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CreakyJoints presents

## Pain Explained: Is My Treatment Plan Working? (Part 5)

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### Set goals and work with your care team to reach them

Research has demonstrated that shared decision making can improve patient knowledge and satisfaction, enhance patient confidence in decisions, strengthen a sense of trust between doctor and patient, and improve health outcomes, according to an article in the [New England Journal of Medicine](#) (Emily Oshima Lee, 2013).

Well, what is shared decision making, and why is it important in health care?

In a 2019 CreakyJoints Webinar, [How to Benefit from Shared Decision Making](#), Dr. Liana Fraenkel, an advisor on this project, said that, *“shared decision making is a model where patients make decisions along with their health care team, based on what they learn about the benefits and risks of the options available to them for the management and treatment of their [condition].”*

A pilot project titled, [“Improving Patient Care by Helping Patients and Doctors Communicate Better”](#), funded by the Patient-Centered Outcomes Research Institute (PCORI), found that patients may avoid asking their doctor questions or disagreeing with their doctor’s recommendations. Patients may be concerned that they may not be getting the best care if their doctors think they are seen as “difficult” (Tai-Seale, 2015).

There are many factors involved in communicating with your doctor, to create a treatment plan that works best for you. You and your doctor may have different treatment goals, so it’s important that you discuss this together. “Shared decision making” helps prioritize what’s important to you when managing your condition.

CreakyJoints conducted a recent study called, [“Barriers to treatment optimization and achievement of patients’ goals: perspectives from people living with rheumatoid arthritis enrolled in the ArthritisPower registry”](#) (Gavigan, Nowell, & Serna, 2020). This study described the many barriers that people living with rheumatoid arthritis face in modifying their treatment and the data revealed that [Patients Prioritize Their Physician’s Treatment Goals Over Their Own](#). This happens even when symptom and disease activity are not well-controlled and can result in patients accepting less than optimal care and outcomes.

*“We found that participants seldom changed RA therapies because they failed to reach treatment goals; instead, treatment was more commonly changed due to continued severe, or even worsening, RA symptoms,”* said W. Benjamin Nowell, Ph.D., Director of Patient-Centered Research, [CreakyJoints](#) and principal investigator (PI) for the [ArthritisPower](#) research registry for people with different types of arthritis.. *“Yet, even in the face of escalating symptoms, our study showed that patients defer to their physicians’ recommendations regarding whether it is time for a treatment change. Given our findings, it is important to find ways to encourage and empower patients to talk to their doctors about how to achieve their treatment goals.”*

But how do you begin to communicate better with your doctor?

One way to communicate is to share with your doctor what your goals might be. Goals can be anything that is important for you and that may improve your quality of life. It could be to get a better night’s rest, or to better remember to take your medications daily so as not to skip a dose. It could involve planning to help you exercise more or change your diet or even attend more social events. No goal is too big or too small- rather, a good way to think about it is to consider what is important for you to help you live a better and fuller life.

In a 2019 CreakyJoints poll, we found that [88% of Arthritis Patients Say Achieving Remission Is a Goal](#). If remission is a goal for you, don’t be shy about letting your doctor or rheumatologist know, otherwise he/she/they may not know what is important to you. Now, your doctor likely has the same goal of helping you achieve remission, however, sometimes the definition of remission can vary. Your doctor may rely on tests and lab work, reasonably so, while you may be more focused on quality of life. It’s important to define what remission looks like to you.

If you are unsure of how to start a conversation with your doctor [CreakyJoints](#) offers many resources that can help.

For example, the CreakyJoints [Patient Guidelines](#) series offers detailed, accessible explanations of symptoms and what causes them, treatment plans, treatment options, as well as how to talk to others about these conditions and how they impact a person’s life and much more.

In the next Podcast, we will also hear from one of our patient advisors on this project, Ashley Newton, who will talk more about how she communicates with her doctor and how she uses evidenced-based research to guide her along the way.

