The Patient’s View Through The Eyes of A Disabled Nurse

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*\*****Disclaimer:****I am a Registered Nurse and I am disabled. This post in no way represents the opinions of any government organization, union, hospital, medical professional, individual or the like. Individual stories have been scrubbed to remove any identifying markers and are used with the consent of each individual. In saying so, I have endeavored to group similar statements together for readability. It should also be noted that I interchangeably use the terms medical professional and healthcare professional. The same applies to the terms Complex Regional Pain Syndrome (CRPS) and Reflex Sympathetic Dystrophy (RSD). This post is not meant to place blame on any one person or organization, it is simply meant to offer another point of view.*

\*Any obscene, inappropriate, threatening or offensive comments will be reported and flagged; such comments may permanently lead to one becoming blocked from viewing this site.

I invited members from several of my online support groups to help me write this post by answering the following question: What is the worst thing that a medical professional has ever said to you? Please help me out by commenting below if you’re okay if I use it (anonymously of course) to help me to support a blog post I would like to write about. Thank you in advance. (I have changed some of the sentence structure and tense for clarity).

I’ve wanted to write about this issue many times, but I was afraid. I was afraid of being blackballed or penalized for bringing attention to this problem by writing a blog post should I ever get well enough to return to work. After several visits to the ER (emergency room) and eight-day hospital admission over the past four years, I realized that this issue needed a voice. It needed my voice and what better way to do it then through my blog. I felt that it would be a cathartic exercise for me, seeing as I too have experienced this type of treatment. I was overwhelmed with the sense that I needed to share my experiences as a patient while utilizing the knowledge that I have as a registered nurse. It is my hope that I can reach even one medical/healthcare professional with my unique perspective. It would be worth every tear that I’ve cried if I could also help other individuals like me by trying to shine a light onto the issues. I hope to spark dialogue between patients and their healthcare team. I also want to take the time to say that though I have been at the receiving end of some very unfavorable experiences with medical professionals, I have a supportive team that is now involved in my care. I recognize that not everyone is a lucky as I am and that is my reason for giving this issue a voice. Not everyone is fortunate enough to be medically trained and able to communicate in medical-‘ese’. In many circumstances, I have been able to engage in my own research and take my health into my own hands, while maintaining open communication with my healthcare team. This was not an easy process and took a great deal of trust from both sides. There are times when I am still “afraid” to go to my medical appointments. What I mean is that in the back of my mind I have a fear of not being believed. I am afraid because I know what is said when that “difficult” patient is admitted or is discharged. I am afraid of getting the label of being a “hypochondriac” or being called a “frequent flyer”. Regardless of medical training we are all human. The one thing that I have found was important to obtaining quality care is to be an informed patient. Know your rights, the laws and health regulations act so that what you are asking for can be supported. In the information age it is fairly easy to find peer-reviewed scholarly journal articles to use for personal use in order to support what you are asking for. It is not enough to simply “google” something and print it off. Just as how we can post something or create web content so can anyone else. A great many doctors will support a well-informed patient.

After spending the last four years coping with several chronic conditions and developing new ones I decided that I needed to write about how it feels to be “on the other side”. I wanted to write this blog post because I’m a big advocate of patient-centered care and was even taught this during my training. As a nurse, I endeavored to treat all my patients with the same care that I would like for my own family. I was by no stretch the “perfect” nurse and I am not sure if that’s possible and no, I did not always say or do the “right” thing. Unfortunately, I took home my work home with me, mentally, emotionally and psychologically. This is NOT something that I recommend for anyone. While advocating is important, as is good care, it is also important that one takes care of their health.

Many medical professionals can sometimes forget that we, the patient, could easily be their mother, father, brother, sister, husband, wife, child, cousin, aunt, uncle or friend. Likewise, as patients we too forget these professionals are humans and may even have faced similar experience. It is unfair for either side to paint the situation with the same color of paint or with the same brush. Since becoming sick I have heard a variety of obscene and uncalled for comments, statements and questions from some of the professionals that I encountered. I am ashamed that the profession that I care so much about treats people this way. In order to not just express my own opinions I asked others with chronic conditions some of the worst things that they have heard from the medical professionals that they have encountered. The aim of this post is to bring attention to the blatant disregard of patient’s rights and a denial of basic human rights. It is my hope that if this post reaches some of the medical professionals we encounter daily that change will come.

