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CreakyJoints Presents

Pain Explained: How to Stay Connected (Part 6)

Finding Support Groups

Living with chronic pain and other symptoms from a chronic condition like arthritis can often be overwhelming. You may find that the people in your life may not always understand what it's like to live each day in pain (though they may try) – even friends or family members you have known for years. This may cause you to feel isolated, frustrated, and sometimes misunderstood. It is also important to remember that because pain can be invisible, it can be difficult for our loved ones to understand what you may be going through. And also- it might be difficult for them to see you in pain.

That is why finding other individuals who live with chronic pain and who understand the experience of living with pain, can make a significant difference as you face the challenges of your condition. There are many ways to connect with people who are living with a chronic condition. Support groups are one way of creating this connection.

Support groups can offer essential information about your condition and effective ways to manage it including information around coping strategies. These groups provide a safe space for you to talk about the impact of living with chronic pain. They may be an outlet for you to share frustrations and allow you, in turn, to offer comfort or advice to others. Common intervention activities used in support groups include education about your condition and strategies for coping, including mindfulness. These skills can help you feel more confident in managing your condition. And one of the most important benefits of these groups is the realization that you are not alone.

As we know from Parts 2-4 in this *Pain Explained* series, the experience of pain is not only physical – it can impact you emotionally, financially, and socially. That is why support groups provide added value as you navigate your chronic pain management.

While many social support programs are delivered in-person, the rise of virtual patient communities are shifting towards online formats, and while support groups may not work for everyone it's something patients can consider in managing their pain.

Finding resources and tools



As you might know, [CreakyJoints](#) is a digital community for millions of arthritis patients and caregivers worldwide who seek education, support, advocacy, and patient-centered research. All of our programming and services are always provided free of charge.

Through our interactive social media channels, CreakyJoints members can directly connect with the arthritis community and ask questions of health care professionals who participate in regularly scheduled webinars and #CreakyChats. Visit us on Twitter (@CreakyJoints), Facebook, YouTube, and Instagram (@Creaky_Joints) for 24/7 live positive support.

Being part of our online community is a pathway to connect with others, access free resources and support, become informed about science-based information around various chronic diseases and learn about ways you can better manage your pain.

Patients are partners in research

Whether you are connected with an online community, participating in research, or being active in advocacy, patients are influencing and impacting the healthcare landscape. At the Global Health Living Foundation (GHLF), the parent organization of CreakyJoints, we value the critical role patients have in improving disease management and treatment experience, alongside researchers, clinicians, and other community partners. Since we emphasize the importance of partnering with patients in this way, we have a group of patients (Patient Partners in Research or PPRs), dedicated to providing input and advice about how studies are designed, conducted and results shared with the public.

Patients play a central role in identifying for researchers, what's important to be studied and prioritized from a patient's perspective. But research cannot be meaningful unless it is shared by and with patients, healthcare providers and policy makers. We need to spread the word, or "disseminate" research findings in order to improve outcomes.

All the information you have been learning about in Parts 1-6 of the *Pain Explained* series is part of a larger project called, "Encouraging Patients to Manage Chronic Pain Using the Latest Evidence from Research". This project is funded by the Patient-Centered Outcomes Research Institute (PCORI) and includes a coalition of patients, patient advocates, researchers, and physicians. The project is committed to preparing people with arthritis and chronic pain as ambassadors in the dissemination. Our goal is to, together, spread the word about evidence-based information on effective chronic pain management.

For more information on how you can help share evidenced-based research in your community, visit the resource page after you complete the one-question survey.

The importance of staying updated on research

It is important to stay informed during your treatment journey so you and your doctor can make the best decisions together. As mentioned in Part 3 of *Pain Explained: Where to Start*,

patients do not have to be trained as scientists to learn about the latest research. By participating in research studies, either as a participant or as a patient advisor or partner and by sharing evidence-based information about health, you are a patient partner in research.

To keep yourself informed on latest research, the Patient-Centered Outcomes Research Institute (PCORI) sends regular emails highlighting results of their funded studies, in language that is easy to understand. Their aim and mission is to help you and others in the patient community better know what is new and recently discovered. You can also participate in a PCORI-funded study or clinical trial.

To learn more about this organization you can visit www.pcori.org and click [subscribe](#) to receive their weekly emails.

Other ways you can stay up to date on what is happening in chronic pain research include staying connected with [CreakyJoints](#) and [ArthritisPower](#), attending [online webinars](#) which we conduct, staying informed about opportunities to attend in person conferences and attending community events when possible.

How you can contribute to your community

Many patients from the CreakyJoints community have shared a desire to turn pain into purpose. With that in mind, there are many opportunities for patients to get involved and take action, whether through contributing to research and/or joining our advocacy efforts. If you are interested in advocating, please join the Global Healthy Living Foundation's [50-state network](#) to learn more.

The National Institute on Aging (NIA) describes a clinical trial as “participants receiving specific interventions according to the research plan or protocol, such as drugs or devices; procedures; or changes to participants' behavior, such as diet” (NIA, 2019). The NIA also explains them as a primary way that researchers find out if a new treatment is safe and effective for people. It is also a way to test other aspects of care, such as ways to improve the quality of life for people with chronic illnesses (NIA, 2017).

By participating in clinical trials, you can contribute to the advancement of medical research, gain early access to new therapies which may be more effective than other treatments, and help scientists learn how you as an individual respond to certain medications.

If you are interested in being part of a clinical trial, there are opportunities to learn more and get involved. The [National Institutes of Health \(NIH\)](#) maintains a website where you can learn more. [ClinicalTrials.gov](#) is a database of privately and publicly funded clinical studies that are being conducted around the world. You can find studies that might be relevant to you by searching by disease and country.

For example, two trials in rheumatoid arthritis (RA) are currently being conducted in the US that do not involve testing a new drug: StopRA and TARGET. To learn more about these two clinical trials, visit the [CreakyJoints website](#).

You can also learn more about PCORI-funded studies or clinical trials by visiting www.pcori.org.

Another way to get involved in research is to participate in a research survey. ArthritisPower, which we discussed in Part 5 of the *Pain Explained* series, shares opportunities to participate in various research studies as an advisor, consultant or a participant. Your participation allows our research team to learn from your experiences, as someone living with chronic pain, and at the same time helps advance research in rheumatic and musculoskeletal disease. You can also share the results with your doctor and adjust your treatment plan accordingly.

Visit arthritispower.org to learn more.

For more information on non-medication interventions refer to Parts 2-4 of the *Pain Explained* series. Thank you for listening and we hope you found this information helpful. Remember to take the one question quiz to receive your free resources.