Episode 4: Dr. Wright

Narrator 00:00
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Dr. Grace Wright 00:12
When you get the diagnosis, there is a sense of relief of, "Oh my God, I have a name. Now I have to do something different." And what is that different than to be because it's completely unknown.

Daniel Hernandez 00:22
Welcome to Let's Get Personal, a podcast that shares the rheumatoid arthritis treatment journey. Hi, I'm Dr. Daniel Hernandez from the nonprofit Global Healthy Living Foundation. Through my work, I have the opportunity to speak to many inspiring people living with rheumatoid arthritis. And we wanted to share some of their stories with you. So welcome to our podcast, where we'll chat with people within our community about their experiences and hopefully through their stories inspire you in one way or another. In this episode, we'll hear from Dr. Grace Wright, a superstar rheumatologist and advocate for patients rights. Dr. Wright has been treating people with all types of rheumatic conditions for years, and gives us insight on the point of view of a rheumatologist. She gives us tips on how to improve your relationship with your doctor, and even how to speak to your doctor about getting a second opinion. Let's start. Thank you so much for being here with us.

Dr. Grace Wright 01:19
My pleasure.

Daniel Hernandez 01:20
I'm really interested in hearing your thoughts on precision and personalized medicine. As you know, this is a tool set that drives towards the approach of the right treatment for each individual patient that can be done in the clinic. So could you tell me how these two concepts play out in your practice?

Dr. Grace Wright 01:40
This is a really critical issue. And different people use different language to describe this. I mean, for me, this is sort of the core of of how I practice. But I know that there are wide practice ranges across the country, across the world. When I think about precision medicine, it's twofold. It's about taking the tools that we currently have available to make the right diagnosis. Because if I miss the diagnosis, than everything else is moot, so there's precision in the diagnosis, and then precision in the care and the precision there are says how can I choose the best therapy that allows this person to have the greatest chance of success, and really sort of acknowledge that there are side effects, there are comorbidities or other diseases that may come into the picture that I have to also think about and manage. And choose the one that's ultimately best for them. Personalization is even one step further. It says for the person in the room in front of me in their particular circumstance. So do they have young kids at home? Are they a school teacher where they're always around four year olds with, you know, runny noses? Or are they a farm worker who has sort of long hours and heavy labor? Are they sitting at a desk all the time? Do they have access to certain things that some other groups may take for granted. So it's personalizing the care. So that person has the best chance at success and really sort of providing a level of equity.
So it really is an even more nuanced approach. And then it also says, what does that person prefer? Are they really not keen on having a medicine that they have to inject themselves every day, every week, every month? Or would they prefer a pill or is an infusion actually the best thing for them. So personalization takes into account that individual's choice, whereas precision takes into account the diseases' perspective. And it's really bringing those two together. That allows me to make to have a conversation that allows that person to make a decision.

Daniel Hernandez  03:41
If a person previously diagnosed with RA is not feeling like their medications are working properly, but he's hesitant to speak to the rheumatologist about this because the labs are coming back fine, what is your advice on how a patient can broach this conversation with their doctor? And possibly change treatment plans?

Dr. Grace Wright  04:01
Yeah, that's really so key because, you know, we're all trained to look at joints and are they swollen and tender? Is the blood work normal? Does a person sort of look normal? And then I say, okay, so your RA is controlled. However, you can't sleep, you're so fatigued, you can't get out of bed in the morning. And you're achy, even though things look normal. So I always say, you know, never come into the office just saying, "I don't feel well." That's valid, but it's too nonspecific. So what I love to hear is, what are the things that make you say you don't feel well? Are you so tired you can't get out of bed in the morning? Are you crashing by four o'clock in the afternoon? Is your medication making you so nauseous that you're probably skipping a couple of doses here and there and even though your joints may look normal, are they so stiff, that you're having trouble in the morning getting dressed and functioning? So it's the detail and it's easier to remember that when you're not on under pressure. So when you're not in the office. Come in with a list just so that it keeps you focused. And we don't have this sort of just large sort of roaming discussion that might miss some of the key things that are important for you. So I'm, I'm a huge fan of people, I have my patients, you know, make a list. We may not get through all 30 items. So give me your top five, we can really focus on that so that I understand what you're living, because all I have is what I see on the day that you show up. And three days before or three days after, it may feel really different. And so that's always important. If you happen to have a device that can take a picture, take a picture, maybe your joints were swollen, and I didn't capture it that day. You had a bad ulcer in the mouth from one of the medications that we gave, take a picture and show it so that I can really sort of understand what you're feeling, I always tell my patients to give me an idea of the experience that they're living, not just the data points that we check off when we do our disease activity assessments. So yeah, lists are great, but thinking through why I don't feel well, that's even better.

