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## Podcast Script: Part 5 Interview with Ashley Newton (1)

### Jessica

Global Healthy Living Foundation welcomes you to Pain Explained, an introductory discussion on tips for talking about pain with your healthcare team. I am your host, Jessica Boles, Licensed Social Worker with Global Healthy Living Foundation and ArthritisPower. We'll be joined by our guest, Ashley Newton who is the Chief Operation Officer at Centerstone's Research Institute. She is also patient advisor on this project, a longstanding member of the CreakyJoints community, as well as a volunteer on the Patient Governors' Group with the ArthritisPower network. Ashley has kindly dedicated her time to ensure that the patient voice is represented in today's session as well as all the work we do here at Global Healthy Living Foundation.

In the next session, Ashley will share with us what she has learned in her experience as a patient living with Rheumatoid Arthritis as well as offering tips on how to communicate pain with one's doctor.

Welcome Ashley, thank you for joining us.

### Ashley

Thank you I'm glad to be with you today.

### Jessica

Great! So, Ashley, if you don't mind, can you just start by telling us a little about how long you have been living with chronic pain – and really if you don't mind sharing when were you first diagnosed and what happened after you were diagnosed what that experience was like for you.

### Ashley

I was formally diagnosed with rheumatoid arthritis in 2016. Though I had symptoms prior to that, they hadn't risen to the level that my doctor was able to diagnose or treat them. In 2016 the difference was that I had a running injury that wasn't getting better and so the symptoms that I was experiencing were much more severe. When I went in for treatment, some of the lab work really helped us to identify that arthritis was one of the underlining causes and actually we were able to identify a couple of autoimmune disease disorders. That really changed my process around getting an accurate diagnosis because there are multiple issues that we needed



to treat and that needed attention. I do have people in my life and my family who are also impacted by arthritis and because of that they were able to refer me to a doctor in my area that came highly recommended, who was very skillful in this area. That doctor was able to work with me to run a series of different lab work to understand specifically what type of arthritis I was living with and then he spoke with me about various treatment options. He provided me with education about rheumatoid arthritis itself and what it meant to live with that disease and kind of what the disease progression looked like. Then, he also was able to talk to me specifically about medication options and non-medication options that would help me to better manage that condition moving forward. One thing that was particularly helpful is that he was mindful of what my insurance would allow for. That helped us to really come up with some practical suggestions as to what treatments and medications was best suited for my needs as well as what's actually available to me based on my resources and my insurance plan.

### Jessica

Well, thank you so much for sharing that. I wanted to get your thoughts on communicating pain with your doctor. Are there specific things that you do to communicate pain with your doctor?

### Ashley

This was actually a learning process for me. I found that I actually struggle at times to communicate my pain in a way that's meaningful to my providers and so one of the things I did early on that was really helpful is that I spoke with other patients about what their experience was like and any tips or tricks that they could share with me that might be helpful. The other thing I did was I actually spoke directly to my doctor about this and let my doctor know that I was having trouble verbalizing how my pain impacted me or where it was occurring or how it felt and I felt like that was a barrier in helping him to better treat my condition. Some of the tips and tricks that were shared with me that I had found helpful as well was that I actually do prepare for my visits. I track using an app called ArthritisPower where I actually track my symptoms and I can get a graph that shows change overtime as a result of that. So, taking that app into my appointment or printing the graph and being able to hand it to my doctor I find that really helps him to look over a period of multiple months or years to see how the medications or the interventions that we're trying really are helping or not helping me. That helps us to make better choices about what my treatment should look like. One other thing I would point out is that I have noted that sometimes there are unique circumstances where my symptoms are more challenging. For instance, travel or vacation, where you're required to go on airplanes or multiple modes of transportation is one thing that has a significant impact on my personal experience with pain management. Recognizing and being able to note where that happens, I think was also helpful for my doctor because it allowed us to better prepare for those events when those events occur. When I'm planning a vacation or traveling for work it allows us to do things more proactively as well.

### Jessica

That's great! I think travel tips are definitely something that patients don't always think of, so I love that, and I love that you use ArthritisPower to communicate. That's awesome. I want to talk to you a little bit about non-medication approaches for a moment. So, if you don't mind, could you share with us where you get information regarding non-medication approaches and what kind of sources do you rely on. As a patient, what I'm wondering is, how important is it for you to make sure you are accessing evidence-based information. I know that question is kind of tricky, but whatever you think you can share with us I think would be great.

