Building Your Personal Pain Plan

Hosts: Rebecca Gillett, MS OTR/L, and Julie Eller
Guests: Rachel Aaron, MA, PhD
Claudia Campbell, PhD

Whether you have rheumatoid arthritis, osteoarthritis or some other chronic pain condition, there's no one-size-fits all approach to treating pain. Pain is personal, shaped by various biological, emotional and psychological factors that influence how you experience and cope.

In this episode, listeners will learn how to build personal pain plan by recognizing and identifying the different factors that affect them most, including how their attitude impacts their ability to effectively manage pain. Listeners will also learn about a new research study exploring the efficacy of various coping and self-management strategies for pain and details on how to participate.

Guests:

Rachel Aaron, MA, PhD

Dr. Rachel Aaron, MA, PhD is an Assistant Professor at the Johns Hopkins School of Medicine. She is trained as a clinical psychologist and specializes in pain psychology. She treats patients with various acute and chronic pain conditions in both inpatient and outpatient settings. Dr. Aaron researches psychosocial factors that contribute to the experience of chronic pain, particularly the role of emotional factors in the development and maintenance of chronic pain. She applies this research to develop novel approaches to improve treatment outcomes in individuals living with chronic pain. Dr. Aaron's research has been funded by numerous grants, and she has received awards for clinical practice and teaching.

Claudia Campbell, PhD

Dr. Claudia Campbell, Ph.D. is an Associate Professor in Psychiatry and Behavioral Sciences at Johns Hopkins University. She has a broad and integrated line of research investigating the mechanisms underpinning individual differences, psychosocial and behavioral factors influence on pain sensitivity

and clinical pain. Dr. Campbell directs the Psychophysical Pain Testing Program at Johns Hopkins University. Her current studies focus on modifiable risk factors leading to pain chronification. Her interests include how psychosocial/behavioral factors, that are common among people suffering from chronic pain (e.g., depression, catastrophizing and sleep disturbance), influence pain-related outcomes and how these factors confer heightened risk for the development and maintenance of persistent pain.

Additional resources:

Arthritis Pain Relief Strategies: Backed by Science: https://arthritisfoundation.zoom.us/rec/share/3ZLE-NS8-ImiCuLNZQhNECzj9y9RRE0qpiD-j7NavgdQ5_VU_gzm6Zz50zjG6yg.f3Q7aF4YsYBAmZFY

The Connection Between Your Brain and Pain: https://www.arthritis.org/health-wellness/healthy-living/managing-pain/understanding-pain/pain-brain-connection

Stop Worst-Case Thinking: https://www.arthritis.org/health-wellness/healthy-living/emotional-well-being/stress-management/stopping-worst-case-thinking

Emotion-Pain Connection: https://www.arthritis.org/health-wellness/healthy-living/emotional-well-being/emotional-self-care/the-emotion-pain-connection

Brain-Pain Connection Live Yes! With Arthritis Podcast: https://liveyeswitharthritis.fireside.fm/6

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 on this episode of the Live Yes! With Arthritis podcast. We all know with arthritis that pain can be very personal. There are so many things and factors that can shape someone's experience with pain. And Julie, I don't know about you, but I know there are a lot of things that can challenge me when it comes to pain. What's your No. 1 thing that affects your pain?

Julie:

I think probably stress, right? Stress because it impacts my sleep. Stress because it impacts my ability to slow down and meditate and have those coping skills. So yeah, that would be my No. 1 thing. That if I'm stressed out, my pain is right next door and it's at the surface. What about for you Rebecca?

Rebecca:

I think same. I mean, I just, even as my anxiety goes up and my stress level goes up, I can feel my pain level increase

So, whether you have rheumatoid arthritis or osteoarthritis or some other chronic pain condition, there's no one -size-fits-all approach to treating pain. But the first step in effectively managing pain is definitely to identify your unique challenges and triggers.