Daniel Hernandez  06:07
This brings us to the next question, which we've also been hearing a lot about, which is the wait and see period, this latency period, that period after you begin a new treatment and have to wait a few weeks to see if it's working or not. What should a patient be doing, paying attention to, during this time? And also, when should they reach out to the rheumatologist during this wait and see period?

Dr. Grace Wright  06:32
Wait and see periods can be some of the most frustrating times, right? Because you don't know how long to wait or what you're expecting. So for me, I dial it back and say, at the point in time that a decision is made to do X, ask, "When should I expect to see something? Is this because of my RA? Or is there something else that I need to do?" Because sometimes it's not about changing treatment, it's
about changing diet, working on sleep habits, trying to reduce whatever stressors there are, and then find out you know, does this drug take three weeks, three months, six months to work? And can I actually accommodate that? Do I need to be able to get up and go to work next week? I don't have to be months to wait, because then maybe the decisions and the choices that I made for you or with you can be changed. So I think it's really important to do that. And once you set expectations, then it's much easier to manage sort of that fear of what is coming, what is not coming, the frustration of not having an immediate response. I like to say to patients, I can't fix this overnight. But here's the plan, we're going to first do this. And if we see this, then we're going to do that because now they have a roadmap. And if your physician doesn't do that, or your healthcare provider doesn't do that, then ask them for the roadmap. Many of our drugs, unfortunately, we don't have lots of predictive things to say, this is definitely the one for you. We all think it and feel it. But we're really hoping and wishing, right. And so we're also setting expectations for ourselves. And that's a discussion that's really easy to say, "I'm not sure. This really looks like the best and the safest one for you. And I expect to see something over the course of the next four to six weeks." But ask for that.

Daniel Hernandez 08:21
Dr. Wright also had advice on what you can do during this wait and see period, she talks about paying attention to your symptoms and doing the work of wellness.

Dr. Grace Wright 08:32
I said, you know, it's really important that both the provider and the patient participate together in doing what I call the work of wellness. So don't become frustrated. And you know, just sort of give up hope. Do the work of exercise, working on sleep, taking your meds appropriately. If you're having a side effect that is not great for you, some people don't mind nausea, very few people I know will sort of dismiss nausea. But if you're having a lot of nausea, if you're throwing up, if your skin is burning, let the doctor know so that you're not waiting for the three or six month visit to then know, oh, I didn't have to suffer all along. There's also being aware of what's happening and what's working and sort of what you can tolerate based on your life. And then contacting the office or resetting your expectations yourself.

Daniel Hernandez 09:24
I think this is a master class not only for patients on how they should be interacting with their physicians, but also for physicians on how they should be interacting with their patients.

Dr. Grace Wright 09:33
Yeah, you know, I look at this essay, these are relationships. This is a person who's feeling unwell, and a person who's trying to help them feel well. It's a relationship it's like two kids meeting in the sandbox for the first time. And we have to take care of each other's emotions. And so sometimes when a provider is really doing their best and they themselves are frustrated because they're not making you better fast enough. It may seem that they don't care. For the most part, rheumatologists really care for their patients. So really just explore it from that angle, "I know you really care for me. But this is not working for me because," and that's sometimes where they just sort of takes all of the tempers down. But it is also very important, I speak about this all the time about finding your voice and having your voice heard. So never be afraid to speak up, because this is the person with the degree and I'm just the patient. No, you're the person living in the experience, I'm here to serve you. So really always, you know, even if it's to the nurse, the medical assistant, the front office staff start wherever you think you can. And then and then work your way upwards. But never, ever give up your voice. Because it's the only way that we on this side will know exactly what's happening to you. So there's no right or wrong
way to do this. Some people write little notes, they send a little thank you card and put a little thing in there that says, "Oh, by the way, I need to talk to you some more the next time," right? Sort of, it's about working out that relationship. These are diseases that don't disappear overnight. So 5 years, 10 years, 15 years later, even if things are under control, you're going to be checking in with this person. So always manage this from how do I keep a long term relationship? Right? How can we work on the same side and not be adversaries, but still watch out for each other's needs? And I think that, you know, as humans, we all appreciate that. And it just helps to move that needle along so that you can speak and I can effectively listen.

