

I am so happy you are reading this. When I wrote this I was 4 years into my pain journey and it was so well received, I knew it was time to make change and start something for all people with pain. Since I wrote this in 2007 some important factors have changed in my life. We started US Pain Foundation, an organization created by people with pain for people with pain. After writing this open letter, it was clear that almost all people with chronic pain can identify with it and our experiences are all very similar. It was and is clear we need one another, because we are the only ones who can really understand each other on so many levels. We want everyone to know that you are not alone and together we can make huge change in our lives and in the lives of all people with pain. The most asked question I get is "Do you still have pain since you are able to do this work" the answer is "Yes" my physical pain has not changed but the way I look at it and approach it has changed. I realized the difference between suffering and pain. I surrounded myself with people who understand me on a level in which I needed understanding. It is amazing the change that happens when you have people in your life who understand you, I call them my family of choice. I have worked to heal emotionally, mentally, and spiritually. All of this has changed the way I react to my pain, I am able to function even with the pain, I realized I can have a fulfilling life even with pain. I realized it was up to me to make the best of this situation and to empower myself. I know in my heart if I could do it, then I know anyone with chronic pain can do it because I am exactly the same as everyone else. We want to be there with you to guide you on this journey and lead by example that we all can do it.

Thank you for reading this letter I wrote below and please know you are not alone.

PAUL - Founder/President US Pain Foundation inc

A Typical Day for someone with Chronic Pain...(Written 4 years into my pain journey in 2007)

The other day a friend of mine asked me if I would share with her loved ones the experience of being an RSD/pain patient - what we go through on a daily basis, the struggles we face, and the importance of medications and therapy. I thought the best way to do this was to share what other Pain sufferers wrote and add in my experience as well. Mr. Orsini, a pain sufferer for more then 30 years, set up a wonderful template for us to

follow in order to show what a typical day was like.

I myself have had RSD since 2003. I also have Degenerative Disc Disease, Failed Back Syndrome, Nerve Entrapment, Fibromyalgia, Nerve Damage, Spinal Stenosis, Arthritis, Bursitis, Depression, Anxiety and the list never ends. I first developed RSD when I was 30 years old. Since then, I have talked to many other RSD patients and other Chronic Pain patients, and we all experience pretty much the same things with minor differences.

I have actually had people tell me, "It must be nice to not have to work and just sit home all day, you're lucky", or "What do you do all day? Watch T.V.?" If I thought they were really interested in a reply to their ridiculous statement I would tell them that having RSD and/or other Chronic Pain Diseases, however severely you have it, is much more work than ANY full-time job! And we don't get to call in sick, get vacation days, and our work week is 24 hours a day 7 days a week!

As an example for those who do care but are unsure what a typical day is for us, I will try to explain. Please don't take this letter as mean-spirited in anyway, I know some of it may be hard to read. It is not an attack, we just want our voices heard.

Now understand that quite a few RSD patients (also known as RSDers) and Chronic Pain patients have other diseases as well as RSD, such as Fibromyalgia, Spinal Stenosis etc., and that some RSDers have RSD in one limb and for others it is more, some have less movement while others a little more. Some take a few medications and some take a lot more. I myself take a little over a total of 20 pills a day (not different ones, but altogether). Contrary to some people's opinions taking a bunch of medications does not make us "druggies". A "druggie" is someone who takes drugs for recreation. A pain patient is someone who takes medication because he/she has no choice and who can not have some sort of normal day without them, you see we don't get HIGH from them and none of us can fathom someone who takes narcotics for "fun and/or recreation"!

There are patients who use different types of machines or who have Spinal Column Stimulators or Pump units installed within their bodies in an attempt to reduce their pain, and of course some deal with the wheelchair issue as well. A few patients, the lucky ones at least, also do some form of physical therapy such as swimming, weights, massage, to help them continue to be able to do the basics things like walking and using their

hands, feet, arms, etc. Most pain sufferers cannot do Physical Therapy because the consequences are worse than the help, because if you aggravate a nerve it can cripple you for days, if not weeks. The bottom line is that I can assure you that most patients deal with the same issues. The idea is to give you an understanding of the issues we face every day, so forgive me for making generalizations.