Julie:

That's why we're so excited to have our first guest here to help us understand a little bit more about the different physical, psychological and emotional factors that can affect the pain experience and to help us hone in on the key areas that can have the biggest impact. Dr. Rachel Aaron is a pain psychologist and Assistant Professor of Physical Medicine and Rehabilitation at Johns Hopkins School of Medicine. She specializes in psychosocial interventions for the management of chronic pain. Dr. Rachel Aaron, welcome. Thanks for joining the show.

Dr. Rachel Aaron:

Hi, Julie and Rebecca. Thank you so much for having me. I'm excited to be here.

Rebecca:

We want to hear a little bit more about the field of psychology and pain and how they intersect with the types of chronic pain patients you work with.

Dr. Aaron:

It's not something that seems super obvious to a lot of people. And that's partly because this is sort of a new way of thinking about pain. We used to think pain was directly related to injury. And what we know now is actually there are all sorts of factors that impact the amount of pain that we experience

subjectively. And one metaphor that I like to share with patients is this idea of stubbing your toe. We all know what it's like to stub our toe on a piece of furniture or something like that. And I always ask patients to reflect on what stubbing your toe looks like on the worst day of your life, compared to stubbing your toe on the best day of your life. If it's me, when I stub my toe on a really bad day, it's really a big ordeal. It's really a terrible injustice. There may be tears, there may be expletives. It just feels very unfair. You know, why did this have to happen on top of everything else? And that's very distressing.

If I stub my toe on the best day of my life on, you know, just a really good day, same kind of injury, same toe, same piece of furniture, same impact, my experience is going to be a lot different. I might laugh instead of cry. I might make a joke instead of cursing, you know, I might brush it off. So, you know, this is just one example of many of how the pain that we experience physiologically in our body is a result of not just the physical impact or the physical injury, but all sorts of other physical, emotional, mental factors that are happening in the moment.

Julie:

I'm glad that you raised that on your best day and on your worst day, you might have a very different pain presentation. I wonder if you have patients that have different disease types, rheumatoid arthritis versus juvenile idiopathic arthritis, osteoarthritis versus psoriatic. Would you treat that pain differently based on those profiles?

Dr. Aaron:

Certainly, it's going to be really important to me, to understand the diagnosis and the etiology of the pain. And you know, really why that's most important to me is because I want to understand the patient's unique experience because even within the same kind of diagnostic category, each person's experience is so different. I'm lucky to usually have, you know, lengthy medical records that can give me more of a medical history in addition to what the patient provides. So, certainly that is a really important part of how I understand their experience.

Rebecca:

Yeah. So, you really are taking that bio-psycho-social perspective and treating people. And those are big terms. So, can you explain what that means?

Dr. Aaron:

The bio-psycho-social model of pain says that pain is the result of biological factors, psychological factors and social factors. So, this is really novel in that way and important, helping us think about how other factors, besides physiology, impact the pain experience. We'll talk about this in more depth, but there's all sorts of psychological factors that can impact pain. There's all sorts of social factors as well. You know, when people have a supportive partner, supportive friends, then it can be easier to manage pain. So, all of these different aspects that are important. And we can't think of, you know, one in isolation.

Rebecca:

So, walk us through what that evaluation would look like if somebody were coming to see you. What are the first fundamental questions that you would go through in an evaluation to get started on creating a pain plan with somebody?

Dr. Aaron:

The first thing that I typically assess is just a description of the pain problem. I've typically looked at the patient's medical chart. I might have, you know, spoken with their physicians, but always, it's so important to get the patient's perspective and their story of how their pain developed. I want to know, when did the pain start? How long has it been a problem? How bad is the pain, you know, um, how would you describe it? When is it worse? When is it better?

One thing that I hear a lot is, "I've tried everything," you know, "I've had injections. I've had surgery. I've had this and that other medical intervention." So, it's really important for me to know what has the patient tried? What works for them? What doesn't work for them?

And then I want to know what pain is getting in the way of. Pain is getting in the way of that person living their life the way that they want to. And so, I want to know what is it that would be different if you didn't have pain? What is it that pain has kind of taken from you and what is it that you want to get back?

