

The University of New England, Harold Alfond Forum, Biddeford Campus

The Science of Pain and the Art of Healing, April 4, 2013

By Paula Orecklin

Today I'm here to give the patients' perspective of living with chronic pain. My name is Paula Orecklin, and I have Complex Regional Pain Syndrome, also known as Reflex Sympathetic Dystrophy. As a result of a twisted ankle, my right lower leg from the knee down has been in pain. I'm 25 years old, and I have been in constant, severe pain since I was 13.

I think the biggest change in mentality for health care professionals when working with chronic pain patients is making the leap from 'this is a difficult patient' to 'this is a patient with a difficult condition'. We are not the problem. Our disease is the problem.

One of the biggest hurdles we have is obtaining pain medication when we need it. I start here because when you are in unrelenting pain, access to painkillers is a major concern. Opiates are some of the most useful drugs for treating severe pain, and the most challenged.

Governments legislate on the basis of protecting people from addiction, but in the process lump chronic pain patients in, and force us to follow strict guidelines about access to medications. In fact, only a very small percentage of chronic pain patients become addicts, and the majority of that small percentage had a history of addiction. Doctors need to be cautious with opiates, but the fear of addiction must not compromise the quality of care given to patients. Doctors must understand the difference between addiction and physical dependence. In the same way, patients must not be afraid to tell their doctors about their reaction to medications for fear of being blacklisted or cut off. I bring all of this up because when you're a chronic pain patient, this is the stigma.

I highly encourage patients to ask their pain doctors for a letter certifying that they have a legitimate condition, and what drugs are being used to treat it. This is essential if you have to go to the ER with a massive pain flare-up that has left you incoherent.

From a doctor's point of view, it's easy to see a patient for an appointment, then go on to the next patient a few minutes later. It's easy to go on to the next person, while the patient goes home and is still struggling with their problems. The problems never go away for us. We're in the doctors' lives for a few minutes at a time, once every few months. This is our life though. It never goes away.

Every single second, I am in pain. From my knee down to my toes, on my right leg, all there is is pain. The pain changes and moves and different parts hurt more than others at different times, but there is always solid pain from my knee down. On top of that pain, I will get other kinds of pains, all different forms. Stabbing, shooting, burning, visceral, aching, throbbing, whatever adjective has ever been used to describe it, I have felt it. On my good days, I will be at maybe 5.5 out of 10. My worst has been about 9.5. I usually average around 6-8/10. This is with all of my medications. Complex Regional Pain Syndrome, or CRPS, is considered one of the most painful conditions around. The McGill Pain Scale lists CRPS as more painful than unmedicated childbirth and nonfatal cancer. Only fatal cancer rates as more painful. Everything I do makes the pain worse. Moving, putting pressure on it, having anything touch it, no matter how light, everything makes it hurt more, on top of the pain I always have. I say this not because I want people to feel sorry for me, but for you to understand the extremity of my condition.

The fact that everything affects my pain makes life even more difficult. Getting dressed is painful because the socks put pressure on my foot and my jeans brush my skin pulling them on and then they squeeze my leg all around. A million things no one else even thinks of hurt me, from a single dog hair that lands on my leg to the air pressure change in an elevator. I've had to make numerous adjustments to my environment to make things as comfortable as possible for me, and if any of you would be interested in hearing about them, just ask me at the end of the speech. Even with them, life is difficult.

The pain really does turn even simple things into massive ordeals. Remember for most of your patients, it was a long and painful road to get to you, no pun intended. Thank them for coming in. Try to be polite and kind – most will have had doctors question their pain, or disregard it, and they'll have seen many health care professionals in the process of trying to find a diagnosis for their pain. Take a second to recognize that. Until only very recently, pain was considered a symptom of disease, not a disease in itself. This is a highly significant change in the way pain conditions are being viewed. Instead of taking months or years trying to find the cause of the pain, with little to no help in the meantime, the pain itself is being tackled as the main issue. For example, if a patient comes into the ER in my city reporting pain that is disproportionate to the injury and of a long duration, they are now sent to the pain clinic within 24 hours. This is a huge sea change in how pain is being treated. If this had been around when I was first injured, I wouldn't have had eighteen months of misdiagnosis, mistreatment, and circular referrals that allowed the CRPS to fully set in. New studies show that if given treatment in early months, a cure is possible. I never had that chance.