First, let's start with the sleep patterns. Unlike "normal" people all pain patients are prone to insomnia and do not get the deep REM sleep. This is the healing sleep our bodies need each day. We either wake often or are in a drug induced sleep. When we do wake, it is physically painful to actually get up and get out of bed. Why don't we sleep? It is because RSD causes changes to the Limbic system of the brain. The limbic system is that part of the brain that controls insomnia, short-term memory, concentration, irritability, ability to find the right word when speaking, and more. We start our day with medications of course. The first of many such times per day. To "look fine" we may take 10 to 30 or more pills a day for various symptoms. Then there are the side effects of those medications to deal with; upset stomach, drowsiness, diarrhea; constipation, headaches, and others. Many also have to fight the "Dry-Eye Syndrome" and must use eye drops two or more times per day. Understand that these pills do not take all of the pain away. They just enable us to get up, move around, and have some semblance of a "normal" life. They allow us to function.

Then a few pain sufferers head to Physical Therapy such as pool exercise or range of motion therapy, massage therapy, and even acupuncture. For the patients for whom these things work, they are lifesavers. Like the medications they allow us to function, to be a part of our families, to enjoy part of each day, and for some they actually give us a reason to get up in the morning. These aren't luxuries but necessities for those who can physically do them. There can be months even years, when allodynia, extreme pain from the lightest touches, sounds, or light, prohibits even simple things. Maybe the person sitting next to you at dinner touches your RSD arm, or your RSD foot gets accidentally kicked at the pew at Church, or your RSD leg gets bumped at school; all these things seem harmless to the average person. They may not understand how those things could ever cause pain, but trust me, they can and do. I know what you are thinking, that is crazy. No. That is RSD. If you think it's crazy, think how a patient feels when they start forgetting things, especially when their pain is high. Or when the slightest touch, even the caress of a loved one, the kiss from a spouse, the touch of the sheet on the foot, the tightness of a

sock... Sometimes even a breeze blowing over the body can cause such pain it will bring tears to their eyes.

When their friends and loved ones sit there and judgement or disbelief, it causes even more hurt. When a disconnected doctor doesn't believe you that is bad enough, but when a loved one cannot understand you it hurts almost as much as the pain. When people ask me to describe it to them the best I can do is say: Imagine if you had RSD in your hand and arm. Now empty the blood vessels in your hand and arm out and refill them with lighter fluid, light them on fire and keep them lit 24 hours a day, 7 days a week. Now imagine no one else can see the flames or believe that the pain is that bad no matter what you say. Another way to describe it as such a deep ache that it feels like the bones are being crushed. The company that produces Lyrica has some awesome ads in national magazines, which show a pair of legs being swarmed by millions of fire biting ants, standing on hot coals. That is RSD.

Whether we patients are walking for therapy, which I assure you is as painful as it is necessary, or doing things that remind us we are alive, there is always a price to pay. It may be extra pain directly afterwards, or even the next day, lasting a week or more. On top of that, you have the risk of severe depression that comes with any pain disorder. Almost nobody realizes that connection, and that it is not all physiological - you see pain receptors eat up serotonin, which is needed to keep depression away. If we get upset or are saddened, the pain gates are opened even more.

While the average person can sit there and say "Go ahead and enjoy the day, you can't let your pain control your life!" they don't realize that we are trying, desperately, to control our pain and not let it control us. We RSD patients are cognizant of that every day, controlling our pain by controlling what we do, where we go, who we see, and so forth. And we try to do things that remind us we are alive... Like trying to help our spouse with daily chores, or reading a book, or playing with our pets, or going to a movie, grocery shopping, running errands. Things that make us feel normal, if only for a few hours. Unfortunately some people who see you during these "good times" believe that is how you are the entire day. What they don't see is the pain you experienced that night and/or the next day because of what you did. Nor do they take into account all the medications you took before and/or afterwards to be able to do that or the fact that you probably had to spend a great deal more time resting afterwards. They never realize how depressed you get because your

always trying to put on a smile, so they will not feel uncomfortable. They don't "get" why you don't stay the duration a family gathering - if you go at all; or why even hanging Christmas ornaments takes several attempts, maybe many days.

The same is true for patients who go to the computer to get support from others with RSD through cyberpals, listservs or websites. Many non-patients do not understand that the time we spend online helps keep us going each day, and informs us of new procedures or medications to educate not only ourselves but our loved ones, and sometimes even our doctors. For most of us it is our lifeline, not our toy. The time we spend on the computer is absolutely necessary to our general well-being; for it is there we can talk with others who truly understand what we deal with every day and every minute.