Everybody is different. Everybody has different values and pain affects everybody differently. And kind of related to that, I'm going to want to know, what do you want to change and what brings you here?

Julie:

So, I would imagine that you probably have a lot of patients that maybe you have a link between some of their chronic pain and maybe some other mental health conditions like depression and anxiety. That's certainly something that I have experienced in my chronic pain experience. I wonder if you could explain a little bit about that link and how you approach it with a new patient; how you navigate those conversations.

Dr. Aaron):

A lot of us do have a tendency to try to kind of avoid or push down these things that make us feel bad, you know, whether it's kind of putting our head in the sand or going 60 miles a minute, trying to just take our mind off things, trying to kind of barrel through. And not everyone will experience depression and anxiety during their chronic pain experience, but a lot of people do. It's very common.

Our mental health is very tightly linked to our experience of chronic pain. And I can give an example with depression. So, one thing that depression makes difficult is getting up and doing anything. A lot

of people with depression or particularly a severe depression, talk about how difficult it is to even get out of bed in the morning. I mean, literally just putting your feet on the floor. And what we know is that actually doing things that are physically active and things that are pleasant, are really important for sort of combating depression, and the same is true of pain. So, when someone is living with pain, it can be very difficult to literally put their feet on the floor in the morning. A lot of times patients with chronic pain find that they only have so much energy in the day. There's only so much that you can do. And sometimes this comes at a cost to anything pleasurable or enjoyable. People spend all their energy taking care of their children or focusing on their work or school or whatever it is, and, and then they're just exhausted. So, there's not a lot of time for pleasurable activities. Having time for joy and pleasure in our lives is so important for our mental health. So, depression and chronic pain can really go hand-in-hand that way. They can make one another worse and that's just a little trickier to manage.

PROMO:

At least two-thirds of arthritis patients feel anxiety, fear and depression — and the number is even higher in the pandemic. We're putting the insights we receive from you into action. To help get you what you need. Take part in our ongoing Live Yes! INSIGHTS survey and be counted — arthritis.org/insights.

Rebecca:

We're conducting this ongoing study called the Live Yes! Insights Program, that's a more of a longitudinal study at the Arthritis Foundation. And what we've heard so far from people, two-thirds of the people who responded report anxiety or depression or fear.

Dr. Aaron:

Mm-hmm (affirmative).

Rebecca:

It is a real problem when it comes to dealing with arthritis pain and chronic pain. Are there any other psychological factors that might feed into this chronic pain cycle? And if so, what are some other strategies you can offer for people to combat them?

Dr. Aaron:

One is just having negative thoughts about pain, kind of worst-case scenario thoughts about pain. So, things I hear are, are thoughts or beliefs like, "My pain will never go away," or "I'm completely defined by my chronic pain problem, and I'll never be the, you know, fill in the blank, that I once was — the professional, the student, the daughter, the mother." And if we feel like we're living in a hopeless situation, it's just that much harder to make changes that help us live a more value-driven life. So cognitive behavioral therapy, or CBT, is one that really gets at these, these, we can think of them as harmful thoughts. And one thing that we do in CBT is we try to look at those harmful thoughts and think about where they come from and try to replace them with thoughts that are more realistic or more helpful. And whether you've had CBT or not, this is something that we've all done on our own in our life, is try to come up with a different, more positive way to look at things. So, we can try to work towards shifting those thoughts, um, to be more realistic. And I always tell people this is not Pollyanna. This is not like, "Everything is good and great and wonderful, my life is perfect."

Rebecca:

Yeah.

Julie:

(laughs)

Dr. Aaron:

You know, this is recognizing that when things are difficult, a lot of us have a tendency to have quite negative thoughts about a situation. And we can start to notice those thoughts. This is a very psychologist thing to say, but this line "don't believe everything you think," you know, it's true.

Another one that I see a lot, and we've touched on this a little bit, is avoidance. Living with pain is uncomfortable and most things that we do are uncomfortable. People fall into patterns of not being physically active at all. So, spending the whole day on the couch is one that I see a lot, because understandably it's very painful and it's very difficult to get up. And even for some people to walk to the driveway to check the mail. But what happens over time is that the more we avoid physical activity; the more physically de-conditioned we get in our body, the more our mood starts to take a hit and take a toll. And over time, this just makes it much, much harder to be physically active.