### Ashley

I think evidence-based interventions are really very important and I think that if you are looking at research around physical health or rheumatology or any other parts of healthcare using evidence-based practices really allows patients to get better faster. It really allows them to get kind of the highest quality of life back in return. So, for me personally, that's very important. The other thing that I think is important is learning from those around us who have lived experiences. Sometimes things that work really well in a laboratory setting or in a clinical setting work differently in real world practice. I think both of the both of those things are important to start with. I tend to look for information that I know is coming from a reliable source. I quickly Google search even. You can pull up different professional organizations related to this area of health care, for example, the American College of Rheumatology. I typically would start somewhere with that and look at the research page on their website to see what kind of resources they recommend. That's typically a good starting point. The other thing that's been really helpful is to actually ask my doctor for recommendations about where to find reliable information. I think that really helps patients to understand what you're reading, whether it's good advice or whether it's just kind of what we would call "noise" or misinformation that's getting in the way of having the most accurate and helpful information. The other thing you asked about was non-medication approaches, and so I think there's quite a bit of information actually about some different kinds of self-guided, perhaps, interventions that patients can try. Even things like making sure that you are practicing good sleep hygiene or that you're getting regular exercise, even if that's in short bursts like a 15-minute walk everyday can do a lot to help you better manage your pain and your conditions or the symptoms of your condition. Also, with diet, there are lots of great resources that you can find online or from your doctor around foods like non-inflammatory foods. I often find there are simple changes that you can make to your daily lifestyle that go a long way in terms of helping you manage your condition.

### Jessica

You know all this starts with talking to your doctor about what the right options are and also educating yourself too, so I really like that. This is a little bit more of a personal question because everyone is different, but how do you and your doctor review if your current treatment plan is working. Can you share with us some of the things you talk about to figure out if you need change, let's say for medication or anything else? How do you do you go about that?

## Ashley

The primary tool that we use is actually a set of patient-reported measures and I track those using the ArthritisPower app that I mentioned on a monthly basis. That provides us a tool that allows us to look at how my treatments, including my medications, are helping or not helping me. I'd say that's the first thing that we look at. There are other pieces of information that are helpful as well. So, my doctor frequently will ask me about side effects that I'm concerned about or that are burdensome or maybe getting in the way of taking my medications as prescribed. He will also ask me about any new symptoms or symptoms that seem to not be improving, where those may indicate that a change is required to the plan. The other thing that he will do is a physical exam where he goes through each of your major joints to look at where you're still feeling tenderness in the joints. I think it's a combination of looking at the patient-reported measures and that physical exam really helps us to arrive at what is it that we need to do different or keep doing the same if it's working really well. That I would say that's typically the process around how we've made changes to my plan.

## Jessica

Awesome! I like how it's shared communication of, you're explaining, you're also looking at what's happening and deciding together. I love the shared treatment discussions you are having. I don't know if I mentioned this earlier, which is significant, is that you are a patient advisor on this project. We are so grateful for that. I would like to ask you a little bit on sharing your experience thus far as being an advisor and to think if there's any research that stood out to you that you found particularly interesting. Do you mind talking a little bit about that? Even if it was just something that you were interested in learning more about or something that was a takeaway for you. Anything you can share on that would be very helpful, I think.

## Ashley

One thing that comes to mind is that we actually reviewed a number of different research articles that talked about different kinds of interventions they were pretty wide ranging. I would say a general takeaway from that, for me, was really the opportunity for patients to engage in kind of these self-guided interventions. It is a big opportunity actually I think that came through loud and clear. Really thinking about the impact of things like diet and exercise and sleep and the role that that plays in both your physical and your mental health stood out to me. The other thing that stands out to me was that sometimes we find that there are interventions that we should have access to sooner in care and in real world practice there are things like, for example, cognitive behavioral therapy for pain management that's actually a very good intervention. It's well rounded in the science of care and in my experience as a patient is that even though that's true nobody's referred me to that. No doctor has yet suggested that to me. So, in talking with [my doctor], I actually mentioned this to my doctor. I think part of the issue, that we observed, was that it's not always clear where patients can find those resources. So, I would say that one in particular stood out to me and since reading and

actually reviewing the article, I have actually gone in search for that myself - just as something that I think would be helpful add to my treatment. I think for patients really thinking about this with our medical care teams, how do we can access to these treatments [that] can be really helpful whereas otherwise it can be barrier to getting appropriate care. One thing that stands out to me about this too is that there's really an increase in technology-based programs that can help to fill some of those gaps in care that we experience. With CBT for pain management, for example, there are a number of online web-based tools that patients can use. I would still caution to patients that you want to be sure that whatever you're using is still coming from a reputable source and your doctor may be able to help you with that. But, I found that is one way I was able to address that and add something to my treatment plan that's actually benefited me quite a bit that I didn't otherwise have a clear path to gain access to.

