

When Things Seem To Go from Bad to Worse...

BY LINDA LANG



This past winter I had to go into the office everyday. No longer did I have the luxury of working at home,

which afforded me the opportunity to work around my pain, lie down when necessary, and work without constant interruptions. The office is very large and I found myself walking a great deal. I came home exhausted and my pain level skyrocketed. Although I enjoyed working outside the house and interacting with others, I had to do something to make it work better

My doctor suggested an intrathecal pump because I was on very high doses of opiates. My digestion was a mess and although my endocrinologist felt the CRPS/RSD was causing the peristaltic

movement to have slowed tremendously, I believed that the opiates had something to do with it. With the pump, I could theoretically take far lower doses of pain medications and receive better results.

After a great deal of thought, I decided to go ahead with the trial and I even became guardedly optimistic that this procedure could make a big difference in my life. Three days after the surgery I did feel better. I wasn't entirely sure if it was the medication or the fact that I

have the wherewithal to have the phone turned on or even to ask the nurse to call my family. My heart rate was dangerously low and I was hooked up to machines. My body began to clench violently and the pain was unbearable. It took several days to calm down.

In the meantime, the doctor had decreased the flow of medication from the pump. She insisted that a bug that I probably had picked up during my first hospital stay triggered the severe

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had been lying in bed and had no responsibilities. The doctor sent me home a day earlier than planned; I felt well enough, so I wasn't concerned that my home health aide would not start until the next day.

That evening I started feeling nauseous and dizzy. I began projectile vomiting and the world was spinning around me. I literally felt like I was going to die. I could no longer think—it never occurred to me to call for help or an ambulance.

The next morning, my health aide got me to the doctor, where I was put on IV and sent by ambulance the two blocks to the hospital.

It was very frightening. No one knew I was in the hospital and I did not

illness; however, I associated the event with the pump itself. Maybe if I hadn't been so worn out physically I would have made a different decision, but as it was, I had to rely on my instinct and my instinct said to stop the trial. So the pump was removed and I went home.

Although it has been almost six months since the incident, I still feel much weaker than I did before. I also find that I have a kind of Post Traumatic Stress Syndrome; I relive the events of that awful 24-hour period as if they were happening all over again.

I had allowed myself to hope that the pump would make my life better. I was becoming depressed and I was feeling very sorry for myself. Although I know research is ongoing, I did not see any-

thing on the immediate horizon that could change my situation. Most people have their own way of extricating themselves from the blues; for me, it is tackling a large project that might make a difference in the lives of others. In the next calamity, I found my cause.

New HMO, New Battles

Since Healthnet bought Guardian, my health insurance company, I have been involved in a weeks-long battle to get OxyContin®, which I use to manage my pain. Healthnet's drug provider has, to date, told me the following regarding my prescription:

1. They never received my prescription.
2. Once they found the prescription, the pharmacist could not read the doctor's handwriting and I should have her call immediately.
3. The doctor called, and after bouncing her around for an hour said they had no idea why the prescription hadn't been filled.
4. When I called again, they told me it would take another week and I would have the meds. I explained at that point I would be out of medication. Healthnet suggested that I get the doctor to give me some. Well, OxyContin is not something that doctors give away.

I looked at the Healthnet site and discovered that OxyContin was on a pre-approval list. I tried to log on to see how to get "pre-approval," but I didn't have a password; Healthnet, would have to send it through the mail. Another week went by before that happened. I sent e-mails explaining the problem and asked for a pre-authorization form. A week later the form arrived without any explanation as to why I was having so much trouble getting my

prescriptions filled, even the ones that did not require pre-authorization. Of course, by this time I had been without OxyContin for weeks and I was in bad shape. It had been over a month since I had ordered the drugs.

Does Pre-Authorization Mean No Authorization?

Meanwhile, I had gone on the Internet to find out more about this pre-authorization process. It seemed that just about any non-generic drug on Healthnet's list required pre-

authorization. So I decided that it was mainly about money; in actuality, pre-authorization clauses in medical insurance provider contracts allow a health insurance company to over-ride the medical decision of the physician.

For example, Pacific Care's (a medical insurance provider) contract section on *Pre-authorization for Selected Drugs* states: "Selected medications require a member to go through a pre-authorization process using criteria based upon FDA indications or medical findings and the current availability of the medication. Pacific Care reviews requests for these selected medications to ensure that they are medically necessary, being prescribed according to treatment guidelines consistent with standard professional practice, and are not otherwise excluded from coverage." The problem is that there is no definition of what is medically necessary.

The American Medical Association (AMA) and the Florida Medical Association composed a letter to Aetna/US Healthcare in 2002, stating, "The definition of 'covered services' and 'medically necessary' give Aetna the final authority to determine whether a service is 'medically necessary' and consequently, on whether it is 'covered,'

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regardless of whether the service would be considered ‘medically necessary’ under accepted standards of medical care. By inextricably intertwining ‘coverage’ decisions and ‘medical necessity’ decisions, Aetna is giving itself the ultimate power to supersede a physician’s determination regarding the necessity of medical service and to deny even clearly needed medical care.” The Employee Retirement

continues to grow, we can expect the government to pass more ERISA bills that limit their availability in order to stem the rapid increase in Medicare spending. It is working. Drug expenditures actually decreased 14.9% this year. Consumer groups feel this may be as much from patients just giving up in their losing battles to gain the drugs they need as much as from the fact that generic drugs save money.

experiences that I am having, we might be able to make a difference.

If you are having problems obtaining your medications, please send a brief email to me with the medication name, manufacturer, insurance company and the problem. I promise to follow through and notify everyone who can make a difference; however, please understand that it may take a while since I am also working full time. This pertains directly to your quality of life, so please take the few necessary moments to respond. At the same time you will help me to feel more optimistic.

Send your stories to me at:
RSDSA, 99 Cherry Street, Mildord, CT 06460
or via e-mail to living.with.rsd@rsds.org

Linda Lang is the author, with Peter Mokovitz, MD, of *Living With RSDS*. She also serves on the board of directors of RSDSA.

Of course, by the time the appeals process is followed, the patient could die.

Income Security Act (ERISA) bill gives them the same degree of power over drug prescriptions.

Some states require pre-authorization when an individual needs to fill more than a certain number of prescriptions per month. This hits hard those of us with severe chronic health problems. The state of North Dakota requires pre-authorization for all brand name drugs. In Maryland, even if a patient is allergic to all generic drug alternatives, the brand name drug will still not be dispensed. The situation must be life-threatening, result in hospitalization or severe disability, or require intervention to prevent further damage or impairment. Of course, by the time the appeals process is followed, the patient could die.

As the cost of prescription drugs con-

Call to Action

Those of us with CRPS/RSD can not remain silent over this issue. When I went to the New York State site for consumer complaints against insurance providers, there were only 67 complaints relating to medication. Are we so beaten down that we cannot speak out for ourselves?

I know that I can’t be the only one having difficulty getting prescriptions filled. To this date I still do not have my OxyContin and I have yet to receive pre-authorization for Actiq®. Despite the fact that pain has been declared the fifth vital sign, insurers have the final power to deny pain medications or procedures that may help limit pain. If I can gather enough credible evidence that others are having the same kinds of



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