Another place I see this in pain is with social activities. So often, you know, engaging in social activities can be very physically demanding. And then just general coping strategies. So, we all have different ways of coping with pain and coping with stress. And they range from kind of helpful to unhelpful. Strategies that tend to be helpful are things like journaling or talking to a friend. Using distraction to take the mind off of pain, relaxation practices like deep breathing or meditation. And other ways of coping with pain that can be unhelpful are things like avoidance and having negative pain-related thoughts.

And another place where this comes to play is substance use.

Julie:

Yeah, I think it's hard because when you do develop a coping strategy that brings you comfort, it's difficult to realize that your coping strategy maybe isn't the healthiest one, like when that one glass of wine at night turns into several glasses of wine every night before bed. What advice might you have for someone who is looking to replace some of those unhealthy patterns with maybe healthier ones?

Dr. Aaron:

We all know what it's like to use coping strategies that aren't necessarily going to serve us in the best possible way. So, this is very, very normal and we all do this at different times. But certainly, people can start to have bigger problems when it becomes a pattern or a habit. And, you know, substance abuse is a really tricky one in that sense, because substance abuse involves all of these other sorts of chemical and neurological processes that are happening that become very reinforcing. One thing that I'll say to patients, you know, particularly when there's a question of dependence or an addiction is, you know, doing five minutes of deep breathing or writing in a journal is never going to take your physical pain, emotional pain away, like a bottle of wine or, you know, a handful of pills. And for that reason, people really have to want to make changes to their behaviors. Whether it's substance use, whether it's physical activity, social activity, anything.

And this is why that first intake is so important just to even get a sense of what the patient wants to work on. We all have all sorts of things we want to change all the time, but behavior change is not as simple as that. And that can be tough because I think that sometimes we sort of think, culturally, that that should be the way that it is — that we should just be able to turn on and off these sort of bad habits.

TYLENOL COMMERCIAL

Julie:

Dr. Aaron, can you share a little bit about how people can be empowered to start building their own pain plan to mitigate some of these factors in their life and what some steps they might take could be?

Dr. Aaron:

Not everyone needs sort of professional help. There's a lot of things that we can do on our own. We know that sleep and pain are very tightly related and that actually getting a poor night's sleep can lead to worse pain the next day. And, of course, being in pain can make it harder to get a good night's sleep. So, I'm always going to want to assess a patient's sleep quality, how much sleep they're

getting, are they able to fall asleep at night, what's getting in the way, if they're not. I'm always going to want to know about their physical activities.

So, we've talked a little bit about activity in the context of avoidance. One thing that I like to kind of assess is whether a person is more of an over-doer or an under-doer when it comes to activity. So, it's very common when someone is living with pain to under-do activity, this makes a lot of sense — you know, you're in pain, you don't want to move. Unfortunately, this can lead to sort of worsening pain as the body becomes weaker and we're not getting that movement that we need to stay healthy.

A lot of people also tend to be over-doers. So, people tend to really overdo activity despite pain. Overdoing activity is very common and unfortunately, this can be a little harmful too, because often people will overdo themselves sometimes to the point of hurting themselves and often to the point of needing to take a few days off. It's not a sustainable cycle.

I'm always going to just want to get a general sense of their health behaviors like nutrition and hydration and understand whether there're goals there.

I want to what their family looks like. You know, who their support system is, what their home life looks like and how they are communicating with their family about pain and their work about pain. And a lot of times, there's some work there around setting more assertive boundaries about what someone needs when they're living with pain.

