back pain? Especially now given the pandemic, we are limited in access to treatments we might usually do.

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**Dr. Roy:**

One thing that's very, very important is that people sit at a desk with proper posture. When you're thinking about sitting at a desk, we talk about these three things that you need to do. You need to make sure that you're sitting in a chair with your back in proper alignment. Don't work on the couch and don't work in bed. Those are two big things that we say, is you sit in a proper chair, have both feet on the ground, have your computer at eyesight so you're not slouching over, and have your hands at proper level. So, you've got to create a work environment that protects your spine, and you're going to be sitting there for a while. We say set a timer for 30 minutes. Every 30 minutes stand up. Stand up, stretch. What is stretching? Simple things, arms overhead, reach back behind you, do simple stretching. So, sit properly at a desk, every 30 minutes get up, stand and stretch. Simple yoga stretches that you can do. We recommend that people introduce stretching into their morning and evening routine. So, after you brush your teeth, before you get in bed, drop and do your five stretches and go to sleep. In the morning, you wake up, you get out of bed, you do your five simple stretches, you brush your teeth you start your day. So, we really encourage people to put that into practice in their lives. It doesn't have to be complicated. And some stretching can actually be done in bed.

**Rebecca:**

Jed, do you want to add anything to that that you have found helpful for you right now?

**Jed:**

I do my stretches. Like I put my back up against the wall and kind of wing out my arms and lift them up over my head. And that's a really helpful stretch that I do. After that, I take breaks, you know, like I do not push myself further than I need to, unless I absolutely need to. Don't feel like you need to go further than you, than you should. That if your body's telling you to stop, take a break. It is OK to take breaks, you know, because you only have one body. Take care of your body. And also for me, diet has been ridiculously amazing. I found out that dairy and sugars and starches are all killers for me. And I cut those out and no doctor told me to do that. I just experimented. So, you know, cut something out of your diet for 30 days and then introduce it back in. And if you go from great to terrible, you know that that's a trigger for you. I found out those three things are killers for me. So, I cut them out of my diet. And it's been one of the best moves I've ever made. It's just little things that you can do just to make yourself feel better. If it makes you feel better, go for it. That's my advice.

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**Dr. Roy:**

I'm glad, Jed, that you mentioned nutrition. We talk about the importance of nutrition to taking care of your spine. Body weight is a contributor to degeneration of the spine. So, it's important to maintain a proper body weight. It's important to practice nutrition, you know, good nutrition. Your bone health is important. So, calcium and vitamin D intake is really important. So, you could go outside and take a walk on a sunny day and get your vitamin D and your movement done — all at one time. And the other thing that's really, really important to spine health that a lot of people don't realize, is that smoking is really bad for your back. The deleterious effects of smoking on your spine and your disc health, it is well documented in research. So, the movement, stretching, good nutrition, bone health with vitamin D and calcium, and quit smoking. But actually putting that into practice is a challenge.

**Rebecca:**

Yeah, you have to create a routine to really kind of get those in place and just make it part of what you do every day. Basic treatments as well for managing chronic pain is hot and cold therapy. I know a lot of people rely on that. I actually use acupuncture myself and find it helpful, especially with my fusions. And I have lumbar spondylosis. So, having my regular visits really helps with that pain and of course massage. It's tough to manage that pain, but we're all in this together. So thank you guys for offering some of those suggestions.

**MUSIC BRIDGE**

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**Julie:**

Both of you are esteemed patient leaders. I wanted to ask you both kind of how you made that choice to move from a patient experience that you were having, to a patient experience that you wanted to lead through? And Rita, if you don't mind, I'd love to start with you.