As I brainstormed ideas for this post, I was not expecting all responses that I received. As I read through each and every one of the comments I was shocked, horrified, ashamed, appalled and embarrassed that I was trained as a healthcare professional. I realize that there are two sides to every story; previously I was privy to the medical viewpoint. Now, I am privy to the patient’s perspective. It is my hope that while you read through the following statements that your method of care for the individuals you encounter exudes empathy and becomes truly patient-centered. Here are some of the things that we have heard from healthcare professionals; they are in no particular order and are not listed by level of importance. They have been separated into statements and personal stories.

**Statements**

* (If the specialty of the person saying the statement is known it will appear in brackets).
* “Can you do circus/party tricks?” (Doctor)
* “You are too complicated for my scope of practice.” (Doctor)
* “You’re an enigma I don’t know what to do to help you.”
* “I’m going to refer you on, as I am not comfortable with [fill in the blank]”.
* “If you lost [x] amount of weight all your problems would go away by themselves.”
* “How can a person have so many things wrong with them?”
* “[Insert blank]? Well, that’s a terrible diagnosis to get.”
* “It’s all in your head, you’re thinking too much about it.”
* “Why are you lying?”
* “You just like opioids.”
* “You don’t have [fill in the blank] you just need to get moving.”
* “You’re a medication seeker; you need to stop seeing doctors.”
* “Is there any clinical proof that you have [insert blank], as they grab, poke, prod, pinch or rub affected area expecting you not to react?”
* “Stop over reacting to the pain, it can’t be that bad as you have already had enough [fill in the blank].” (Nurse)
* “Have you ever had problem with drugs, as I don’t think that you are really in pain and feel that you may be after a fix or high?” (ER Nurse)
* “I don’t know what is wrong with you, maybe try some Ibuprophen” (Doctor)
* “For goodness sake you’re not in pain, people with cancer have pain, not people like you!”(Nurse)
* “I think everything will be ok if you would just think more positively. This entire situation is dependent on your attitude.” (Doctor)
* “It’s narcissistic of you to think that just because you are [x] age you should be able to walk, ice skate or do aerobics.”
* “You can’t possibly be in all that pain from a floating piece of bone.”
* “You can only have pain from the in the CRPS affected limb. It is for it to spread anywhere else.”
* “This is the craziest thing I’ve ever heard!” (I was later diagnosed with occipital neuralgia.)
* “It’s all in your head. I can’t help you anymore.”
* “You are my first failed surgery.”
* “I don’t know why you have pain, I’m clearing you to return to work, and if you don’t like it…find someone else!”
* “You may as well get used to being disabled for the rest of your life!”
* “I don’t know what you want; I can’t do anything for you!”
* “You’re complex and complicated that’s the problem!”
* “Do you know that I think you may have convinced yourself you can’t do it”? (A few weeks later I went through a battery of testing that proved otherwise.)
* “Do you really have all the health problems that you listed”?
* “That’s what happens when you get older, there is nothing I can do for you”.
* “I’ve treated another patient with CRPS; I will bring in a photo of the patient who died from it to show you what CRPS really looks like.”
* “You have an aversion disorder because I can’t see anything wrong. It’s in your head and usually only a woman thing.”
* “The pain is in your head, have you ever thought about getting a tattoo to cover up the scar on your ankle”? (Surgeon)
* “You have RSD, go home take your pills there is nothing we can do for you”!
* “What is RSD/CRPS I have never heard of it?” (Doctor)
* “You were just made this way”.
* “Most of our RSD patients claim its spread but I do not believe that it can spread.” (RSD Specialist)
* “All women are lazy liars”, “I don’t believe that you are in pain and I’m going to clear you to work at your next appointment. I do not care that you’re having this imaginary pain. I bet you want to just stay home and collect a cheque.” (Doctor)
