

"If you could turn the clock back, and start your journey with pain again, what things do you wish you had known then that you know now."

Feedback from members of *Chronic Pain Champions – No Whining Allowed* Facebook support group (8/26/20) <https://www.facebook.com/groups/painchampions/>

Chronic pain isn't fixable. The pain isn't causing additional harm to my body. Chronic pain can be managed using a comprehensive biopsychosocial approach. There are many non-pharmaceutical self-management tools I can use to live well, despite pain. There are pain rehab programs.

1. The doctor isn't going to 'fix' it and 2. Knowing the source/cause of the pain doesn't matter nearly as much as I thought it would because, at least for me, it was never 'fixable' anyway... At least not the easy fix I was looking for... Like a quick procedure or surgery etc...

1 don't treat a disease unless you have all the information.

2 go forward with dignity, and having gathered all opinions from the experts, use that information, but NEVER let go of your own power. At the end of the day, I live with those decisions.

There are 7 stages of grief (shock or disbelief, denial, bargaining, guilt, anger, depression, and acceptance/hope) when it comes to chronic pain and you will go back and forth between these until you finally accept it as a part of your life. Be kind to yourself because this going to be a tough ride.

If I'd known when I was young that I have hypermobile Ehlers Danlos syndrome, I would have worked harder to maintain muscle and protect joints.

1. It isn't in my head 2. Gather all information and come to your doctor appointments with questions. Be your own advocate. 3. Love myself as I am where I am 4. Don't take for granted the little things in life.

Surgery isn't always the answer.

Knowledge is power. I know my body better than any health professional and I'm my own best therapist. There's NO shame in being in pain. I can build a care team that works for me. I can say NO. I can fire health professionals that don't treat me well. I am more resilient than I know. I can live a better life without dependence on fixes or false promises. The things I'm told are "wrong" with me and what I'm supposed to do about it are often wrong...

I would have started seeing a rheumatologist in my twenties and started sports physical therapy at that time too. I would have have been more vocal about my pain. Also I would never had had both my knees replaced without my spine surgeon consulting him about the effects of my scoliosis and making my legs the same length was a really bad idea.

It's a stunning failure of our health systems when they lean on a purely biomedical approach to treating persistent pain. Like you Linda I have left those practitioners who are unable to offer a holistic BSP response to persistent pain behind. I'm no longer willing to look for a fix and part with my time and money for services that predetermine more pain. Discovering what pain science offers in helping me take control and manage pain has been liberating.

That it wasn't my fault. I blamed myself for years, for not being diligent with exercise (when I hurt myself every time I tried). I know now that I'm built differently from other people. Some bodies are like that old crappy car that you love but what a pain in the ass. In my case, that's literal.

1. When your diagnosis is RSD, the type of care you receive is highly subjective...and varies widely from one 'pain doc' to another. There is no widely accepted 'standard of care'.. It is ALL trial and error, so you MUST ask a lot of questions and do a lot of personal research before you allow them to give you ANY course of treatment. The days of 'just trust him..he IS the doctor' are lonng gone.
2. There is NO cure. What works for one patient may not work for another; in fact, it MIGHT make another patient more ill than when they submitted to the treatment. Proceed with caution regarding ALL treatments offered.
3. After each fall, sprain, strain and new injury, you will REDEFINE what the pain scale of 1-10 means.
4. NOBODY will truly understand your pain, struggles and achievements if they have not had RSD. Be patient with them, and remember that before you had it, you would not have believed it either. In the absence of blood, bandages, stitches, bruises or other obvious signs of injury, your critical thinking mind would have also struggled to accept the intensity and frequency of this pain experience..and its impact on the most basic daily living activities.
5. Being you, as you know you to be, is a rare blessing..do not expect it to always be your 'normal' state of being.
6. Though you did pretty good, save more, spend less because it can all change in the blink of an eye, and there are a lot of people depending on you...
7. Spend even more time on community outreach, building up your close circle of friends, and giving back, because one day you will really need help from those resources...
8. Accept and acknowledge that you are human, on a journey, and all journeys have hills and valleys. All journeys require rest and learning new skills as you go...
9. Forgive yourself for not being ready to embrace this 'new normal'... No one grows up dreaming of being disabled. No one is ever prepared to say goodbye to so many of their relationships and pastimes in the blink of an eye...take it a moment at a time.
10. Remember that you are the only you on this planet, and you have plenty to offer the world...

My chronic pain started with the death of my Momma. The physical pain was intertwined with the psychological pain and grief. So I didn't understand that the physical pain was forever. Along with the psychological pain. The only thing I could do turning back the clock was to spend more time with my Momma. My Mom got sick and in one year died. She told me she was dying. I did not want to believe it. I guess I did not react the same way as most of you did. Maybe similar. I went to my doctor, they ran tests. The tests did not give clear answers, so I went to a specialist, rheumatologist due to the pain in my hands, and flu like symptoms. And at the same time I grieved. My rheumatologist told me the death of my Mom was what triggered my pain. That was 31 years ago.

I would say Pain is not a good indicator of tissue damage. Understand that persistent pain lingers long after tissues heal and that pain science has discovered that social and psychological factors effect persistent pain. An over sensitive pain system can be reset back to normal by retraining our pain system using social and psychological interventions.

Medicine was not the answer for me - it only made things worse. Instead, I should have focused on neuroplasticity, cognitive therapy for pain, exercise, relaxation, meditation, acceptance, etc. I also would

have spent less time mourning my former pain-free self. Learning to accept one's present situation and making the most of it is all we ever have.

Just say no to spine surgery. No matter what they promise.