Many patients will cancel or reschedule their appointments. Try not to be upset with 'no shows'. Patients don't want to miss appointments, especially when they're in a lot of pain and need their doctor most. Maybe they were sick all night from their medications. Maybe they were in so much pain they couldn't even manage to call. I've had to reschedule so many appointments over the years, I can't even tell you. Sometimes, you're just in no condition to manage to get up and go anywhere. Please remember that, and don't blacklist them.

To make things easier, my doctors schedule me in the late afternoon, when I'm at my best. Try and work with your patients in making appointments. My family doctor and therapist schedule me at the end of their days so if I have to cancel, it's not as big a problem for them.

My family doctor sees me once a month. I save up all of my concerns, and bring them to her. She's not my pain doctor, who is so busy I can only see him every few months, but it makes me feel my medical concerns are being taken care of and are being listened to. One of the biggest things I can suggest for patients is that they keep a list of their concerns as they develop. That way, when they do get to the doctor, they don't forget anything and even if you're not able to speak coherently during your appointment, the doctor still knows what you wanted to talk about. Memory is also affected by pain, so I write things down as soon as I think of them. I recommend writing down everything important the doctor says, for the same reasons.

At home, I keep a daily diary, noting how much pain I've been in, and when I've taken painkillers for breakthrough pain. I note any unusual symptoms and my general condition for the day. This is very important for two reasons – first, by writing the time of when I take painkillers, I ensure I don't overdose myself, and secondly, I can look back on how well I've been doing with my medications and therapies. I can search my files and find out that since a new drug kicked in, I've been doing better or worse on average.

Doctors need to understand that as much medical knowledge as they have, the patient knows their condition better. It is our lived experience. The doctors might have the technical knowledge, but we have the daily reality of living with a disease. Listening to the patient and thinking outside of the box when the standard procedures aren't working are essential for any complicated case. You can't just say "well, this is the way we always do it", and leave it at that, when the way you always do it just is not working.

One of the most difficult to treat issues I have is the development of skin lesions, and the loss of toenails. My wounds are very difficult to treat. Initially, some doctors accused me of scratching and picking at my skin. Skin lesions didn't immediately fit the doctors' pre-existing knowledge of the disease, so the automatic assumption was that I was at fault.

I go to a monthly wound clinic, where the nurses are used to seeing all sorts of chronic wounds that don't heal well, from terrible burns to the complications of diabetes. I've tried all of the products they have that might help me. My skin, when you follow the normal procedures of keeping the wound moist, just sort of gets wet and mushy and wipes right off. The wounds, however, get dry and bleed. The only way to treat me is through trial and error, trying all sorts of dressings and prescription lotions and creams. The only adhesive tape I can actually use is ostomy tape. If the nurses at the clinic or the dermatologist were only working with the standard arsenal of wound care, I would be in much worse shape. Being open

to suggestion and listening to the patient when they say something isn't working is the only way to deal with patients. Otherwise, you'll just add to their problems.

When I have a flare-up of increased pain, the lesions show up consistently within the next day or two. The lesions start out looking like small red dots or a thin red line but quickly get bigger, open up, and bleed, causing even more pain. The lesions last for weeks and heal very poorly. At this point, my skin is so dry and fragile that the normal bacterial flora that exists has started to cause even more problems with my skin, my fingernails, and even my scalp, though at least these issues are easily resolved by my dermatologist. All of this naturally leaves a toll on my self-image.

I know that as doctors, you're keenly aware of the limits modern medicine has. One of the worst feelings I've had as a patient is knowing I am literally at the limits of medicine for CRPS. I am just looking for the next study, the next paper, which might help me. Everything that has been mentioned for my condition I've either experienced or had ruled out by my doctors for one reason or another. The last few things that were tried for me came from new research we found online.