### Jessica

Well, you kind of touch on this, that you have brought the information to your doctor and you also mentioned a little bit about kind of going online. I think people call it *Doctor Google*, right? But do you have any tips you can think of about how patients can filter that misinformation out to bring that conversation in with their doctor?

### Ashley

Yeah, I think you know the first thing for me that comes to mind when you're looking at doctor Google, sort to say, is that I would advise patients to be very mindful of what information they are looking at and really making sure that it's coming from a reliable and reputable source. I think that's the advantage in starting with the professional organizations, is that it helps you figure that out more quickly. It's really difficult as a patient, especially if you're newly diagnosed, it can be challenging to know which sources are reliable and there's a number of them that aren't. I navigated and kind of looked up the resources offered and then I signed up for a couple of newsletters or I follow institutions on social media and that I feel like helps to put some of the information in front of me more often in more of these bite sized digestible chunks. So, a short article to read instead of a long document to read, for example, or to be able to watch a short video that's available on social media, I would say that's the first thing and kind of the fastest way to cut through some of the noise. The other part of your question, how do we introduce this into our health care discussion, I would say my biggest tip for patients is really to think about your rheumatologist and your doctors as being your care team partners. I think the relationship that we have with doctors really is shifting toward that model and that a good provider will really be able to include you into treatment decisions as a partner in terms of your own health. When that's true, when you have that relationship, it creates a sense of safety for the patient that if I find information from Doctor Google or social media or things that I hear from other patients. Even it gives me a safe space where I can come in and ask questions about it and trust that my provider is going to be able to speak to those with my best interests at heart and understanding my unique needs. Our doctors don't know what we don't tell them and so if we are not comfortable having those discussions, they don't know how to help.

## Jessica

Excellent points that you bring up and this is all tied into that communication being so important to have and feeling that you can reach out and ask questions. I love that you said that. Did you have any final thoughts or anything that we hadn't covered that you are thinking about?

## Ashley

I think my last thought, and this is part of my day job too and my role of the Research Institute, is really for patients I've seen a shift in my own medical care team in terms of how frequently they use measures to inform treatment decisions and to inform care and the value that that's placed on that. I think that tends to be one of my biggest recommendations to patients is to really to understand that using measures to inform treatment like patient-reported measures, for example, that's how valuable that is and how much that really can help support your care team in making the best decisions for you. It also [helps], if you're in a situation where it's unclear as to whether you should change medications or not and there's pros and cons to doing so. I think that if you're really on the fence it can feel risky to patients and that may prevent you from making a change that otherwise could have been really helpful. So, I guess my biggest suggestion would be to really sample using those measures, give it a shot, and take that into your doctor because it really gives you a peace of mind in terms of understanding how your treatment interventions are working or not working. And if you're on the fence that could be the tipping point where you say, "Oh, you know looking at this now, I realize that my symptoms haven't improved or they've gotten worse over the last three or four months". Maybe on a day-to-day basis, maybe I didn't realize how long they had been happening but being able to see it in front of you and looking at it change overtime in that format can be really helpful to you. It really should be helping to drive treatment decisions with your doctor.

## Jessica

Wow, that's so beautifully said. Thank you so much your insights on this discussion that I know were brief, but I think very helpful. So, thank you so much. Wow, great, so I kind of hate to go, but to our listeners, please remember to answer your one-question survey at the end of the session. This will give you access to our free resources which will include a lot of the areas, things that Ashley had mentioned, and we will try to share links and go into a little bit more detail. I'd also like to thank the PCORI the Patient-Centered Outcomes Research Institute for supporting this project and to all the patients caregivers and providers anyone really listening and engaging in this session or some of our other ones, we thank you for that. Thank you again Ashley! It's been such a pleasure.