

# Community Speak: A Collection of Knowledge, Wisdom, and Experience

*By sharing stories of our experiences we help circulate & transfer our unique life knowledges. This document is 100% compiled by individuals relating the experience that chronic pain, injury, and illness has had on their lives; including ways that they have come to resist and reclaim their lives from its effects.*

## **A lewd rude attitude**

"Attitude plays an important role: The way we think has a big impact on how our body feels."

"At home we can easily think too much about our pain, which often causes it to get worse. You're constantly being reminded of it. This leads to an unstable mind. If you think too much about pain it will not only likely get worse, but also stay worse. The less time we spend worrying about it and thinking about it the less it will impact us."

"It's all about your mind and how you release it. Telling myself, "You can do it," was very helpful. The body responds to what the mind tells it. Instead of telling yourself, "I can't do it;" or, "I won't do it," tell yourself, "I *can* do it; I *can* get better; and, I want to get better."

"Feeling pain and *thinking pain* bring its own stress."

"What bothered me most was not knowing if or when I would feel better. It took hitting rock bottom to propel an attitude change. I eventually realized that it was more a mental thing. I started telling myself, "I gotta get better," and, "I can't stay like this." It came down to 'waiting vs. doing what I can in the meantime.' Doing things that make you feel more like yourself made me feel like I was getting stronger. I think everybody has to get to a point where they tell themselves they have to start trying something different."

"It's a daily task to remind yourself the reality of the situation and what you have to do to help yourself."

"Struggles don't make us strong right away. They can offer a key to the door of self-growth or self-destruction."

"Pain may not resolve quickly no matter how many tablets you take. It's a frame of mind: Ninety percent is up here (pointing to head); and, ten percent is here (lifting arms as if to do bicep curls). You have to prioritize what you can do, but always try to be content with life so that it doesn't disrupt your peace."

"Although I have to live with this pain for now, I'm not going to allow it to control me. I'm going to do the best I can."

"I can't, doesn't exist in my dictionary. I can! And I will!"

### **About friends**

"Regarding friends, I found it was better to tell them; open yourself up. Telling them the truth and going out helps mentally, which helps with the pain. I used to be shy about telling my friends, but keeping it a secret made me really stressed and emotional. Friends are there to support you. Sharing is the most important thing you can do, that, and convincing yourself you can do it."

"Friends can help by encouraging us to get out of the house."

### **About hope**

"Walking, stretching, and meditation have been very important to continue along our journey. They have contributed to a more positive mentality. This has been crucial in helping us resist the influences of the pain to view ourselves as incapable. Pain tries to cause people to lose hope and sometimes we have to fight hard to get it back. Every small success has helped restore a sense of hope. Holding onto hope has been our best indicator of success."

"As best you can, keep a positive and optimistic mindset when looking ahead to the future."

"If you can get thinking today's going to be a better day, it will."

### **Talking, yes indeed**

"Talking helps take the stress of the problem and free it from your mind. It would weigh down my mind if I didn't get it out somehow."

"Talking about things has helped draw out new understandings and put into perspective what is most important to me. It has also given me the opportunity to self-reflect. This has allowed me to think more about what's possible and to re-embrace my potential."

"Talk things out until you out talk it."

### **Poor me days**

"In the midst of constantly trying to be as upbeat as possible, sometimes I just get tired of it and it wears me down. A "poor me day" is an allotted time where it's okay to mope, it's okay to sleep for half of the day. It's a time where I give myself permission to think about how bad I feel, or how mad I am. The benefit is that we're not using all kinds of

days to experience it. It's taking a self-compassion break. This way we can be better prepared to capitalize on and enjoy the days where we say, "It's not too bad today." You have to be looking for days like this; they can be easy to miss. These are the times to do something you really want to, or something you wouldn't normally do."

### **What, me a burden!?!?**

"Yes, your attitude has a big effect on those around you, but you need to let your friends and family know. You need to be honest with them. You DON'T need to HIDE your pain from people. Trust me, you're more of a burden if you don't tell them! If you think you're hiding it from them, you're not. In fact, they feel worse because you're not letting them know. Be honest with your friends and family, and with yourself, especially if people see you need help."

"Understand there will be good days and bad days, and times when you might need some help with something you usually do."

### **The real journey**

"A diagnosis can make it easier to deal with, and explain to people. It can even make it easier to accept things for yourself. But not everybody gets a diagnosis, not every pain can be explained, and most people have more questions than they do answers. The journey that most people with chronic pain are on is not concerned with "medical." Sometimes the only thing they can offer you is a pill. The real journey is, "What can I do to make my journey easier?" And for this, you have to rely on PEOPLE! Help them understand your situation and allow them to feel comfortable with your circumstances."