I know how dissatisfying it must be, to see a patient coming back to your office every few months, in as much pain or more as they ever were, but you cannot let that affect how you treat the patient. That irritation can't lead you to distance yourself from the patient or get upset with them. As frustrating as it is, remember, the patient is even more frustrated. It's not the fault of the patient for having this disease.

It can be tough to deal with chronic pain patients. We can be emotional and angry and even lash out at our doctors. Legal, pharmacological, or medical reasons can prevent the doctor from giving the patient the amount or kind of medication the patient feels they require. But instead of acting defensively or dismissing the patient, try and remember that they are not mad at you personally. Sympathize with them. Legitimize their concerns. Don't send them away, or refuse to see them again.

No one goes into medicine to deal with patients they can't fix. Despite a patient's and a doctor's best efforts, chronic pain is frustrating and emotionally troublesome to deal with, day in, day out. It is essential that this burden is not taken out on the patient.

It is hard to see something you prescribed hurt the patient because of unintended side effects. One prescription can turn your life upside down. I was a student at the University of Winnipeg. I was very happy there. Unfortunately, my pain got to a point that my doctor prescribed oral ketamine for me.

Ketamine is used to stop the memory of pain, but has many side effects. All my higher thinking processes were shut down. My memory was so bad, I forgot words in nearly every sentence. My mind was in a complete fog, and my body was no better – I gained 60 pounds in a single year, even as I dieted. My emotions spun completely out of control, and my stomach was totally upset. There was no choice but to drop out of university.

My doctor looked into other drugs, and found with an Alzheimer's treatment, memantine. Memantine still compromises my ability to go to school, but at least I can have a conversation without wanting to break down and cry. However, the mental deficits are still enough to bother me on a regular basis. I tend to remember things only for brief periods, so I have to write them down. I've always really enjoyed going to school and learning. So you can understand that having to choose treating my pain over my education was personally devastating.

When I was 13 and first hurt my ankle, and the pain wouldn't go away, the pediatrician thought I was exaggerating or acting out. His perception of me as an overachieving perfectionist worrier blocked him from seeing the extremity of my pain. Perception is everything. It took eighteen months for a proper diagnosis, and by that time, the CRPS had fully set in.

I credit the pain clinics at Health Sciences Centre and the Pan Am Clinic in Winnipeg, and my pain specialist, Dr. Jeff Doerr, and his team at both clinics, for rescuing me. One of the best medications they've prescribed for me was nabilone, which I still take every day. Nabilone's active ingredient is THC, and it stopped the pain spasms in my leg that developed

every time something touched it. Nabilone enabled me to get off the crutches I'd used for four years. I also owe more than I can say to the physiotherapists at the Children's Hospital in Winnipeg. It was a physiotherapist who first suspected CRPS, long before any doctor did.

Even today, after twelve years of treatment and the best pharmacological regime I've found yet, I'm not independent. Far too many days are spent in bed dealing with massive flare-ups of pain. I just lie in bed and scream. My wounds open up and I bleed. Even with the memantine, though its side effects are less than those of the ketamine, I still don't feel sufficiently competent to return to school.

One thing I haven't touched on until now is the emotional effect of being a chronic pain patient. Obviously just being in pain is bad enough, but then there are the effects of being isolated from society, from significantly downgrading your plans for life, and from not being understood. Lack of understanding from the medical professionals' side can be devastating. One thing in particular that really got to me was learning that my condition doesn't originate in the peripheral nerves in the affected area, or the nerve cluster in my spine, but in how my brain receives and transmits pain signals. I'd always been told, for so many years, that the pain is "in my head".

When I learned that it literally was – that was emotionally crippling. I went into an emotional tailspin. I have always believed that my brain has been mine – even that it had been me. Me trapped in a failing body, but me nonetheless. To find out that my pain was so deeply rooted inside of my brain was a shock. More than a shock – it was a betrayal. The seat of what I thought I am, that had promised such a bright future based on my mental acuity, was in fact what tore that future away from me.