### **Using ArthritisPower to better communicate pain with your doctor**

Beyond sharing how you are feeling at the time of your doctor’s appointment, and discussing goals that are important to you, there also various tools such as ArthritisPower to track your symptoms. It is important to keep track of how you are feeling on a consistent basis and as much as possible. Sometimes keeping track of your symptoms may help your doctor understand how you have been doing between appointments. A pain scale, for example, may be a tool you use to tell your doctor about your level of pain which as every chronic pain patient

knows can fluctuate every day and sometimes even within the same day. Imagine keeping track of the fluctuations so you and your doctor can see a trend. Further, using pain scales can help to rate or quantify your pain thus giving voice to your pain, so you can talk about it with your doctor, other health care professionals, or even your friends and family.

There are different types of pain scales that are available. We use [Patient Reported Outcome Measures](#) in ArthritisPower (an app and web-based tool that lets you track your disease while also contributing your data to research), which were developed by the National Institutes of Health (NIH). Using these measures can help you capture information about your symptoms, such as fatigue, pain, or even depression and anxiety. This is standardized in a way that doctors and researchers are able to use them to better understand how you are feeling, and what kind of treatment adjustments you may require. Often doctors will combine this with other information from your blood work and lab tests to get a more complete picture of your disease.

Again, [ArthritisPower](#) is a research registry, or a database that connects patients to research opportunities. It is also a data collection tool that can help you keep track of your symptoms. At the same time the information you contribute about your symptoms helps researchers and clinicians better understand your disease and in turn advances research in rheumatology and musculoskeletal disease conditions.

Visit [arthritispower.org](http://arthritispower.org) to learn more.

### **Understand self-appraisal tools and how they work**

As we have learned from Part 2 of *Pain Explained: How the Brain Influences Pain*, pain is clearly not only experienced in a physical way - it is also felt - experienced through our thoughts and emotions. Many of us worry about pain, and find it challenging to cope with. These experiences are important to communicate and help your doctor understand the different ways in which chronic pain impacts your life.

In a study called, [“Developing Measures of Pain Appraisal and Pain-Related Efficacy for People Living with Chronic Pain”](#) 795 people with chronic pain conditions were asked a series of questions to measure two aspects of living with and managing chronic pain: pain appraisal and pain-related self-efficacy [\(Amtmann D, 2019\)](#).

So, what do those terms mean and what did it find?

Pain appraisal describes how people think about their pain. It measures how much people worry about their pain and how well they cope with pain or distract themselves from thinking about it.

Pain-related self-efficacy describes how confident a person is that they can live well with pain. Things like “I feel okay”, “I know I can manage this pain”, “How will I ever be able to live by

myself with this pain?, are examples that indicate how confident a person may feel about living with chronic pain.

As part of this study, two pools of questions, called item banks, were created by researchers to measure these aspects of living with chronic pain in a standardized way. The study resulted in 2 new scales to measure coping and confidence as it relates to chronic pain that patients can share with their health care team. When treating a chronic pain condition these pieces of information are important things for your doctor to know so they can help you manage and live better with your chronic pain condition.

To view the full study and more on the measures this study used, you may visit the resource page at the end of Part 5, following the one question survey.

As we are learning about all this information the next step is advocating and applying these concepts to our everyday treatment. One of the goals of research on these topics is to help us incorporate these scales and routines into our care to improve outcomes for patients. However, we cannot make these shifts until our communities know that these exist.

That brings us to why we are sharing this information with you – we cannot make shifts in how chronic pain is managed and treated without your help. We are partners in research. Unless this research is shared, and understood, we cannot impact change.

In Part 6 of *Pain Explained: How to Stay Connected*, we will talk about ways you can get involved as a patient partner in research and how you can help us share research with others in our communities.

Thank you for listening and we hope you found this information helpful. Remember to take the one question quiz to receive your free resources.