How to Talk to Your Doctor and Loved Ones About Chronic Pain

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Talking About Chronic Pain to Others

Attempting to explain in words what your chronic pain feel like can be frustrating. The closest comparison I can think of is trying to translate a word from one language into another that has no equivalent word with the same meaning.

Also, the consequences of living with chronic pain, such as needing to cancel plans or to ask for help, present even greater communication challenges. After all, relationships can be tricky enough without the additional complexities of living with chronic pain!

I hope some of the tips here can help you to feel more comfortable and confident communicating about your pain, and its consequences, to the people around you.

Communicating With Your Doctor About Your Pain

Doctors often attempt to simplify the problem of describing pain by asking patients to rate their pain on a number scale out of ten. Personally, I find this frustrating because one number cannot capture the whole picture of what my pain feels like.

When I researched this topic, I found a great tool, called the LOCATES scale (Health), for overcoming this challenge. It provides a framework for explaining all the dimensions of chronic pain:

- **L**: Location of the pain and whether it travels to other body parts.
- **O**: Other associated symptoms such as nausea, numbness, or weakness.
- **C**: Character of the pain, whether it's throbbing, sharp, dull, or burning.
- **A**: Aggravating and alleviating factors. What makes the pain better or worse?
- **T**: Timing of the pain, how long it lasts, is it constant or intermittent?
- **E**: Environment where the pain occurs, for example, while working or at home.
- **S**: Severity of the pain. Use a 0-to-10 pain scale from no pain to worst ever.

Try writing out your answers to each corresponding letter before your next appointment and share them with your doctor. I hope it helps you feel like you've communicated all of the dimensions of your pain!

Communicating With Your Loved Ones About Your Pain

When it comes to friends and family members, pain is a thorny subject. Chronic pain causes stress and heightened emotions. It's entirely natural to snap or get upset during a difficult conversation when you're in pain.

Sometimes just letting your loved ones know how you're doing that day can help them adapt accordingly.

You can try to use the LOCATES scale with your family members to help them understand more fully what you are experiencing.

The *Chronic Pain Couple* recommends "logging your daily pain levels in a pain app and screenshot and SMS the daily summary to your partner before they get home from work. This will help your partner understand what your physical capacity is so that they can adjust their expectations of you accordingly."

I sometimes read about conversations people living with chronic pain have in which their loved ones doubt that their pain is real, criticize how they handle their pain or even accuse them of being lazy if they have to cancel plans because of pain. Even the most supportive people can sometimes be insensitive or say the wrong thing.

I've found that knowing how I want to handle different communication challenges associated with chronic pain ahead of time is incredibly helpful to improving my communication with the important people my life.

Decrease Stress to Express Yourself Clearly

Feeling like you aren't being heard or that you are being judged when you communicate about your pain is frustrating. On top of that, it's difficult to express yourself clearly when you are hurting and feel emotionally reactive or defensive.

After a difficult situation, I sometimes realize that I wasn't specific enough in explaining what I needed, or took something personally that wasn't really about me.

One way to de-escalate tension and have a more productive conversation is to take a pause before responding to an upsetting comment. The first step is to notice that you feel angry, hurt or upset.

If identifying the feeling is tricky, look for physical cues of emotional reactivity – clenched jaw, stomach knot, tight chest, constricted throat or increased heart rate. Then intentionally take a pause until you feel ready to respond from a place of calmness and self-awareness. This could be as short as counting to 10 or as long as waiting until your pain flare has passed to continue the conversation.

Sometimes I find going into another room and taking a short mindful meditation break (focusing on my breath for three minutes) can be helpful.

Dealing With Unwanted Advice

In my experience, there are two types of advice: well-meaning suggestions from someone who genuinely wants to help and judgmental statements framed as "advice."

In responding to the former, I like the advice from *Live Plan Be*: "The key is to find ways to respond to others that don't drain you or get you riled up… You can give them a positive response without agreeing or committing to follow their advice." An example might be "Thanks for the suggestion. I'll keep that in mind."

Dealing with judgment in the form of advice ("maybe if you got off the couch and exercised more you would feel better") is another story altogether. Getting angry and upset in front of someone who you feel is judging you just feels awful – like you're making their point for them.

Rather than feeling the need to explain yourself, and going around in circles, I find it's best just to be direct and say politely that you aren't interested in their advice: "When it comes to my health, it's important to me that I do what I think is right. When you tell me what you think I should do, it's not helpful to me. It would mean a lot if you would not do that anymore."

If you're struggling with expressing yourself in important relationships, you might find books by best-selling psychologist Dr. Harriet Lerner helpful, especially *The Dance Of Anger.*

Establishing Boundaries And Sticking To Them

This is good advice for everyone, but it's particularly important for people with chronic pain. The reality is that we face physical limitations, and pushing them has severe consequences in the form of pain and fatigue.

It can be hard for the people around us to accept these limitations and not take them personally, such as frequently needing to cancel plans. These limitations can put a strain on our partners and families, whose lives are also changed by our chronic conditions.

The urge to avoid disappointing people is hard to resist and to learn to put your health needs first is a difficult transition for many of us. But speaking up is important for your health and well-being!

The first step is to work out beforehand what specific change you need to see in your loved one's behavior. Confronting someone about the problem before you have a solution to suggest is most likely going to pointlessly make them defensive and escalate the tension between you. It's beneficial to talk this over with someone else you trust before initiating the conversation.

The second step is to make the request to set the new boundary in a constructive way. Ask in a calm but firm manner, at a time when the other person is more likely to be receptive. When you clarify a new position in a relationship, speak regarding "I" rather than "you" to minimize defensiveness on the part of the other person.

It's important not to get sidetracked into justifying your request or arguing other points – how you feel is how you feel. Finally, it's important you also stick to the boundary you have set. Otherwise, it's unlikely the other person will too.

Live Plan Be suggests a helpful tool for setting boundaries called the 'Feedback Formula':

- When you call me at 11 p.m. (describe the person’s behavior),
- I feel upset and frustrated (describe the emotion you feel), and the result is my sleep is interrupted, and it that increases my pain (describe the effect of you experiencing that emotion).
- Would you be willing to call me before 8 pm instead?” (make your request)