* “You just have a very low pain tolerance.”
* “You need a Psych doctor, I don’t treat addicts”.
* “I don’t believe in fibromyalgia.” (Doctor)
* “You need to get my bowels straightened out and you will be ok.”
* “RSD is a temporary thing, it doesn’t spread, and furthermore you’re addicted to your pain medications.”
* “You need to be hospitalized!” (The doctor said this VIA webcam and had me committed!)
* “Please leave my ER” (ER Physician)
* “Take this Valium and soak in a hot bath.”
* “I am sorry, but I don’t know what really is happening and cannot help you.”
* “Suck it up buttercup!”
* “Why do you think you have that, do you want surgery?”
* “People spend too much time googling things”.
* “All you need is a clinical massage”
* “Why are you back here?”
* “I’m a pill man, so just tell me what you what?”
* “The only people who don’t want spinal cord stimulators are drug addicts.” (Pain Management Nurse)
* “Suck up and deal with it”.
* “You have CRPS you are useless to everyone.”
* “Your neck problem can’t be causing my migraines because the brain and neck aren’t connected”. (Doctor)
* “I’ve never heard of that so it doesn’t exist.”
* “It’s not my job to look into your medical problems (I was then dropped as a patient.)
* “I know what is wrong with you! You’re a drug addict! “
* “People with Ehlers-Danlos Syndrome don’t experience pain when they dislocate something”.
* “You can’t have that, because it’s rare”
* “You don’t have any goals in life, so you’re not really depressed”.
* “There is no such thing as a dislocating hip…”
* “You have fibromyalgia because you’re a woman and as such are over emotional.”
* “Well it doesn’t matter, you can’t have EDS, you are too short and your fingers are not long”. (Apparently if this extremely old doctor had access to the Internet he would know the difference between Marfan’s and Ehlers-Danlos Syndrome.)
* “Go home and meditate, everything will be fine”.
* “You are just seeking attention”. (My answer was, “and I am not getting it!)
* “You can’t dislocate a hip. It can only be reduced during surgery.”
* “EDS is really just a family trait, see I’m hyper mobile too.”
* “I’ve got news for you, every time a patient comes in I charge. The more often I see someone, the more make. I’ll be honest and say I’m here for the money.”
* “The only thing wrong with you is you need to exercise!”
* “You are not disabled. You should pay your taxes just like I do.” He said all that when tried to get a disability tax form fixed (my previous doctor missed something when he filled it out and had retired due to health reasons). (Doctor)
* “Why the hell do you have that damn boot on your foot if nothing is wrong with your foot!”
* “Get out of my ER. I don’t support people who use narcotics. I’ve never taken narcotics and you don’t need them either”. (ER Physician)
* “You can’t possibly have CRPS/RSD your foot doesn’t look as bad as the other patient I treat.”
* “If I can’t fix it with medication, you shouldn’t come back.” (Doctor)
* “Why do you want to have something rare?” (Doctor)
* “You look good it’s not as bad as other patients”.
* “Can’t you just drive back to the old state you moved from to get your meds?” (It’s a 6hr ride each way.)
* “I’m sorry there is nothing I can do for you just suck it up and deal with it.”
* “Your insurance was willing to pay for you to have acid reflux but not for you to have a heart attack. (The fact was I had had three (3) within a few years time.)
* “I have bad luck. I have to treat a chronic pain patient who is allergic to pain medications.” (Those curtains aren’t soundproof. Emergency Room Physician).
* “Grin and bear it.”
* “I don’t think RSD even exists. This woman is just hysterical”.
* “You are only here seeking drugs. We are not giving you any even though your blood pressure is so high.”
* “You’re young…you’ll bounce back.”
* “I don’t know what else I can do for you. We can do another injection, because that’s what I do.”
* “Maybe you will have spontaneous remission”.
* “I’m just burned out on this job”.
* “What do you do? Sit around and cry all day?”
* “You smoke marijuana? My religion doesn’t allow me to treat you with pain medication” He then went on to say “What? You want help detoxing after two years on Lortab? Too bad, should a thought about that before you smoked marijuana.”
