



# One Woman's Dance with the Pain Experience

The author recounts how her struggles as a patient being treated for a chronic painful condition, and learning that thousands of other women have had similar experiences, opened her eyes to the effects of gender-based disparities in pain treatment and led her to take a lead role in advocating for change.

By Cynthia Toussaint

I was 21 years old, nearly three decades ago, when chronic pain turned my life upside down. Up until that time, I had a love affair with performing; as a ballerina, actor, and singer, there was no doubt in my mind I was going to enjoy a long life in the bright lights of show business. Then one day, a simple hamstring tear suffered while at the ballet barre triggered the chronic pain disease Complex Regional Pain Syndrome (formerly known as Reflex Sympathetic Dystrophy) in my right leg. The pain was so fierce, it felt as though my leg had been doused with gasoline and lit on fire.

For the first 13 years of my illness, my doctors told me that my physical problems were all in my head. Meanwhile, the CRPS spread throughout my entire body and ravaged my vocal cords, leaving me bedridden for a decade and unable to speak for five of those years. During these hellish years, my physicians refused to acknowledge the severity of my pain, telling me that I was merely suffering “stage fright,” and that I had “tendonitis from Mars.” One had the audacity to tell me that I was “enjoying the secondary gain I was receiving from my attentive partner.” Another doctor even suggested that I shoot myself if the pain really was so bad. And when my arm folded into a permanent contracture, another doctor told me that I was folding up my arm “with my mind, just the way one levitates oneself.” All of this abuse was framed by a constant reminder that I was only a woman anyway, and my pain didn’t matter because it was all in my mind.

Suffering the endless indignities from these physicians became worse than battling the CRPS—the disease was innocent, the doctors were not. I’ve paid a high price for their harsh words and dismissal of my pain. My chance for a cure is long gone; I’ve since been diagnosed with lupus,

fibromyalgia, and RA, and I continue to be challenged with the physical and the emotional pain that accompanies these conditions. I lost my absolute passion, my career as a performer. I am unable to marry John, my partner of 31 years and the only person who has stayed by my side throughout this ordeal. I lost my ability to have a child. My family and friends abandoned me, and although some have reentered my life, my family will never again be whole. And during the many years when all hope seemed lost, I constantly struggled with thoughts of suicide. Taking my own life appeared to be my only way out, the ultimate painkiller.

Although I never believed the pain was all in my head, I was filled with anger and a sense of violation, which later turned to shame and guilt. Somehow *this was all my fault* because I was undiagnoseable. I was certain of only one thing: I was alone.

### A rallying point

In 1995, my life took a dramatic turn. I was at last diagnosed with CRPS and I began receiving more effective medical care. I focused my energies on health care reform, taking every chance to tell my story to the media. Then something amazing began happening. Whenever I mentioned being told by my doctors that they didn't believe my pain was real, I received a wave of responses from women who wanted to share with me their own stories of being dismissed or denied. At first, this was a comfort as there was definitely a pattern emerging—this was not personal and I was not alone after all.

After founding For Grace ([www.forgrace.org](http://www.forgrace.org)) to reach a broader audience and raise awareness of gender disparities in pain treatment, these stories from women in pain became a part of my everyday routine. However, after a while, hearing these stories was no longer a comfort—the sheer numbers were too disturbing. I heard from women with CRPS, fibromyalgia, TMJ, pelvic pain, migraine, and every other kind of pain I could imagine. They all told the same story of having their pain dismissed while being labeled “hysterical,” “malingerers,” and “drug-seekers with ulterior motives.” Too many of these women ended up in psych wards. Too many women took their own lives.

These collective experiences crystallized the day I read “The Girl Who Cried Pain; A Bias against Women in the Treatment of Pain” in the *Journal of Law, Medicine & Ethics* (<http://hcp.lv/o8cgPe>). This report, written by Diane Hoffmann and Anita Tarzian in 2001, perfectly articulated and exposed the unfolding tragedy of women's pain being systemically discounted in this country. The report confirmed my suspicions of an epidemic. I was no longer comforted and long past disturbed. I was now haunted and horrified. I knew I had to take action.