"It's important to be around people who understand."

### **The real problem**

"I finally realized I was acknowledging the wrong problem. I was acknowledging what can happen instead of what I'm staying away from doing. It's like I was doing different things to prevent a cold rather than taking the medication to get over it. In order to start moving forward I had to let go of some of the preventative measures and accept that I had a cold (problem). Accepting the real problem made it more possible to take back control."

### **Finding yourself**

"Look at your inner-strengths; this will help you focus on learning to accept where you fit into the world. Ask yourself, "How am I letting this situation affect me; vs. How can I actually be?"

“After my diagnosis things were chaotic: the number of appointments I had to attend, trying to make sense of what this all meant, etc. I ended up losing who I was. It took two years, but I finally asked myself, “At what point can I stop being the patient and let myself be me again!” I’m not just a set of diagnoses and symptoms! I started thinking about who I am aside from the diagnosis: “What do I like?” And, “How else can I be?” It’s been very empowering. This feels like a big development.”

### **Moving forward**

“Find a reason to make yourself get up and go. This will require you to look outside yourself to those who need you. It will require you to look inside yourself as well.”

“You can’t dwell on it!”

“Consider getting a pet. Pets love you, need you, and rely on you.”

### **I need to do this!**

“A psychiatrist once said to me, “You must really want to get your life back!” He told me, I’d be improving faster than others, because I was willing to keep doing the things I used to do. Sure I was more cautious when it came to things like driving, or lifting, but I was determined to do it. I told myself, “I need to do this!”

“When I had my car accident I had just started a new job; my dream job. I had waited 10 years to land this position and knew I couldn’t afford to take time off. Despite the pain, I was determined to complete one year at the very least. This goal kept me focused and pushed me to adapt and think outside of the box. Driving was tough: The drive to work took at least one hour, and sitting in one position for more than half-an-hour would cause my back pain to flare up; eventually causing numbness down my leg. So I would get up extra early, and on my drives to work I would literally pull over to the side of the highway sometimes, get out of my car and stretch. I did whatever it took. My mentality was always, “I need to do this!””

### **Habit check**

“The problem can have a tight grip on people, but some people can start to hold onto the problem too. It’s not just the other way around. It can become an excuse not to push yourself as hard.”

### **About spirituality**

“The belief that God was watching over me and helping me, gave me more courage to do the things I needed to do in order to get back to my normal life. I felt like I was not alone.”

### **My goal for today**

“I was getting too comfortable being a hermit since the accident and subsequent stroke. So I decided, for starters, I’d call a friend or send a message to someone on Facebook at least once a day. Each day I challenged myself to do one more minute of whatever it is I was doing, be it writing or reading, or exercise, and I’d feel good when I reached my goal. Feeling motivated to do better each day continues to be my goal. There have been many difficult moments, but I eventually made a conscious decision to begin overcoming some of these hurdles. My typing skills have been hammered since my stroke, but I keep at it and hope to get back my dexterity. Responding to your email was my goal for today before I closed my computer.”

### **So, what did they say!?**

“My past experiences with illness and injury have taught me that different doctors can have vastly different opinions. Knowing this has made me less freaked out when hearing their prognoses.”

### **My body and me**

“Like a car, if you haven’t turned it on in a while it won’t work.”

### **Getting busy**

“A number of years ago I had a knee injury where I was wheelchair-bound for a period of time. I thought about it non-stop, so much so, that it blocked out everything else in my life. This time around I’m thinking of my condition less, because I’m doing more. In fact, I haven’t really stopped doing anything!”

“I knew that before I could go back to helping others, I needed to help myself. I began by looking for opportunities to be social, and would often go out with my friends; joining in on conversations that weren’t about my accident or injury. Even going to the grocery store would be a good opportunity to just see other people. I continued going to my aerobics class as well. At the beginning, it could be uncomfortable, but I just did what I could; I’d experiment. For example, if the instructor said, “Bend your knee,” I knew whether I could bend it 90 degrees or 30 degrees. If she asked, “Why aren’t you lifting your arm,” I would just point to it and she’d know I was in pain. You will likely need to

make adjustments to the way you do things, but the faster you get back to doing what you normally did, the better you'll be. Conversely, the longer you wait, the more difficult it will be. I still have to be a bit careful how I do things -- I injured my arm, my back, and both knees. The pain is still there, but overall it's become less bothersome. Gradually, I'm starting to feel more normal again."