* “Have you ever thought of having below the knee amputation?” (Primary Doctor on more than one occasion.)
* “Since the pain medication I prescribed you can’t handle, you don’t have RSD”
* “I think we are going to have to amputate your leg because I don’t know what else to do and there is no cure for RSD.”
* “You have the healing ability of a corpse”.
* You over report your symptoms”.
* “Patient appeared neat, wore jewelry (bracelets and multiple rings and earrings) and had neatly manicured nails”. (This was written in my chart. Furthermore my nails weren’t even polished!)
* “You are oversensitive to my “perceived” impairments and have a tendency to exaggerate my level of dysfunction.”
* Your use of opioids is what is causing your cognitive difficulties it isn’t related toe “fibro fog” symptom from also having fibromyalgia.
* “It won’t kill you.”
* “You’re crazy for wanting a child with all your medical problems.”
* “I think you have RSD. Go home and Google it”.
* “You looked like a junkie”. (I wasn’t even on any medication then.)
* “RSD and CRPS are not the same thing; furthermore you can only get it from a bad injury.
* “Go get a Natural Remedies book, because I couldn’t help you anymore.”
* “I don’t really find anything wrong with you or find why you have so much pain so I think our next step is a psychiatrist.”
* “It’s normal that your foot turns completely purple after surgery.”
* “I don’t care if you piss all over yourself, you’re not using that bedpan every again.”
* “Losing weight will cure PCOS.”
* “It’s mind over matter you shouldn’t need medication and should be thankful that you don’t have the ‘bad’ kind.”
* “Is there a circus major at [local university]?”
* “I know nothing about EDS, and I have no intention of learning.”
* “You can’t have lupus, if you just stopped sleeping around you’d get better.”
* “There is nothing wrong with you. Let me help patients who need me.” (ER Physician)
* “That there’s no cure for EDS, you have no hope. “
* “All you can do is “hit the gym 3 times a week and lift weights” to get rid of pain.”
* “All you need to do is stand against a wall and it will all go away”
* You need years and years of psychotherapy to get better…. this is all in your head.”
* “Being a mother is a title you have to earn and by your age and with all your health issues, you’ve missed your opportunity. That’s probably why you’re not married too
* “You don’t want to die on them like your mother.” (My mom has been fighting cancer for year.)
* “Everyone your age has joints like you.”
* “Well, I’m not sure what you expect me to do to help you. It’s not as if we can brace your entire body.”
* “What are you doing here?”
* “EDS doesn’t cause any pain.
* “You need to change your diet…it is all in your diet. “ I had to have emergency colon surgery three days later)
* “Have some Vicodinn and go sleep it off.”
* “You’re weird” (As he said this he stuck his hand to my head and pretended to shoot!)
* “It may look like 5mm to a radiologist but I’m the one in people’s brains and it really isn’t. Surgery won’t help you”. (After asking what else I could do.)
* “I don’t know you’ll have to ask someone else. I can operate on you if that’s what you want.”
* “It doesn’t hurt to be a little bit bendy”
* “Respiratory lung tissue weakness or patient wasn’t trying hard enough.”
* “It’s too stressful for a woman to be not to be married”
* “ some internet research, get depressed, and cry about it.
* “Well you don’t look like a person that has EDS. You have big boobs.”
* “EDS is not life changing and has no effect on your daily life! If it does you clearly have mental issues!”
* “We \*all\* have to deal with a little discomfort.”
* “Just because you are hypermobile doesn’t mean you have EDS. You have to have broken bones.
* “There’s no magic cure for Ehlers Danlos Syndrome, you know.”
* “What am I supposed to do? Test you for every disease in the world?”
* “Take my pain medication forever and shut up.”
* “I bet if professors didn’t give you any extensions, your ‘medical issues’ would magically disappear.”
* “It’s all in your head; get up every day and have a hot shower and stay up all day do this for twenty-one (21) days and you will be cured.