Women are predisposed to all of the chronic pain diseases. Studies show that we feel pain more severely than men and have a lower pain threshold. However, when women report our pain to our physicians, we're often told it's “hormonal” or “all in your head.” We're given sedatives and anti-depressants, whereas men are much more likely to be believed and given painkillers.

It is time our cries are heard and our names cleared. We have committed no crime. The dictum “First, do no harm” must apply equally and without bias. I drafted my Women In Pain petition (<http://hcp.lv/qjRmgj>) and posted it online as a manifesto to rally around so women's voices would at last be heard. I received thousands of signatures and testimonials of support. Women had spoken out loud and clear, and I believed we had only scratched the surface of an issue that was ready to boil over.

## Diagnostic Criteria for Complex Regional Pain Syndrome

### International Association for the Study of Pain (IASP) Criteria for CRPS:

The presence of an initiating noxious event, or a cause of immobilization

- Continuing pain, allodynia, or hyperalgesia in which the pain is disproportionate to any known inciting event
- Evidence at some time of edema, changes in skin blood flow, or abnormal sudomotor activity in the region of pain (can be sign or symptom)
- This diagnosis is excluded by the existence of other conditions that would otherwise account for the degree of pain and dysfunction

### The “Budapest Criteria” for CRPS:

- Continuing pain, which is disproportionate to any inciting event
- Must report at least one symptom in three of the four following categories:
  - Sensory: Reports of hyperesthesia and/or allodynia
  - Vasomotor: Reports of temperature asymmetry and/or skin color changes and/or skin color asymmetry
  - Sudomotor/Edema: Reports of edema and/or sweating changes and/or sweating asymmetry
  - Motor/Trophic: Reports of decreased range of motion and/or motor dysfunction (weakness, tremor, dystonia) and/or trophic changes (hair, nail, skin)

Must display at least one sign at time of evaluation in two or more of the following categories:

- Sensory: Evidence of hyperalgesia (to pinprick) and/or allodynia (to light touch and/or temperature sensation and/or deep somatic pressure and/or joint movement)
- Vasomotor: Evidence of temperature asymmetry (>1 °C) and/or skin color changes and/or asymmetry
- Sudomotor/Edema: Evidence of edema and/or sweating changes and/or sweating asymmetry
- Motor/Trophic: Evidence of decreased range of motion and/or motor dysfunction (weakness, tremor, dystonia) and/or trophic changes (hair, nail, skin)

There is no other diagnosis that better explains the signs and symptoms

Source: <http://hcp.lv/ncgrat>

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### Just listen to the patient

We live in extraordinary times. Biogenetics, stem cell research, gene therapy—medical and scientific advances abound. The Clinton administration proclaimed the '90s “The Decade of Pain Control and Research.” The eradication of suffering associated with chronic pain may be within reach over the next horizon or two.

But I submit that the greatest advance in our understanding of pain and its management is well within our grasp right here, right now. The key to progress is for physicians and other health care providers to simply believe a woman when she reports she is in pain. The patient's experience of her pain should be the guide. The “Pathophysiology of Pain and Pain Assessment” module of the AMA's “Pain Management” series of CME activities reminds physicians that “Pain is inherently subjective and the patient self-report is the gold standard in assessment” (<http://hcp.lv/pFlkEr>). Further, the authors of a study published in the *Proceedings of the National Academy of Sciences* reported that “Undetectable physical differences in injuries or disease processes can result in chronic pain for one individual but only minimal deficits for another. Furthermore, an individual's subjective experience of pain can vary substantially from day-to-day despite being evoked by a temporally invariant stimulus... Pain is defined by the first-person experiential perspective and must be diagnosed and treated with significant consideration of the subjective report... the subjective report will likely remain the single most reliable index of the magnitude of pain” (<http://hcp.lv/pOlRJ7>).

In July 2011, the Institute of Medicine crafted a groundbreaking report on pain that essentially said pain care is in short supply and that it's a national disgrace how people, especially underserved groups such as woman, are allowed to suffer needlessly due to disregard for pain as a health crisis (<http://hcp.lv/q7krdw>).

