

The Comorbidity of Pain and Disability, and Tips for Pain Practitioners

BY JEANNE LAZO

To understand the world of pain and disability, ask someone who lives there. I do.

I never thought pain would change my life, but it did. It stole my livelihood, eliminated my choices and shrunk my world. It diverted my focus from happy, productive pursuits to basic survival chores.

At the same time, it introduced me to people I hoped not to meet: healthcare professionals, attorneys, disability insurance company representatives, and Social Security administrators. It spawned a mountain of medical and disability paperwork. It gave me excessive free time, not for activities I loved, but time to vegetate and watch myself become increasingly irrelevant in my own life. In short, disability followed the pain, which, in turn, caused more pain.

My Story

It began in 1997 at a family picnic, when I joined in a game of tug-of-war. The opposing team yanked hard on the rope, and I twisted my foot. Months passed and my foot didn't heal; instead, the pain increased. I began to feel extremely fatigued, and I experienced numbness in my extremities, as well as painful electric shocks all over my body. I often felt mentally confused and my eyesight was affected. In March, 1998, these problems became so severe that I had to quit working. The pain in my foot continued to rage as it spread up my leg. The entire limb swelled, turned red and was hot to the touch. Eventually, the pain put me in a wheelchair.

Prior to this health crisis, I had a life: a 23-year career in telecommunications, Bachelor and MBA degrees; part-time jobs as a college math teacher; and tutor of disadvantaged teens. I was a wife and mother. In six short months, I lost most of my identity and joined the ranks of the permanently disabled. I was 45 years old.

From the time I quit working in 1998, three years would pass before I was diagnosed with fibromyalgia, five years before I would find a physician who recognized what was wrong with my left leg—complex regional pain syndrome (CRPS)—and eight years before I would find a physician who knew how to treat CRPS. Prior to receiving these two diagnoses, I had never heard of these diseases.

I knew even less about disability benefits. I searched for books to help me understand, and when I did not find any, I decided to write one. Over the next four years, I researched disability insurance, Social Security disability benefits, and Workers' Compensation. I met Carol J. Amato, a professional writer, and together we co-authored *Persistence is Power! A Real-World Guide for the Newly Disabled Employee*, a nationwide guide to help others navigate through the disability maze. I became an advocate for people with disabilities, and this set me on the path to becoming whole again.

During the early years of my illness, physicians did not know what was wrong with me, and were reluctant to admit this until they had conducted exhaustive, expensive tests. Many physicians did not realize the financial impact

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of these tests: what portion I would be required to pay and whether or not I could afford them. Many years, I incurred more than \$6,000 annually in out-of-pocket expenses, which depleted our family's savings.

In addition to being sick, disabled, and battling screaming-out-loud pain, my good character was questioned. Some physicians did not believe that I had real pain, and said so in my medical records. I had never been accused of being dishonest before, but since my pain and fatigue were largely invisible, I had no way to prove I was telling the truth.

To some specialists, I was only one body part. The

problem with this approach was that I did not just have one broken body part, but a chronic, systemic illness and a disabled life. The specialists did not realize that if a cure was not found quickly—months rather than years—my former life would be gone and could not be easily

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recreated. Things change; people lose jobs, homes, spouses, friends and family in the fallout of pain and disability. Time is of the essence.

No healthcare professional addressed my disability, or mentioned a residual skills assessment, disability counseling, career counseling, or retraining/rehabilitation services.

The Legal Right to Work and Receive Disability Support

The very act of applying for disability benefits adds a legal burden to patients dealing with pain, even though they may be ignorant of disability laws and unaware that they are in a legal situation. For example, to qualify for Social Security disability benefits, claimants must prove that they are unable to do any substantially-gainful activity because of their medically-determinable physical or mental condition, which can be expected to result in death or which has lasted or expected to last for no less than one year (1). Amendments further specified that physical and mental impairments must be “of such severity that an individual is not only unable to do his previous work, but cannot, considering his age, education, and work experience, engage in any other kind of substantial gainful work which exists in the national economy, regardless of whether such work exists in the immediate area in which he lives, or whether a specific job vacancy exists for him, or whether he would be hired if he applied for work” (2).

To be required to swear under oath that you cannot do any work in order to receive support—from an insurance system that you have paid into for years and



desperately need when you have a disabling condition—is extremely demoralizing, and violates the basic human right to work as defined in the United Nations’ Universal Declaration of Human Rights (1948).