**Daniel Hernandez 11:36**
We've heard about this duality of emotions from others. The feelings of unknown slash fear, but also of excitement of potentially feeling better than right now. What's your advice for your patients managing the seesaw of emotions?

**Dr. Grace Wright 11:53**
It's a roller coaster of emotions, right? And sometimes it's a roller coaster of symptoms to add to that. So it's this duality that you have. Your head is doing one thing, your heart, another and your body is completely in a third space. And yes, you're right. When you get the diagnosis, there's a sense of relief of, "Oh my god, I have a name, there's a title to what I have. I'm not crazy. I'm not making this up." And then it's like, "Oh, my God, I have a diagnosis. Now I have to do something different. And what is that different going to be?" Because it's completely unknown. And I think the first thing is just to acknowledge that both of those emotions are okay. It's okay to be excited that there's a title. And it's okay to be in dread that your life has just changed because your life has just changed. And many times I find that we try to minimize one or the other, and there's no need for that. Experience both. Accept both. And then it's about taking the first next step to say that, okay, this is where I am, I'm really sort of completely panicked about this. Let me get information. Let me talk to somebody, let me get a support group and find other people like me who have walked this path, so that we can hold our hands together. And it's because we've accepted that. And you know, also to share that with your healthcare provider, whether it's a clinical nurse specialist, nurse practitioner, physician, and so it doesn't really matter. The other person on the other side, share that with them. Because when you walk in and I look at you, I go, "Oh, you know, he looks okay, he doesn't look afraid." And you're actually shaking in your boots on the inside. I can't help you with that emotion. And sometimes you really just need somebody to say, "It's okay to be afraid. Here's how we're going to handle that." So yeah, accept the fact that it will be highs and lows. And you know, when you have to then change your medicine, it's highs and lows again, "Oh, there's a drug that can help me that's better than the one I had before. Oh, my God, I have to change my drugs." That's part of the journey. That's why it's a you know, it's not a you walk in, you're cured and you walk out, this is not a sneeze or a cough, right. This is something that we're going to have these this waveform going through. Then to really stick with the plan. But if there's an issue where I'm too depressed to exercise, well, then let's talk about the depression. Let's talk about the fact that I have no place to go to exercise, let's find a solution. And for me, that's what I call the work of wellness. It's you doing your part as a patient to help the plan along and me then working to support you. And then the final piece of it is sort of this idea of maintaining hope, of understanding that the moment you despair and say it's all over something within you just quits. And that quitting is a thing that is going to drive you away from doing the work of wellness. So if you're feeling hopeless, and you're feeling desperate, talk to somebody about it. Persistence is defined as continuing firmly or obstinately in a course of action. And all of this in spite of difficulty or opposition. Chronic illness such as rheumatoid arthritis has been described by patients, as a persistent journey to everything that we've been speaking about. Being
persistent, seems to be key. Could you talk to us a little bit more about this persistent journey? I know that there's going to be highs and lows not only for a patient, but also for a physician that's treating this patient. How do you motivate yourself when things aren't going as easy as you thought with a patient? Yeah, I mean, this is where I call the wellness fatigue, right? Because patients will look at me and say, Do I have to do this for the rest of my life. And that is the beginning of the of the acknowledgement of, "I have a lot of work to do, and it's going to go on forever. And I have to persistently do this." My response to that always is, the rest of your life is a very long time. Let's talk about the next five days, the next five weeks, the next five months. You have to put it into compartments that you can manage, because it allows you to persist for five months, and then another six, and then another one year. When we try to do this, I'm just going to start it I'm going to plunge through, often we fail, right, because it takes a lot of emotional and physical energy to do that. So yes, it is a journey. And it's something that you have to continuously work at. Every once in a while, you know, things go really well. And they stay really well for a period. And for many that could be weeks, days, months, I've had patients in that state for years. But we never forget that there is this thing that could rear its ugly head, because of some external thing, you had an infection, you had a stress or something else happened. In this day and age you you know, you got COVID, something happens, and we can't control those uncontrollables. But that persistence is important. So part of what I think is important as a provider is to acknowledge that it's a lot of work for a person to continuously work at, you know, managing their health, managing their life, managing their jobs, managing their families, and not to demand so much of them, that, you know, they have to be superhuman to accomplish all of this, to provide the support that says you're doing a really good job, I know it's really hard. Let's see if we can improve this one thing next time so that you're not fighting everything. You're just working on one thing, I'm going to do that for the next four weeks. So you get a bite size plan that you can manage, and so that your persistence can continue. And then for the provider, just imagine that it also has an emotional toll on us taking care of patients who you know, have lots of demands that may be outside of the realm of traditional medicine. And so it's important for providers to maintain that sense of well being because we have so, you know, overwhelmed ourselves and not taking care of ourselves, not gotten the support that we need, so that we can support our patients. Right. So it's everybody in the system has to have some self care. And that's the only way that we both get through it. Because as we said before, this is a lifelong relationship. It's a lifelong journey.