Simply believe her. *Simply believe her.* To the physicians who continue to downplay or disregard the pain of the women you treat, I request that you reassess your old, dated misconceptions, re-examine your faded pre-conceived cultural biases, and find in yourselves the humanity to treat all patients in pain to the best of your ability as you swore you would do. Undertreatment of pain is probably the most inhumane and unethical inaction, as well as the most obvious, complete form of patient abandonment, a physician can practice.

### A hopeful future

I'd like to share a quote from my petition; ironically, it's from a woman named Grace. She said, “The doctor who is supposed to be managing my pain informed me ‘There are some treatments, but they are tedious. So I guess I'm just going to let you dangle for now.’ My life is falling apart due to chronic pain. I believe if I were a man, I wouldn't be left ‘dangling.’ I'm on the verge of giving up altogether. And I don't think this petition will help because women in pain aren't deemed worth

treating and no amount of begging and petitioning can change the prejudice of doctors against us.”

When I first read this quote, I was stunned and frightened. What if Grace was right? What if we women in pain continue to be witches burned at the stake? If she is right, then we are lost. I am committed to making sure that the fears expressed by Grace and thousands of other women become a thing of the past. Women in pain do indeed have a hopeful future, and that hope is created by raising awareness, educating the public and health care communities, and breaking down barriers to care, compassion, and understanding. I am proud and thrilled to report that For Grace is one of those organizations leading the charge.

For Grace continues to generate local, national, and worldwide media attention about the plight of women in pain. We champion pain awareness months and legislative informational hearings, including the first of its kind in the nation in 2004 that focused exclusively on the undertreatment of women in pain. And for the past four years, For Grace has hosted the annual Women In Pain Conference in Los Angeles, which brings essential tools and resources to promote self-care and patient empowerment, the use of alternative and complementary therapies, and the Integrative Medicine model (<http://hcp.lv/n8ciXv>).

All of this good work, combined with other noble efforts to promote the cause of effective pain care for all patients, makes me hopeful that a cultural transformation is underway within medicine that will at last bring timely, quality care to pain patients, along with the respect and dignity that should be accorded to people challenged by serious, life-altering health conditions. On an advocacy and professional level, this has brought me great satisfaction. On a personal level, as I dance with my pain experience, I have been on a parallel journey that, despite tremendous upset and heartbreak, has ultimately afforded me greater wisdom; deeper, more expansive insight; and, gratefully, better wellness.

I lead a life of contradiction. I've experienced horrific pain, a non-caring medical system, total loss of the career I felt I was born for—and I feel completely blessed. Helping women heal and make positive choices has brought a miracle into my life—a physical remission and emotional healing beyond anything I could have imagined. All of this has been triggered by the wisdom I've gained from my challenging journey. I attribute my healing to a newfound ability to listen deeply to myself. Perhaps most importantly, I began writing my memoir, *Battle for Grace*. This helped strengthen my voice and exorcize my pain, sorrow, and anger, freeing my body's natural healing powers. I strongly recommend daily journaling for women in pain, as it opens the door to their creativity and power to heal. I am also a firm believer in the curative benefits of the creative arts—dance, music, art, theater, and narrative expression.

After being unable to exercise for 19 years, I now swim a mile three times a week. I'm able to sing (I'm even recording my first CD!) and play classical piano again, one of my greatest passions. I'm even walking through ballet pas de deux for the first time in 30 years! I suspect this is just the beginning. I now embrace my “tragedy” as a great gift; it has taught me to listen to myself. My values have deepened and evolved, forging a wiser and more empathic human being. I know how precious each moment is, and on a daily basis I experience the great reward of helping people. I wouldn't go back for anything.

*Cynthia Toussaint is the founder and spokesperson of For Grace, an organization dedicated to raising awareness of gender disparities in pain assessment and treatment. She is also the author of Battle for Grace, a memoir of her experiences dealing with CRPS and the medical system. Learn more about Cynthia and For Grace at [www.forgrace.org](http://www.forgrace.org).*