Audio Guide 2: Understanding Trial and Error in Rheumatoid Arthritis

Narrator 00:00
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Dr. Daniel Hernandez 00:09
Welcome to Audio Guide Two, "Understanding Trial and Error in Rheumatoid Arthritis," produced by the Global Healthy Living Foundation and made possible with support from Scipher Medicine.

Zoe Rothblatt 00:20
This audio guide can help you learn more about coping with the RA treatment journey so you can better manage your RA, and most importantly, start feeling better. Remember, this is not a substitute for professional medical care. Always talk to your doctor about issues concerning your health and medical condition. Let's call it what it is, a burden. The process of trial and error when it comes to finding the right rheumatoid arthritis treatment is really a burden.

Dr. Daniel Hernandez 00:50
That's true for many patients. There are treatment guidelines put forth by the American College of Rheumatology. But for the most part, it is a lot of experimenting, because not every patient is the same. And therefore, not every person will respond the same to treatments.

Zoe Rothblatt 01:06
Right. As some people will find relief and success on certain treatments, others may not, which brings about a lot of frustration when you have to just try a treatment and wait and see if it will help you.

Dr. Daniel Hernandez 01:18
We discussed the good news in our first audio guide, that precision and personalized medicine can help with this and hopefully reduce a lot of that burden. But while many people are still experiencing the trial and error, let's talk about the emotional toll and what you can do about it right now.

Zoe Rothblatt 01:36
You know, maybe the most important place to start is just to say that it's normal to go through this as a patient. I think that many newly diagnosed patients are surprised to learn about this treatment journey and don't really know what to expect. There's often a sense of relief that comes with a diagnosis like: "ah, there's the answer." But then all of a sudden, you're faced with this whole other battle of starting and staying on treatment, which can be really lonely.

Dr. Daniel Hernandez 02:03
That's a really good point. No, you're not alone if you are going through trial and error and waiting for treatment to start working.
Zoe Rothblatt 02:10
So, Daniel, why does trial and error even happen?

Dr. Daniel Hernandez 02:13
Today, we have more choices than ever to treat rheumatoid arthritis. Unlike decades ago, when our understanding of the causes and progression of rheumatoid arthritis was more limited, and medication options were far fewer, now we have so many different treatments, and many of them have different mechanisms of action. What does this mean? It means that these treatments have very different ways, specific ways that they work in your body. So this means that you really don't need to settle for a treatment that isn't helping you feel better. But it also means that you're more likely to experience medication stops and starts along your treatment journey because of this. And because every patient is different. And there are a lot of variables that go into finding success on a treatment, it has to be something that you actively work towards.

Zoe Rothblatt 03:01
Okay, that makes sense. Like, it's good that there's so many options. But this also means that because there are so many options, it takes a little bit of time to try the right one. So, you know, let's go through some of the reasons that patients even switch medications. I would say that the first one that comes to my mind is that maybe the medication you currently take isn't controlling your symptoms or isn't working like it once was and you feel like you can't function in everyday life as you want to.

Dr. Daniel Hernandez 03:30
That's a very important one. Another reason could be that the medication schedule or the method doesn't fit into your lifestyle. Maybe you don't have the time or ability to sit for a few hours for an infusion.

Zoe Rothblatt 03:43
You know, another could be the side effects are so bad that they outweigh the good or the medication interferes with another part of your treatment,

Dr. Daniel Hernandez 03:51
Or you're newly diagnosed and just beginning this treatment journey.

Zoe Rothblatt 03:55
True. You know whether you're newly diagnosed or living with the condition for a while, chronic disease can be lonely. Plus, living in chronic pain and symptoms while you're waiting for relief from a treatment is physically hard and emotionally taxing. So how do you cope with all of this when you're overwhelmed by your chronic illness?

Dr. Daniel Hernandez 04:14
I think the first step is to talk it out and get help. Whether that's talking to a rheumatologist, a mental health professional, or to a friend, describing how you feel, venting about it and just getting it out can help release difficult feelings.
Zoe Rothblatt 04:30
That's so true. Even with everything in life, just getting it out really helps. And I would emphasize that speaking to your doctor is so important. It goes back to what we talked about in Audio Guide 1, how personalized medicine can really help you work together with your doctor to better convey your treatment preferences and lifestyle and your emotions are certainly part of all of that. Daniel, I would say another way to cope is with self-care treatment. You know focus on what you can do and what you can control.

Dr. Daniel Hernandez 04:58
That's very true. Self-care can be anything from stretching, doing exercise, to getting a massage, eating a well balanced meal, taking a bath, even reading or watching TV to get your mind off things. Whatever brings you comfort and helps take away the pain, even if it's for a little while, it's something worth attempting to do.

Zoe Rothblatt 05:19
And on that note, also focus on respecting your limits and the things that you cannot control. A common temptation for people with chronic illness is just to, you know, push through the pain and force your body to do what you feel it's supposed to do or what you could do before your diagnosis. But I would say give yourself permission to rest, pause and think about what you need in that moment.

Dr. Daniel Hernandez 05:40
It seems like it's such obvious advice, but we see it time and time again, that a lot of people within our community try to push themselves because they feel if they don't push themselves, they're going to be judged. It's important to be mindful and try to listen to your body as best as you can. It's battling enough you can give yourself grace to rest and take it slow. Another way to cope is connecting with others. Nobody understands the complicated feelings quite like others in similar situations. And thanks to the internet, it's easier than ever to connect with other people living with chronic disease.

Zoe Rothblatt 06:16
Speaking of connecting with other people also just choose to surround yourself with others who make you feel comfortable and are supportive of your situation. You know, if there's a certain friend that makes you feel really good, maybe on a bad day, reach out to them and lean on them for their support. Lastly, I would say pay attention. You can do this by journaling your symptoms. We talked about arthritis power earlier, it's a great app in order to track what's going on with your body and just don't ignore or minimize what you're feeling.

Dr. Daniel Hernandez 06:46
That's a really good point. Try not to minimize what you're feeling, it's valid. Bring it up with your rheumatologist because then you can work through it together. If you don't bring it up, it's not going to start that process of trying to treat it. And if you're really struggling, get professional help with a mental health provider. You don't have to carry this burden alone. There are professionals who can help.
Zoe Rothblatt 07:09
There are communities out there like ours, CreakyJoints, who can also provide support. Overall, we know that the process of trial and error is challenging. But we also know that the relief that comes when you do find the right treatment is really helpful.

Dr. Daniel Hernandez 07:25
Yes, we've seen it quite a lot in our work, and it is always something that gives us hope for everyone else within our community. It's very important to take these things into consideration and also be aware that you're not alone. Thanks for listening to our audio guide on the trial and error that goes into finding the right rheumatoid arthritis treatment. I'm Dr. Daniel Hernandez, Director of Medical Affairs and Hispanic Outreach for Global Healthy Living Foundation.

Zoe Rothblatt 07:56
And I'm Zoe Rothblatt, Associate Director of Community Outreach for GHLF. For more information on rheumatoid arthritis treatment and precision medicine, check out the Let's Get Personal podcast available wherever you listen to podcasts. This audio guide was made possible with support from Scipher Medicine.

Dr. Daniel Hernandez 08:15
And for more information about managing rheumatoid arthritis and to join a free worldwide support and advocacy community of RA patients and their families visit CreakyJoints.org, which is a part of the nonprofit Global Healthy Living Foundation.

Narrator 08:31
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