Finally, I'm going to want to know if the patient has any kind of relaxation or meditation practice. When we're living with any kind of pain, we've got additional muscle tension in our body. Pain is like a little fire alarm that's going off in our body and it's telling our brain, there's something wrong. This is really, really helpful when we do something like step on a nail or touch a hot pan. But once the pain becomes chronic and regular, it's not helpful anymore, because it's always there. It's like a car alarm that goes off all the time. So, you never know when there's a real threat. So, I want to know what sorts of practices someone has to help down-regulate their system. A lot of times this is a deep breathing practice. Sometimes a meditation practice. Sometimes it's time in nature. Sometimes it's soothing

music. So, I'm going to want to know, really in anyone I work with, what strategies do you use to reduce that tension in your body?

Rebecca:

One of the things you touched on, I do want to follow up on is, wanting to know how they communicate with their family and friends and loved ones in that social support. I think that for people living with chronic pain can be really hard. Trying to communicate what your pain is and asking for the help that you know you need, but you're too stubborn to ask for it.

Dr. Aaron:

Yeah.

Rebecca:

Is there a suggestion that you offer to people on how to practice being better at that?

Dr. Aaron:

A lot of us still have this biomedical model of pain ingrained in us and how we think about pain. This idea that pain is 100% linked to some damage in the body and there can be no other factors that impact pain, is very strong and that can lead to a lot of stigma for people who are living with pain. I encourage the patients that I work with to strive for assertive communication. And we'll talk about the spectrum of passive communication, which is not asserting your needs and aggressive communication, which is asserting your needs above the needs of someone else. Passive communication is "Your needs are more important than mine. My needs aren't important. I'm going to be quiet. I'm not going to tell you what I need. I'm not going to ask for that accommodation. I'm not going to tell you that I'm struggling right now." Some people do struggle with aggressive communication when it comes to how they communicate about their pain problem. And that's like saying, "My needs are more important than yours. I don't care about communicating respectfully

with you." But assertive communication is really meeting somewhere in the middle and it's acknowledging that everyone's needs are important.

Julie:

Can you share a little bit about how you work with patients to determine their treatment goals and what tips you might give our listeners that they can develop their own plan at home?

Dr. Aaron:

So my recommendation to listeners or to people living with pain, would be to really reflect on some of those first questions we talked about, you know, what do you most want to change? What's most important to you to work on? You know, what do you most want to get back? And after that reflection, just really thinking about how you can break that down into the smallest steps possible. The example that I give to patients is I'm going to clean my whole house this weekend. I'm going to clean my whole house, top to bottom, it's going to be sparkling clean by Sunday night. And when I set that goal, none of my house gets cleaned because the goal is too daunting. I'm completely overwhelmed. And then Monday, I feel like, you know, a total slob and a failure because I can't manage to clean my house. So, when I tell myself, you know, this weekend, I am going to sweep the floors in the living room and in my bedroom and I'm going to clean the bathroom. Then I'm so much more likely to get that done because it's more realistic.

And one thing that can be helpful with goal setting is to set very specific and realistic goals each week. And then check in at the end of the week about progress made. If you're finding that week after week you're not making progress towards that goal, then I would recommend revisiting the goal; make it more realistic, make it more specific, just make it more feasible for you. We got to set ourselves up for success when it comes to making these big changes. On the flip side, if you're just sailing through your goals, no problem at all, you know, then up the ante a little bit and increase the challenge. This is really hard work and deciding to make changes in some area of your life is really wonderful. And you deserve all the pats on the back for that. So, I would just encourage you to be as kind as yourself through the process.

Rebecca:

So when we're talking about factors that can feed into chronic pain and we are living in the world of a pandemic with COVID-19 right now, with avoidance in social situations or even physical activity, how is that coming into play right now, and how is that different pre-COVID?

Dr. Aaron:

In some ways, you know, social activity is easier to avoid when we don't have scheduled social events or we're not, you know, seeing, seeing coworkers in the halls or whatever the case may be.

On the other hand, some people are more likely to be social now because some of the pressures of that in person gathering aren't there. And for some people using digital means of communicating is much more comfortable. So, you know, I would say avoidance and those negative pain-related thoughts and those pain coping strategies can creep their way into anything, and certainly living in the time of COVID-19 is no exception.