**Personal Stories**

* I went in for abnormal bleeding, I was potentially hemorrhaging; I was having fist-sized clots. Stuff that became normal until I got a doctor to listen. “You don’t have to worry the clots are just from sitting all day.” As I am a wheelchair user… surely I must. So I pointed out that I do not just sit still, I move in my chair constantly, and oh… at that point I was still sexually active. (The bleeding only stopped with a recent ablation so I had no choice but to stop due to the pain factor). So after this protest I was told I was a liar and …the actual worst thing? “You can’t have sex, when you become disabled your vagina seals off.”
* I have CRPS in my right shoulder and I struggle to write as it’s sets off the pain, and one doctor said to me “see when I write it doesn’t hurt my shoulder” an to make it worse he wouldn’t let my mum come in with me an I was only 14 at the time and already thought nobody believed me.
* My doctor told me in my face in 2012 “You do not have Chiari”. Meanwhile he had the report of a scan in 2008 that said I did. He also had a letter from my old neurologist that said I did. He proceeded to told me that a “psych hospital was the best place” for me.
* When my hand was at its worst and I didn’t know exactly what was going on.. I had a Specialist take one look at it… “Well it could be RSD” then he looked at me (looked me up and down cause I am an overweight woman) “Nahhh! You are not moving it enough!” He was really rude throughout the entire visit. He ripped the ER splint off and jammed this hand into a wrist brace. He had me in tears he was so awful! And that was my intro into the CRPS world.
* Doctor comes in and asks me “have you tried Ibuprofen or Panadol” and I said “I wouldn’t be here if an Ibuprofen could fix it”. At this point I’m almost in tears and he points to his foot that’s in a boot, as he had fractured It or something and said “well, see this. I’m in pain to and ibuprofen works for me…I think your overreacting”. (ER Doctor)
* My physiotherapist asked me one day if there were any problems at home or school that my daughter might not want to face. I said “no, why”? She replied, “ We have to make sure her pain is real”. I burst in tears and said, “Don’t you ever suggest she is making this up”. From that day onwards the physiotherapist has been nothing but supportive. My daughters CRPS stems from her breaking her fingers. It has now spread to both her legs making her unable to walk. What child who was a strong dancer would make this up.
* “Just buy some soccer knee pads and put them on your elbows backwards so your arms stay straight, and that will help improve circulation and reduce the pain you think you have”. (Neurologist)
* After witnessing one of the worst flares I have ever had. My hands and feet turned blue in the presence of the doctor. They did a Doppler. He came back to see me and said, “medically there was nothing wrong”. When I asked about the constant burning and my extremities changing from red and blue he turned looked me square in the face and said that my diagnosis was an enigmatic condition. He did not realize that I knew what an enigma was. After I finished with him he did.
* An orthopedic surgeon still discharged me after I was still in pain. He left after he said “ I hope that it magically get better by itself”.
* I had lost 20lbs in three weeks when I told my doctor about my weight loss instead of being worried about sickness. He said, “Well that’s not a bad thing”!
* My pain doctor said I didn’t have RSD because I would have hit him with my right hand while he touched my left hand. He then sent me back to work. Almost four years later I’ m still going to the pain management clinic.
* One of my doctors asked my mom if it was possible that I was making it up for attention.
* A doctor at the local ER department reported me to the local police & the Department of Human Services for child abuse as they believed I had my daughter on prescription drugs that were too strong for her at her age (15) and that they had never heard of RSD, as it was called back then. This was even though she was under the care of both a GP (General Practitioner) and Pain Specialist who were prescribing and monitoring her medication.
* I was told I didn’t have CRPS by a neurologist, even though someone else had already correctly diagnosed me. He said if I did, I couldn’t be symptomatic all over my body, because that wasn’t a “region. He also told me I was fine and that he should know because he “teaches on this subject.” He needs to go back to school.
* Doctors have repeatedly told me over the years that I am too fat to be a mother. I am now fighting for IVF (in-vitro fertilization) treatment cause no one should ever be told they are too fat to be a mother. Especially when there are women bigger than me popping kids out like they are nothing.
* I saw a specialist two weeks ago not entirely helpful but I chuckled to myself when he said that he could confirm the diagnosis of CRPS from two years ago was correct. He then proceeded to say that the condition only lasted seven years maximum and that I had only five years to go before the condition will disappear. Yeah, I was finally diagnosed 2 years ago but I have had the condition since I was a teenager undiagnosed sure, but the pain is the same just in another part of my body.
* One of my doctors tried to tell me it was “all in my mind”. My swollen limb and scars from operations proved otherwise. I told her where to go in the end.