Many of us have to nap in the afternoon to rest our bodies. One of the problems this leads to is when our loved ones try to do something nice for us and plan a whole day of activities. It is just too much for us. We have to change our thinking to moderation. It is much easier to do something in the late morning or early afternoon. Usually mid to late afternoon we are done for the day. You also have to factor in physical therapy and doctor appointments that wear us out for the day.

Another strange symptom that has to be factored in to our daily lives is that many of us are bothered by vibrations, noise, light and even an off comment can actually make the pain skyrocket! Due to the noise, light, vibrations or even an off comment which cause us extra pain. Places most people take for granted and wonder why we are not there or not talking on the phone, why we can not go to family or friends houses sometimes, why we rarely speak on the phone to others after mid day if at all, or why sometimes crowded areas are off limits. If there are a lot of people making noise for example, even if it is simply singing or clapping, even family gatherings, have to be cut short sometimes due to all the typical regular noise generated or go off to another room, where you need to sit in the dark. Going to families or friends can also become depressing due to the fact, you either can not join in to the activities, you can not take the noise, or someone might say something off key which upsets you.

Imagine saying to your boss, "Sir, I have to go home, the thunder is causing me great pain and the wind blowing so strong hurts as well." Oh yeah, they would love that. Sorry I can't come to your birthday party because there will be too many people having fun and enjoying

themselves and making noise. Yeah, that makes sense! I can only imagine the restrictions parents with kids have to place on their children so as not to hurt their RSD limbs, after all kids will be kids. How about dealing with the fact that you always wanted kids but because your pain disease is getting worse, you cannot have them, first because it would be too much of a strain on your spouse; second and most important it would not be fair to the child, growing up watching a parent suffer and get worse, and the disappointment of being unable to have a catch with them or go to their first day of school. It would be selfish of us to have a child just to make ourselves happy and not think of that child's well being for the rest of their lives.

I have heard so many stories from so many people with Chronic Pain telling us that their families, friends, spouses, and parents, tell them how they are just babying their pain, that they need get out of bed more, that they stay home and do nothing all day, or the best is they do not feel they are respected for the few things they try and accomplish each day, ect. Great advice from the uneducated and seemingly uncaring. Instead of saying things like that, why not read up on the disease, go to the web and do some research, see what the truth is regarding the pain, see how depression of a pain patient can be helped, maybe attend a support group with them, if your really concerned that much about their well-being then these would be the proper steps. You don't know how much it would mean to the patient if you took just an hour here and there to do that.

Our medications, our therapies, and of course our spouses are what get us through each day. The value of these things can not be measured. It seems no one appreciates what a spouse does for the patient, they see everything, the mood swings, spasms, crying, pleading, and the agony they go through. I have been blessed with a wife who puts up with all of this, works, and comforts me relentlessly no matter how many times I complain about the same thing.

Pain does not just bring physiological changes to our body but psychological ones as well. That doesn't mean our lives end, they just change. And RSD/CP patients require tools to make those changes possible. Tools that include medication, various therapies, exercise, diet changes, and lots of support. You can be a positive part of it or you can be a hindrance, it is totally up to you.

Now some may view this as being obsessed with the disease, that we think of nothing else but our disease, our pain, that we are too focused on

it and that is why we are so depressed, so sad, we hurt so much. Seriously, the fact is that for us, Chronic Pain is our life. It has to be factored into every decision we make, if it isn't we will pay for it later, as will our loved ones. So we need to work within it, we need to keep our minds busy in order to keep ahead of the disease. Constant Pain is a funny thing it always reminds you.

I often worry that my friends and family will get sick and tired of talking about Pain, and suffering with me. But then I think, it is no different than if we had cancer, or another disease more recognized (which some pain sufferers have). People are just used to hearing those words more. Yes we will lose some people along the way, whether it be friends or family that is inevitable, some just will never try to understand or never believe in something they can not see but we will also gain some new wonderful supportive friends and those will be amazing true friends who will be in it for the long haul.

I hope this gave you some sort of idea, what a regular day is for a person who suffers from any of the many pain disorders. There are many groups and foundations set up to help people who suffer from pain and their families.

Thank you for taking the time to read this letter/article, hopefully this is the first step in the right direction.

Paul Gileno