Only after a lot of thought and cognitive behavioral therapy was I able to get a handle on these types of thoughts. This is a very important point to mention. Without therapy, I would not be able to speak in front of you today. I certainly wouldn't be able to talk honestly about how the pain has affected me emotionally. Therapy has allowed me to get a grip on all of the negative thought processes that develop from being in this much pain, for this long.

I think a lot of patients are reluctant to try psychological therapy. One of the leading causes of death in CRPS patients is suicide. The mental aspect of being a chronic pain patient is essential to deal with, despite how difficult it is as a patient to recognize it. Only once I had a bit of a breakdown did I finally admit to myself I needed real psychological support. Learning to examine my emotions and thoughts has made a really large difference in my life. It took a year of therapy, but I was finally able to feel as though I had some control over the conscious part of my mind. Therapy gave me an element of control, something I didn't have over the rest of my body. Only then did I gain a lot more confidence.

I wish all of my secondary issues to the CRPS had such easily accessed treatments. When it comes to the main complication that's developed because of the pain, I fall in a crack in the medical system. The problem, which I touched on earlier, is that I develop skin lesions. My pain doctor can't treat the sores, and my dermatologist can't cure them because it is not a skin disease. I'm stuck in an odd space between two specialties, and neither doctor can do enough to help me.

Needless to say, I have a number of different medical issues, and while they are interrelated, there is no one doctor who is able to deal with all of them. Despite the frustration of needing so many different specialists to look after me, I can take a lot of comfort in knowing that I have the best care I can get. I have world class care. I've been to the Mayo Clinic, and have been told that there is nothing they could do for me that my doctors at home are not already doing.

I know I have a lot of personal benefits. I've been working on graded motor imagery and mirror therapy with my physiotherapist, and believe it holds a lot of promise for the treatment of CRPS. It is also one of the easiest, least painful – and least expensive – treatments I've heard of, and comes from a very new and exciting way of looking at the disease. I've also had access to a wealth of professionals to treat specific side effects from being in so much pain, from registered massage therapists, to a sleep specialist when the pain began to cause insomnia. I have been exceedingly lucky in my treatment.

I am constantly looking for new research, and I have sometimes been the first patient from my particular pain clinic to access new therapies or drugs. I live with a very supportive family, with a mother who is a full time caregiver, and a caring father. I have a best friend who is literally a doctor, and a supportive boyfriend. I have all of the advantages that a patient could ever want. And I am still here. I am still in too much pain to do so many things. With involved, active friends, family, and doctors, I have every advantage going for me, including socialized medicine, and I am still in this much pain. I live at home, I can't go to school, I can't work, and I can't drive. The prospect of being 25, living at home with no real likelihood of a job or independence or, it sometimes feels like, even happiness, can consume your life. At least I live in Canada, where I don't need to worry about the economic aspect of it, but your patients will not have that comfort. . It's difficult knowing that if this is as bad as it is for me, then for all the other patients who may not have all of the supports and resources that I have in place, it must be even harder. You can understand where emotional turmoil comes from.

That said, one thing that has helped, is starting to look into ways to make some constructive use out of my experiences. In the past year, I've started thinking about disability advocacy. I'm looking into volunteering in a position where I can share my experiences and in some way feel as though out of all this pain, some good might come.

I'm very pleased to have had the opportunity to come here today to share my story as a chronic pain patient with the next generation of health care professionals. In particular, I want to thank Dr. Bilsky and his team for inviting me, and giving my parents the opportunity to be here with me today. I also want to thank the university for putting on this conference. I think it's wonderful that students of so many different specialties are interested in helping chronic pain patients. I hope what I have said today might give you some insight into what it's actually like to be one. I would like to think that all of this might help someone else. I'm standing in a room of health care professionals, and if anyone has any ideas for me, please come talk to me. Anything I can bring back to my doctors would be wonderful!

Thank you all!