* I was told that I had psychiatric issues and was on a lot of drugs. They then proceeded to tell me that post-traumatic stress disorder (PTSD) and CRPS are not real. They are in my head and I needed counseling because of it and my PTSD was from a traumatic attack. I was like but my MRO shows shit wrong in my shoulder. The other doctor told me that I needed to get it looked at.
* My primary physician, who I’ve only been seeing for a year, said I didn’t have CRPS because, if I did, I wouldn’t be able to touch my own hands (hands were folded on my lap). My response was that I’d had extensive physiotherapy and that helped me get through my initial injury and attack five years ago. He didn’t see me at my absolute worse and only knows the medicated me. I think he thinks all symptoms must be present at all times
* I was 11 and my doctor told my mom (in front of me) to take me to a psychiatrist because I was depressed and faking for attention.
* An EMG technician got really angry with me and said told me that I was over-reacting when I said I couldn’t continue with the test.
* I was told at thirty-three (33) years old to take it like a man. I had been working since I was fifteen (15) and just kept working. As I got older I was able to get better jobs but now it has to come to what it appears to be the end of work for me is not easy to take as a man.
* I had the following interaction with a nurse. “I am a Nurse and I had a patient who had CRPS in his hand. You know if someone has CRPS, you can tell by their skin, it changes colors. You would know if you had it.” That’s when I told her again all of my symptoms and reminded her it was my foot! I went on to tell her how she has never seen my foot! My doctors said I had it. She then says, “Well, you know the medications you are on are very expensive, and they are the same medications they give to cancer patients. Are you seriously trying to tell me you need the same medicine they give people dying of cancer? You can’t possibly be in that much pain!”
* The first neurologist told me that RSDS does not exist in his opinion, that anyone with the diagnosis is “just crazy” and needs to be hospitalized for psychiatric treatment. The second neurologist that came in said he heard of RSDS, but never treated anyone with it. He told me there was probably no hope for me.
* One of my doctors told me to go home and learn how to walk on my toes (my RSD is in my left heel, leg and lower back, I’ve walked on my toes for over five years now). Then the guy turns around to walk out of the room. So I yelled at him. He turned around and told me he was the best in his field and if he didn’t know what my problem was NO ONE would!
* “Your numbness is all in your head. I don’t know if it is past sexual abuse, spousal abuse, work stress or kids. You need to take care of it. I’m not doing anything else for you, and if you try to see anyone else they will want your records and won’t want to see you either. Oh, and then he diagnosed me with “psychogenic spells” and put it on my record. All this was after an EMG that showed radiculopathy in my c7 and c8. Um, that couldn’t cause numbness?
* I was told to get a massage my one of my doctors. The last time I was told that was in September. My response was, “that sounds nice…the last time I got a massage I got pericardial effusion”. He said….”oh that’s right”.
* I have a tilted hip, and the specialist said that was imposable because if it was I wouldn’t be able to be up walking around.
* My baby had a severe chest wall deformity and the orthopedic surgeon, an EDS specialist was going to take her to the OR to do ‘cosmetic surgery’ to correct the deformity. When I asked if there was any possibility of her ribs being dislocated. He replied said sternly, “of course not ribs do not dislocate”. He would have done major chest wall surgery rather than even consider what was in fact the cause.
* “Yeah I didn’t think you were one of those crazies who claim to have fibro”. I then asked her why she would think some one was crazy because they thought they had fibromyalgia. I didn’t even get into the fact that she diagnosed me with it. She answered with “people drug seek all the time so they make up diagnoses “.
* I was told that I was just looking for pain meds, “obviously you have become a drug addict”, she laughed at me, literally laughed, told me I was lying, and that all the strange bruises I had, (I had zebra stripes of bruises up and down my legs) must be from my husband beating me.
* An internal medicine specialist walked in my isolation room and scoffed about the fact that my doctor had me in isolation. I had open wounds from the bottom of my foot, all around the leg up to the knee. The worst case of cellulitis every doc and nurse that saw me had ever seen…but he scoffed about me being in isolation. I said, well, I have CRPS, which affects the immune system, and he cuts me off mid-sentence and argues with me, saying it does not affect the immune system. He accused me of using Google too much, and that I should not believe everything I read.
* I was told that my son was just trying to get attention, that he was faking his pain, it was all in his head, etc. etc. etc. He was sent to an orthopedic specialist in regards to his leg pain. The doctor sat there and told us that he was sure that it would be fine. He went on to tell him that if it wasn’t fine, he would have to come back for some very painful tests and would probably need surgery…basically he was trying to scare him into not having pain!
* My husband was in the ER several times in a month with a spinal fluid leak from a bad sympathetic nerve block. The Physician’s Assistant called him a drug -seeking veteran. He later ended up needing a blood patch.