Daniel Hernandez 18:09
And my last question, sometimes it has to happen, which is the need to ask for that second opinion. Is there any advice that you could give patients to broach the subject with their physician? There's so many questions about it that I'd love your perspective on it.

Dr. Grace Wright 18:26
Yeah, that's a tricky one, right? Because you first have to say, "Why do I want a second opinion? Is it because I don't trust this doctor? Is it because my next door neighbor's great great niece, who has a friend in another state in a country said, 'oh, there's this new drug and your doctors not giving it to you?" Is it because I don't trust the health care system in general, and so I just go from doctor to doctor to doctor." So that takes a lot of sort of awareness on that individuals part. And often, you know, when this comes up, we're not so self aware to say we understand why we have a query that we want to have validated elsewhere. And all of that aside, it is everybody's right to get another opinion, if they are unsure. And sometimes that other opinion will say your doctor is doing a great job, this is exactly what we should be doing. And you know what, you should stick with this or you will hear what you know, we have had many drugs that could have treated you. There are some other options that you might want to consider. And then you have the choice. Do I stick with my current doctor or do I go elsewhere? And the
other part is when there's just the personality mismatch, you know, and sometimes we don't have the luxury of choice because there is one physician or two providers in the area. And so you're sort of stuck and then you have to work out a bad relationship. But again, I come back to this as a relationship. If you can't communicate if you can't, if this person is not listening to you. If the staff is sort of so dismissive, that you can never sort of have your voice heard, in in view of understanding the work of wellness, it may be better for you to change. And so it's important to understand that about why you're in this situation, so that you're shifting for the right reason, but it's always okay to get another opinion. The other thing that often comes up is, do you tell your doctor that you're getting another opinion? Are they going to feel that you're betraying them, that you're abandoning them? And there are multiple ways to do that nicely. To simply say, you know, think of when you want to hire a plumber, you want to have somebody paint, you just simply say, "That's really great. Let me think about it, I want to ask somebody else." And you can say to your doctor, you know, "I love what you've been doing," or, "I'm a little uncertain." Sometimes I'll hear the imaginary child says I should get another opinion, it doesn't matter. But just it's okay to say, you know, "I want to just get another consultation so that I'm sure about what I'm doing or what the diagnosis is." We all do second opinions, we all have second opinions done on us. It's not, you know, unheard of, or uncommon. So never feel that, you know, it's a betrayal of me. It's your right to do that. It's just about how you communicate that, that can either disrupt the relationship or have a transition to be smooth.

Daniel Hernandez 21:21
That idea of a long term relationship between patient and physician is so strong, and so real. And we have to take care of each other, especially during these times of turmoil. So thank you, Dr. Wright. Please stay safe.

Dr. Grace Wright 21:36
Thanks for having me. It was a pleasure being here.

Daniel Hernandez 21:39
And thank you, our listeners for listening to Let's Get Personal, where you hear about the RA treatment journey. If you'd liked this episode, please give it an honest five star rating and subscribe so you never miss another one. I'm Daniel Hernandez and we'll see you next time.

Narrator 21:54
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