**Dr. Roy:**

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When you're living with a chronic condition and you're able to find relief or treatment that helps you overcome that, you want to sing that from the mountain tops. And I think that, you know, for me, I had a spondylolisthesis. It's a fairly common condition in the spine, where one vertebrae is slipping over another vertebrae, and often is caused by trauma. I think I had a ski injury. I fell hard and, you know, as happens often with these, you sort of, you feel like, oh, you hurt something. Maybe you're in bed for a couple of days. And then you move on with your life and a little ticking time bomb is sitting there eroding the joint space, eroding the disc. And eventually you wake up one day and you say my leg's on fire. Why is my leg hurting? I must have injured my leg. And it's really your back talking to you. It's a fairly common situation. After I was diagnosed with the spondylolisthesis, I lived with it for nine years. And I just thought, you know, doesn't everybody have back pain and isn't this just how it goes? And the answer is, yeah, a lot of people have back pain — 100 million Americans have back or neck pain, but you don't have to live with it.

I found an incredible surgeon, who talked with me about what was going on and said I needed this operation. I think when people are told that they need back surgery, you're immediately faced with fear and confusion, and fear and fear and fear. There's a stigma around having back surgery, that you're going to need another one, that maybe it's not going to work. That, you know, something might not go well. And I was astounded at how incredible the technology is and how quickly I recovered, and how quickly I felt better. The technology has improved, the techniques have improved, the availability of skilled professionals, as the training programs have improved and expanded. So, it's a field that has really come of age in the last 20 years. And I just wanted to connect with other people. I wanted to connect with other people who had gone through what I'd been through. And I also wanted to tell others out there, don't wait until it's too late. Don't wait until you might have irreversible nerve damage. You know, get treatment. Treatment is amazing and will get you back to your life, pun intended (laughing). You'll get better and you will get back to your life. Some people get back better than they ever were before. And I think that's what I get excited about in leading the National Spine Health Foundation and entering the national conversation on what neck and back conditions are, and what the treatment options are, and what the preventative measures are.

**Julie:**

Thank you, Rita. Jed, do you want to share a little bit about what brings you into this leadership space and inspires you to be a patient leader?

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**Jed:**

Yeah, so, like I said I was diagnosed when I was 12 years old. I had a lot of time to think about it. When Facebook opened up groups, I kind of thought, so I'm going to make a group for myself. And then hopefully they'd send me out some breadcrumbs: Hey, if you have AS come to me, you know, cause (laughs) it's safe here.

**Julie:**

If you build it, they will come.

**Jed:**

Exactly, exactly 100% — as just one person with AS and I thought maybe more people will show up. I remember when I got to 100 members, I thought, wow, that's amazing — 100 members — I guess I'm done. And of course, now it's 26,000 members and growing-

**Rebecca:**

It's incredible.

**Jed:**

There's 2.7 million people in the United States with some form of spondyloarthritis. I want to be the one who shares the information. I like to say that AS gave me pride and purpose. I was given this and the ability to write and the ability to speak, and the ability to teach. I might as well group all of those together. I enjoy being the one who brings everyone together, you know? I don't always have to be the expert. I don't always have to be the one sharing the information. But I love the idea of giving people a space to come together, and have a safe space, to talk. So that's really why I got into advocacy, through my disease, to give my disease purpose so that it's not just some disease that puts me in pain all throughout the day. That I could do more with it. Even if I'm not out walking 10 miles, I can still log on and change a couple of lives, and help some people out.

**Rebecca:**

That's so inspiring. It just takes one.

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**Julie:**

It just takes one.

**Dr. Roy:**

Jed, wow, it's awesome what you've been able to do and just ... it's so exciting hearing what you're doing. And I think it really speaks to the fact that people, when they're going through something like this, you really want to talk to other people. They just want, you know, as you describe, a safe space where they can talk to each other and get tips and tricks. I'm just enjoying this. And, you know we do something at the foundation called spine hacks, which is sort of like life hacks, laundry hacks, cooking hacks, spine hacks. Like, you know, here's a quick tip on how to take care of your back, and ...

**Rebecca:**

Oh, that's so OT (laughing).