* I had my large colon removed about 6 weeks ago it was a nightmare. No one knew what CRPS was not the doctors or the nurses. What was supposed to be a five-day stay turned into a two (2) week admission. hey tell me they can’t control my pain because of my CRPS. I am thinking I am dying with the pain but I overheard some nurses outside my door talking about how all I’m wanting is more pain medication. Meanwhile I am crying in pain. I was mad upset I just had this major surgery, was given no post-op pain relief. For them to be professionals and to talk to where I and other patients could hear. I am sick of it I have a very high tolerance of meds and I am still having problems.
* After my surgery I went back for my first post-op visit I was complaining of so much pain my surgeon called me a “drama queen” I told him something was terribly wrong he said it was all in my head and that I needed to start P.T. which was excruciating my sister who is a RN said it was time for a second opinion eight (8) weeks later I was diagnosed with RSD and my surgeon didn’t even recognize my symptoms
* “You are the kind of patient that dies of an asthma attack and nobody knows why.” This is the same doctor who told me I didn’t need allergy tests because it didn’t help to know I am allergic to something I can’t get away from anyway… I have anaphylaxis and my allergies have put me in ICU before.
* This is one of conversation I had with a doctor. “These test results are useless to me. I only diagnose from my own testing and no I won’t give you any pain medication”. I replied, “I don’t want more pain medication, I don’t even want the medication I’m on now!” He went on to say “Well, I’ll make an exception and schedule you for surgery on both wrists. “As I rose to walk out, my husband stopped me and asked, “Just to be clear. Even though you aren’t able to read these test results you are offering to operate on my wife?” He replied with, “I’m trying to be nice about this.”
* There are some doctors that end up accusing patients with CRPS of having Munchhausen Syndrome and harming themselves to get attention, especially when they see the skin ulcerations. Often they are the kind of doctors who think that CRPS is just something that causes pain and nothing else.
* I was told that RSD was just something some doctors say when they don’t know what it is. Then they referred me to a psychiatrist who would prescribe drugs for things I never had.
* A Doctor put in my chart that I was non-compliant during a nerve block and didn’t list any meds used. He actually didn’t read my chart and injected me with a pain med I am allergic to and sent me into a seizure. When I came too, I had an IV and was told they almost lost me but it was okay because they had the crash cart there.
* “You’ll have to forget that dream. You won’t be able to handle the pain of pregnancy, childbirth, or be able to lift a newborn, let alone a toddler”. My now ex-husband took his word as law. In 2004, I began dating a man who researched my medical issues extensively.
* My new doctor discontinued one of my medications because he “didn’t like it” and I “should get used to it. He went on to say “you’re not in NY anymore”. Another time he put me on a med 1/2 the dose I had always been on, then he said he was putting a note in my file that it was not to be increased and if I asked for increase he’d discharge me. He also threatened me to put it in my file that I was drug seeking.
* I had a doctor say maybe I was “faking seizures” when I was rushed to the hospital after my sister, a nurse, rushed me to the hospital. And, the same ER doctor said, “I was ‘faking’ when my sister rushed me to the hospital with a purple swollen arm. I wasn’t sure how someone can “fake” a purple swollen arm. The next morning I was rushed to the ER at the closest hospital when my arm got worse. The doctor at the other ER sent me for an ultrasound of my arm. They caught the blood clot 1/2 inch away from my heart after it had passed through my arm. The Doctor who said I was “faking” the purple swollen arm was fired after the doctor from the second ER notified the other ER and filed a complaint against the doctor. The doctor and ultrasound technician that caught the blood clot saved my life by doing their job. I was very lucky! The blood clot can’t be removed though and it is still 1/2 inch from my heart.
* My doctor told my insurance company that the test trial for the Neuro-simulator helped 80%. I had told him 10 or 15% at most. He told them that just so he could get authorized to put it in. He then screwed up the procedure, which caused me more pain in the end.
* GP told me that my then sixteen month old baby was being a prima-donna by not eating, turns out she suffered from a bowel problem. She also had an enamel problem with her teeth, so was in, what we would call chronic pain.
* I went to get my medicine filled and the pharmacist asked me why I was on so much medication and I told him RSD. He then ask me why I why taking MS Contin. I said RSD. He said you have to have cancer to take MS Contin. I told him to bite my butt and to give my RX’s back to me. I wouldn’t let him fill them. He called the police and reported me for stealing and writing prescriptions.
* RSD is very rare I doubt you have it, on the upside, by visits end they said, well I guess you are really one of the few!
* Because a doctor “wanted to see if I had allodynia”. At the time this was all too new and I had no idea what he was talking about. I only knew that he slapped me on my already very sore, very swollen leg. What a jerk.
* I was prescribed psychotropic and pain meds all level 2 drugs. When I went back to get my SSI filled out, I asked for a copy of my records, he told me I was never a patient of his. His name was on my meds. He said he never prescribed me meds, said I stole the script.