Rebecca:

If our listeners had the three takeaways from our conversation today, what would your three takeaways be for our listeners on how to start building a personalized pain plan?

Dr. Aaron:

Number one, pain is incredibly complex and it can be very difficult to live with. So, it's OK if parts of your life are challenged because of living with pain. Number two, what's most important is that you are finding ways to live the life that you love and do the things that you value despite pain.

And finally, you know, if there are things that you want to change, and most of us have things that we want to change, then I would recommend just starting very small, setting yourself up for success and being very kind to yourself along the way.

Julie:

Those are three perfect takeaways. Thank you so much, Dr. Aaron, we really appreciate it.

Dr. Aaron:

Thank you so much, Julie and Rebecca.

PROMO:

What topics do you want to hear more about on future episodes? Share your thoughts with us by going to arthritis.org/liveyes/podcast. Just scroll down to the bottom of the page and click "get started" to start the survey.

Rebecca:

So, hearing Dr. Rachel speak about the different coping mechanisms to manage pain made me think, Julie, about the types of things I do in my own life to reduce my pain. I know I don't like taking pain medication. It can be helpful, and I know it's helpful for a lot of people, but it's important to balance those lifestyle changes and things that we can do to control some of our pain.

Julie:

Yeah, absolutely. I've really developed so many new pain management strategies since we've started this podcast, Rebecca. One of our first episodes we talked about meditation, and it has become one of my saving graces to sit down and spend five or 10 minutes just breathing and concentrating on that mind-body connection.

I'm so excited to chat with our next guest, Dr. Claudia Campbell. Dr. Campbell is an Associate Professor of Psychiatry and Behavioral Sciences at Johns Hopkins School of Medicine. She studies the use of coping and self-management strategies to combat chronic pain, especially as it pertains to

knee osteoarthritis (OA) and pain and processing. Dr. Campbell, welcome and thanks so much for joining us today.

Dr. Claudia Campbell:

Thank you for having me. I'm really excited to be here.

Julie:

Do you want to tell us a little bit about your interest in comparing different therapies for knee OA and what got you started there?

Dr. Campbell:

Sure. So, I'm a psychologist by training and those kinds of things, especially the modifiable risk factors, are really interesting to me. So, we've looked at many treatments and a lot of what you see in the literature actually gets compared with, um, just placebo or something like that instead of other real-world treatment. So, we've been interested in more comparative effectiveness and trying to understand, how well-established treatments might stack up against other treatments and trying to understand that. One of the things that we've gotten really interested in is not only in comparing these different treatments, but potentially combining treatments to see if there might be added benefit to layering things with each other.

Julie:

I love that. I think it's so important to think about how these tools and resources and management techniques actually play out in the real world.

Rebecca:

So, can you tell us a little bit more detail about this research and what you hope to find?

Dr. Campbell:

So, the first phase includes conservative treatment. So, things like best practices will be physical therapy, potentially weight management, you know, what your provider might give you. Another arm will be duloxetine, which is a medication that's been shown to improve pain. And then another arm in the conservative phase will be how you might be able to put coping skills training to use on top of duloxetine and see if we can get more benefit out of combining those kinds of treatments. The other is procedural intervention. So non-surgical procedural things that you might get at a pain clinic and comparing how responses are different from those kinds of treatments. And then a separate arm is those best practices and duloxetine and coping skills training. So, we can understand if there's any incremental benefit to any of those.

And really what we're trying to learn is about what treatments work best and for how long. So this study will follow people over a longer period than most trials. We're also really interested in knowing what works best for what patients. So we'll be getting a lot of questionnaires for participants to try to understand their profile and march us maybe a little bit closer to more personalized medicine, really try to understand what works for who.

The purpose of the coping skills training is to try to give people more tools, you know, additional resources for them to have in their tool bag. In the lab, we were able to look and see and found that changes in your thought process and negative feelings about pain, so that increase in negative pain actually came before the physical response to pain. So, how much you actually said it hurt. The way you're thinking and feeling actually has this impact on your, you know, what you're perceiving physically. We don't think that people with, you know, certain negative thoughts around pain are just reporting more pain. They're actually experiencing more pain. So, you know, it may be a subtle distinction, but I think it's really important, especially when people are talking to their physicians.