**Dr. Roy:**

And so, we crank those out on a weekly basis. And we just feel like if people could just get one little kernel of information, one little "do this stretch, just this one stretch," you know, or "just take a walk" or just what are the essential pieces that people need to do better. And I think one thing I love what you're saying, Jed, about the 10-mile walk or the five-mile walk, as we age, we all are faced with being able to do less and less as part of the natural aging process. And then you layer onto a condition like ankylosing spondylitis, and that complicates that even more.

**Jed:**

A lot of people need the guidance to figure out what it is they can do. Because a lot of people, they sign into a support group because they're looking for some answer. So yes, giving them that space to say, because most people come in saying my life is over, everything is done. You know, it's like I don't know what to do. I've been given this diagnosis. I mean, even people who ... we get a lot of members who come in saying, "My doctor mentioned this. I want to know more information about it." And they're freaking out. And to have a bunch of people who are able to say, "You know what? It's not, I mean, again, it stinks believe me, I

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won't sugar coat it, but it's not that bad you know. I mean, there are ways to treat it." I kind of want to ring a bell like, "Hey, congratulations, you got your diagnosis." AS is not an easy disease for a lot of doctors to diagnose, especially when you're older because they say, oh, like you said, "Well, well, you're, you're getting older. And you know what, your back's going to start hurting. Your knees are going to start hurting. And I don't know what to tell you. I'll see you in six months." When they have a rheumatologist that says, "Hey, you know what? I think you may have this." And it's like, woof, that's a smart doctor right there. To be able to be there when they get that diagnosis and say, "Hey, it's going to be all right. Here are some things we've tried. Here are some things that may work." I never want to rule out any kind of treatments because like I say, whatever works for one person may not work for you, and whatever may work for you may not work for another person. We're all different.

**Julie:**

Definitely. I think there's something really special about both of you having looked for that connection, looked for that community and said, "I'm going to start it. I'm going to be there. I'm going to do this thing." And it reminds me of one, a volunteer at the Arthritis Foundation, who always says, when she hears that someone is newly diagnosed, she says, "Welcome to the family you never wanted, but we're happy to have you here. We're happy to be here for you and we're happy to be your family and guide you through this process." And that's exactly what it is. It's a very difficult and dark experience to go through chronic pain that's undiagnosed. And then being in that limbo phase of trying to figure out if there is a name for this thing, and then finally having a diagnosis and maybe some treatments. But finding where those treatments are — it can be a very dark and hopeless process. And so, to have two patient leaders here, ready to say, "If you have back pain, I can be your family and I can help you through this process," I think that's pretty remarkable.

**MUSIC BRIDGE**

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**Julie:**

Jed, we know that two-thirds of people living with arthritis experience depression and anxiety based on data from the Live Yes! Insights study from the Arthritis Foundation. And I was wondering if you could comment on whether this feels true for you in your personal experience, but also from that broader community experience of people who live with AS. Does that seem to ring true there as well?

**Jed:**

Oh yes. There is an absolute, present and powerful area of mental health and well-being in the community with ankylosing spondylitis. A couple of months ago during the beginning of the COVID era, a group of friends of mine, we all got together and we started the high risk COVID-19 movement, just to raise awareness that hey, you know, people with autoimmune conditions, we really need you to stop moving around. We really need you to stop the spread of this disease. And we were loving it and we were doing all these media interviews, and then pretty much all at the same time, we all just kind of went and just collapsed and melted. And it was so funny. Like we were chatting every single day, then one day, no one's in the chat. And we were like, "Hey, is everyone all right" And we all just kind of simultaneously said, "No, we're not all right at all." Uh, cause we, you know, we overdid it. We flew too close to the sun and we melted our wings. And that stuff ... like that can take a lot out of you mentally, because you should be able to go mow the lawn. I watch my neighbor across the street, she's probably like in her late 60s. She's out there every single day mowing the lawn, weeding, doing this, doing that. She is one active, hip lady. And, um, I, like yeah, I've been putting off raking the small patch of leaves for like a month now because I just can't do it. And that stuff ... like that can be ... can really bring you down — especially when you're younger.