Healthcare professionals are also drawn into this legal battle, considering that they provide written testimony every time they prepare medical reports and fill out disability insurance forms. Patients’ financial survival often depends upon the timeliness of a diagnosis, sufficient medical evidence, accuracy and consistency of entries and their treating professionals’ medical knowledge. Until the time comes when disability support systems in the U.S. are modernized to reflect the changing nature of work and the basic human right to work, clinicians and patients must work together to navigate through the existing disability and legal maze.

6 Tips for Healthcare Professionals

The following tips are intended to improve the disability and legal process for clinicians and patients:

1. Time is of the Essence.

A medical diagnosis is the essential piece evidence required to prove a disability benefit claim, and without this, claims are typically denied and appeals can add months or years to a patient’s wait for reconsideration.

2. Enlist the Help of a Patient Disability Advocate.

Patients with disabilities often don’t know which physicians to see, what tests to have performed, and what to do next. In theory, the patient advocate role is assigned to the primary care physician but, this doesn’t work well in the real world because general practitioners are too busy and appointments are restricted to fifteen minutes or less. A patient disability advocate is needed.

3. Provide a List of Resources to the Patient.

In some cases, physical impairments may take a back seat to more pressing issues related to finances or daily living adjustments. Patients may need referrals to social workers, disability attorneys, and rehabilitation centers.

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4. Embrace Your Role in the Disability Benefit Process.

Generally, benefit providers will not ask you to render an opinion about whether or not a patient is disabled or qualifies for disability benefits; benefit providers make that determination. What they do want from you are objective data and observations about how a patient’s impairment affects his or her ability to perform daily living and work-related tasks. Since benefit providers give considerable weight to clinician-provided evidence, choose your words carefully, which will also reduce your liability.

When filling out disability insurance forms, discuss questions with patients. One question might ask, “How many pounds can the patient lift?” with these multiple choice answers: a) less than 5, b) 5-10, c) 10-20, d) more than 20. If you answer without asking the patient, your answer could be wrong and this mistake could cause denial of the patients’ claim. If asked, the patient might answer, “It depends on how I feel on any given day, how much medication I have taken and what I did the day before.” Don’t be constrained by the form; reference an attachment with the complete answer.

5. Ask Patients about Their Lives Before and After Disability.

Ask patients how their impairments affects their ability to perform daily living and work-related tasks. Ask about the essential duties required to perform his or her previous job, including, but not limited to, walking, sitting, standing, lifting, driving or traveling, using manual dexterity or fine motor skills, and the ability to follow simple or complex instructions or do multi-tasking. If you classify a patient’s job in one word, such as “sedentary,” benefit providers may not realize the multitude of skills his or her job requires, as well as which skills can no longer be performed or must be modified because of the impairment(s).

Consider the patient’s emotional state. Many disability insurance policies contain a clause excluding disabilities caused by depression, which can present a “Catch-22” situation for patients. It is important to note that the life-changing experience of disability is unique and distinctly different from either depression or grief, although it can include elements of, or be accompanied by, both. Ask patients about their emotional pain, and be open to suggesting secular or spiritual counseling.

Discuss the patient’s financial situation and the cost of the proposed treatment plan. Many patients fear their disability benefits will be denied or cancelled if they refuse tests, treatments, or prescriptions, but worry that they cannot afford them. By discussing the costs and including the patient in the decision-making process, you can help to alleviate their fears.

Ask about the patient’s family situation. How are other family members dealing with the patient’s disability? Is the family on the verge of disintegrating? You may be

able to suggest community resources and counseling services.

6. Explore Adaptive Devices and Technologies

Many adaptive devices and assistive technologies make daily living and work tasks easier or possible. The Abilities Expo (www.abilitiesexpo.com), an annual conference held in various U.S. cities, enables vendors to demonstrate devices and technologies to people with disabilities and clinicians. You can help by increasing your patients’ awareness of these resources.

Conclusion

Today my pain is manageable. I have learned to walk again, albeit with residual pain and balance problems, but, most importantly, I am whole again—mind, body and spirit. If this article asks a lot of already overburdened clinicians, it is because patients with disabilities typically need more help from you than non-disabled patients. It may not be possible for patients dealing with pain and disability to be cured, or returned to their former lives, but it is always possible for them to become whole again. By treating the whole person and addressing disability issues, you can greatly help your patients through this process.



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