* I had a Worker’s Comp physician tell me I could go back to my job as a floor nurse, even if I didn’t have any arms! He then put his arms behind his back to demonstrate.
* I had to do the flex measurement test and in order for a report to be written. She put her hand on my foot and moved it a certain way I jumped. I yelled. The look on her face, she turned her head so I would not see. but she rolled her eyes. I told her it hurt. I had tears in my eyes holding it back and she says, “It’s not real pain, it is mental”.
* I was told that the lesions on my face were because I didn’t have good hygiene. I was appalled.
* My physician told me that I was a waste and should be humiliated that I am draining the economy. He would also consistently laugh at me whilst I described my pain despite the fact that I always made sure I had a witness in the room w me! It took 8yrs, but I finally reported him. He then publicly accused me of being an “addict” and selling my medication!
* I had a new doctor pull a chair up to mine (a bit too close) and suggested I go to see a psychologist. He handed me a card and said “obviously you don’t want to feel better” I did each nerve block precisely as I was directed to in medical school, yet you still claim to be in pain” perhaps this is in your head now”. “Now, Mrs. X you need not get upset and hysterical. I merely suggested you needed someone to talk with”. I was in utter disbelief. It gets better. e then pushes his chair against the door and tells me I’m not going anywhere! I was forced to listen to his tirade for more than an hour. I was only “allowed” to leave once I told him I had to take my son to an appointment.
* A doctor wrote the following in my medical record “patient communicated appropriately and attempted to convince me she was in severe pain by crying.” Then she added, “Patient claimed to not be able to use right hand, but was appropriately dressed in coat with scarf”.
* “Why are you so tired?” I replied by saying, “Because I haven’t gotten any sleep for the past couple of days. You know how that works. Insomnia that’s secondary to chronic, intractable pain. I’ve been up for days and won’t sleep until I eventually crash.” And they apathetically replied, “Well, you know what gets rid of that, and how you get some sleep? Hard work, my dear. Hard work.”
* My doctor was going over my list of diagnosis and when he came to EDS he stated, “oh that one doesn’t matter, it’s nothing” and then went on to discuss my other diagnosis.
* My daughter has been told, when she is screaming in pain because her kneecap has flipped that it’s okay because EDS doesn’t hurt.
* “Ehlers-Danlos is a nonsense diagnosis. My response, ” Maybe you’d like to explain that to the head of your genetics department.”
* Is your mother and father, brother and sister, or is your mother and father daughter and father? Because Ehlers-Danlos syndrome comes from incest.
* “I won’t give you a CT scan because even if you’re having an embolism I wouldn’t treat you anyway.” My husband replied, “But what if she is having the beginning of an arterial rupture?” He responded, “I wouldn’t bother doing a scan for that either. Any treatment would kill her anyway, it would just prolong the inevitable.” My husband was upset, I was in shock, and then my husband asked, “How will I know if she is having a rupture?” He answered, “You’ll know. It will be quick. She’ll just collapse and that’s it.”
* I needed Cognitive Behavioral Therapy when I refused a cortisone shot thirty seconds after meeting him for the first time. I stated why my referring doctor had sent me, possible EDS and of course he said my skin wasn’t stretchy enough and told me I didn’t have it. If I had wanted a cortisone shot like the other twenty patients who sat waiting three hours to see this man
* “Wow, you were right, he is a bleeder. Can someone help me in here?”
* Then said I see you think you have Chiari. Who diagnosed you with that? My reply was “ You did”. He then gave this retort, “well even if you have it, it has nothing to do with your optical nerves. The optical nerve does not run back there.
* A terrible internist told me that I was just fat and depressed (because I cried after being treated horribly) and walking three miles a day would cure me.
* “Patient wanted something for “breakthrough” pain and was very upset when we refused to prescribe narcotics” That was the day they discharged me from the pain clinic because “you’re benign, it’s not like you have cancer or anything” and I didn’t ask for narcotics, I specifically said I \*didn’t\* want narcotics, and listed the ones I’ve been on in the past that didn’t work.

I hope that you made it to the end of this very long post. The reality is that yes we could be making this up, however it is unlikely that hundreds and thousands of patients around the globe are making these accounts up. It is more likely that this is a major problem that needs to be addressed. If we are honest about the state of healthcare and the problem that this creates by overwhelming an already full system with people that have been misdiagnosed as being mentally unstable simply because one health professional refuses to address real patient concerns. Lastly, know your rights. Usually within any health organization a patient advocate is employed who can help facilitate open dialogue. Be assertive and clear about your expectations.

To the health professional who are involved in our care. We realized that your job is thankless however we are humans that have real feelings and real concerns. It is important to care for us without your own personal bias coming into the picture.

-Be Well

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