I know some younger AS patients who, I mean, they just ... they're in pain. And just in the face, crying all the time and, is their pain worse than mine? I don't know. Do they have less ability to handle the pain mentally? I don't know. You know, I don't know them. It can take a lot out of people. The mood can be just completely wrecked. You know, you can go from having a great day and then suddenly that pain hits you, and it's the worst day of your life. And just knowing that it can take a lot of you, like, is my entire life going to be like this? I know a lot of patients that say that. Is my, is the rest of my life ... is this it? I'm never going to have another

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good day ever again? Yeah, I mean, that, that is tough. That is a hard way to think. The family feeling of, of these support groups, are so imperative to help people get through this. Like I said, started off talking with my high risk COVID-19 friends. You know, we're all really good friends. We're all really, really tight. And that we are able to say to each other, "Look, I've hit my wall. I can't do this anymore. I need to take a couple of weeks off." And that understanding of, "Totally do it. Absolutely! We will be here when you get back. The opportunities will be here when you get back."

Julie:

I think you really hit the nail on the head when you said that patients, especially patients who live with chronic pain, sometimes wake up every day, wondering if this day is going to be the worst day of my life in terms of pain, or if I'm going to be able to do the little things, like brush my teeth and open the door handle, or get out of bed comfortably. And I think that that's a really difficult and dark place to be. And Rita, I'm wondering if you can help share how you encourage people to reframe that experience a little bit. Like what would you say to someone who is in chronic back pain?

**Dr. Roy:**

So at the National Spine Health Foundation, our purpose is we give hope. And that's it, that's our purpose. We give hope. We think about musculoskeletal diseases in general as being non-fatal diseases. Globally, we've done a great job, countries have done an amazing job of extending life., making great progress in addressing fatal disease. But what is emerging is this concept of non-fatal diseases being the next major threat to life in the United States. When we think about non-fatal disease, we think about that in terms of years lived with disability.

Musculoskeletal conditions are among the most debilitating non-fatal diseases. And so, people with back pain and arthritis have very, very high rates of chronic pain and disability. This reduces quality of life, limits activities to partake in the things that you want to do, or to join in, you know, family activity and that results in depression. So we have this program called Spine-Talks, and you can go on there and you can listen to the nation's top doctors speaking to patients about the hope and the promise of modern spinal health care. We're doing a study in STEM cell treatments. We're looking at all kinds of different ways of addressing pain, operatively and non-operatively. Back pain is the No. 1 use of opioids outside of cancer treatment. Prolonged opioid use has all kinds of complications, including mental health

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impacts. So, we want to find newer ways of treating pain, newer ways of treating these conditions. And there are lots of conditions in spine, of course ankylosing spondylitis being a chronic condition that at this point doesn't get better.

But that also leads me to my next point, which is that as our aging population increases, so the number of elderly people in our population increases. Average life expectancy is getting to be 90 years old and yet the years living with disability is increasing. We know that the cost of musculoskeletal disease is higher than the treatment of any other disease, any other common conditions. But yet, the research dollars to identify causes, to create new treatments and to reduce pain and to reduce disability, is much lower than that of any other health condition. So, here we have one of the most common causes of pain, disability, mental health outcomes from that. And yet the research dollars don't match the magnitude of this condition. So, we're saving lives. But, if we're saving lives but we have quality of life that doesn't match that, then there's a discrepancy there.

And so that's where the patient voice can be so critical and valuable in helping government and industry and people who can put dollars into research. Maybe there are gene therapies, maybe there's immunology that we need to put more dollars into research for ankylosing spondylitis, for the arthritis, for looking at better spine surgeries, robotics, 3D printing, all these regenerative medicines. All of these areas need to be pursued. You put patient voices together, you connect patients to experts, you create an environment where we are able to give hope.