Julie:

I think what might be a subtle distinction in lab results is really a major distinction for our patient community. It's so important to hear that it's not just in your head, it really is an experience that you are having and that your body is responding to this pain.

Rebecca: Aside from the coping strategies in your research, you talk about some self-management strategies that you're looking into as well. Can you expand on that please?

Dr. Campbell:

Yea. The program that we're using has eight different modules intended to work through one module a week and do practice along with that. But those modules include doing education around pain and why relaxation training is so important, takes you through different relaxation modules to try to practice those. There's also things like activity pacing, where, um, I think so many of us, you know, we might have a good day and then overdo it and then pay for that for a couple of days. So activity pacing is the idea to just chip away in small doses at those things that you need to do, instead of really overdoing it so you don't have to, you know, have this crash period where you're really out for the count.

Julie: I think it's important to get that self-management and get that experience of investing in your health on those good days.

Rebecca: So, can you let our listeners know how they might be able to get involved with this study and any steps that they'd have to take to get involved?

Dr. Campbell:

Sure. So, it's a nationwide project. Probably the best place to go would be our website, which is going to be skoapstudy.org. So that's S-K-O-A-P, study S-T-U-D-Y.org. The site isn't up and running yet. We're not actually starting to run participants until early November, but the site's under construction, so that's probably the best way to get information.

Julie:

That's great Claudia. I think oftentimes getting involved in a clinical trial sounds a little intimidating to some patients who especially might be new at this. Can you talk a little bit about what the process is like in getting involved?

Dr. Campbell:

So for this study, we have a call center that we're working with, and they'll be able to go through a screener where they would answer questions about their knee pain and other things going on in their lives. They could also do this self-screener on the website or they could talk with one of our centers directly to get screened.

After that process, they would get sent some questionnaires to fill out online. And then if they are interested in participating, of course, the coordinator from the set study would talk with them and lay everything out in much more detail than we've talked about here. We have remote sessions, virtual sessions are a possibility. And then, when you actually would have that first session, whether it's in person or virtual, the consent form is always the first thing that happens. We'll talk with the participant about all of the different aspects of the projects, any risks or benefits, what the payment amount is for participating, all of those things and really make sure they understand. So the consent form documents can be a little bit overwhelming. There are oftentimes, you know, 10 pages, but it really wants to give people a clear understanding of what they might be signing up for. All of that said, people can stop participating at any time. There's no obligation to continue if they want to stop treatment or they want to stop participating. This study, even if you want to stop doing the treatment, we'd still be interested in hearing what happens with patients, so that's something that's tricky in clinical trials. Oftentimes, if somebody wants to stop, you don't know if they just want to stop, or if it's because of the treatment. And if it's because of the treatment, that's really useful to know for your trial, because if somebody is dropping out because everybody hates this treatment, you know, that's something really important for clinicians to know.

Julie:

I'm so glad to hear about the multi- multimodal approach that you're taking in this study, because it really, I think it mimics life, and it provides an opportunity for people to continue living their daily life without too much of an interruption.

Dr. Campbell:

Yeah. I'm really hopeful. You know, I'm always surprised to see that there's really not much out there with, you know, different fields coming together.

Julie:

Yeah. it's so rare that we have true hope in our chronic pain space, so it's great to hear that optimism and that hope, and then I'm just so excited to get to chat with you about it. So thank you.

Dr. Campbell:

Thank you so much for having me.

PROMO:

The Arthritis Foundation counts on listeners like you to support the many resources we provide to help people with arthritis live their best life, despite all the challenges. Resources like this podcast and much more. Your gift goes a long way. Please give generously at arthritis.org/donate. Every dollar makes a difference.

Rebecca:

I just want to remind our listeners that we will have information on Dr. Campbell's research in our show notes. So, if you go to our website, you'll be able to find — in the show notes — a link to the research that she's talking about for more information.

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