**Julie:**

Well Rita, thank you for that. I think really thinking about resources and education and thought leadership as places to find hope, to grow your resilience, to combat some of those really heavy elements of mental and emotional health that go hand in hand with back pain and arthritis. That's a really helpful thing.

**MUSIC BRIDGE**

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**Julie:**

Rebecca, I think that we're probably getting to time here where it's important for us to ask each of our guests to reflect on their top three takeaways from the conversation today. Jed do you want to start?

**Jed:**

My takeaway from this episode is that there is a lot of stuff being done in the world of spine health and chronic arthritis. There's lots of groups out there who are doing things. I want to thank the Arthritis Foundation for bringing me on the show today. This has been fantastic. And I hope that groups like them will continue to raise awareness for arthritis and for chronic conditions. Something I'd like to share is that like I said, there is life after your ankylosing spondylitis diagnosis. It's a big scary word, all 21 letters of it. But we have community, this AS community. Some of my AS advocate friends are my best friends in the entire world. Some of them I consider to be family. And we're out there, you know? If you get your ankylosing spondylitis diagnosis, you're not alone. You are so, so far from alone, find a support group, find people, find community. Twitter is a great place to go. Just do the hashtag ankylosing spondylitis and you're going to find a ton of stuff and people that you really should know. My third takeaway is that this was a great show. And, you know, I, I really appreciate all that we talked about today. And I really hope that the listeners will be able to get a lot of great information from it. I think people can learn a lot from everything we discussed today. So, you know, keep your hopes up, you know, stay active. And most of all, just keep living your life the best that you possibly can.

**Julie:**

Thank you, Jed. And remember that this is the beginning of the conversation, you know? The topics we touched on today are broad. They are far ranging, and I don't know that we really even scratched the surface. So, keep the conversation going. Rita, what about you?

**Dr. Roy:**

The No. 1 thing that I have learned today on this podcast and participating today, is that you're not alone. I think that loneliness and isolation are two very common things that happen

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to people when they are diagnosed with a spinal condition or ankylosing spondylitis or any other spine condition. It's a very isolating thing. And that isolation leads to, you know, mental health issues. And the human condition causes us to not want to be alone, right? Humans need to be with other humans. But to feel alone is, is one of the most damaging and deleterious things that can happen to people. So, number one: You're not alone. Number two: While this is maybe one A or one A and B, is I need to know Jed Finley better. I'm so impressed. I have so loved meeting you Jed. And so impressed with what you are doing from a very tactical standpoint. You create this group and people come and find each other and create community, and learn that they are not alone. And that's just awesome. I'm so wowed and I'm so impressed by that and inspired by that. Number two is that I'm so impressed with the Arthritis Foundation. Thank you for reaching out. Thank you for putting this together. Thank you for showing how much you care to do this, to reach patients who are struggling and don't know where to turn for help. And it takes a tremendous level of effort to do something that is seemingly this simple. Our listeners maybe are hearing something that sounds like, you know, it's easy to do, and it's not that hard to do. But you know, thank you for organizing it, reaching out and putting us together. And I guess the third thing is I just loved hearing from everybody, this concept of embrace where you are. Embrace where you are and do what you can. Don't focus on what you cannot do, focus on what you can do. And find others who can help you understand what you can do. And so I think, you know, big third takeaway is, focus on what you can do and do it!

**Rebecca:**

Try to find the things you can do and focus on the positive. Yeah, that's hard to do some days, but it's what you have to do every day to make it through.

**Julie:**

And it's made easier when we see representative leadership and patient communities. Folks who are really authentically living and offering those solutions, offering that hope. So thank you both for doing what you do, we really appreciate it.

**Dr. Roy:**

Great. Thank you. This is wonderful!

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**Jed:**

My pleasure. Thank you so much!

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