

Interrupted Sleep, Pain and Fatigue ... Not What You Think

Baldwin Keenan, Irvine, California (keenanwhelan@cox.net)

In March 2003, when I told my friends in our post-polio support group that I was only getting one to two hours of solid sleep per night, several of them were convinced that I had sleep apnea. They thought the pain in my left leg and hip was greatly aggravated by the lack of REM sleep.

I contracted polio in 1950 at the age of 2. My left lower leg was affected, but after three surgeries I could walk pretty well and even play some sports. I worked in heavy construction and later spent long hours as a union organizer. In 2000, my left knee snapped while refereeing a soccer game. Susan Perlman, MD, at UCLA, diagnosed post-polio syndrome in 2001. I drastically cut my work hours, but I couldn't seem to significantly bring the pain and fatigue under control. At the urging of Stewart Shanfield, MD (an orthopedist who trained under Jacquelin Perry, MD, and is now at St. Jude Medical Center in Fullerton, California), I retired in August 2002.

Retirement brought great relief from both pain and fatigue for about eight months, and I enjoyed retirement activities such as photography and picture framing. But prolonged walking or standing, even using crutches, started a downward cycle. In April 2003, I explained to Dr. Shanfield that the pain at night was keeping me awake. He advised me to reduce my activities and to bring my conditioning back to the immediate post-retirement level. He sent me to physical therapy twice a week to learn pool exercises for my upper body and "good" leg. He also prescribed a power wheelchair to minimize walking and standing.

None of the above measures improved my sleep, so Dr. Shanfield asked my family practitioner to order a sleep study to rule out sleep apnea. I went to St. Joseph's Hospital where the sleep

lab technicians attached many electrode patches all over my body and fitted me for a nasal mask in case continuous positive airway pressure or CPAP, the standard treatment for sleep apnea, was needed. All the connections were hung in a harness attached to a strap over my neck. Wearing all that gear, I had serious doubts that I would be able to sleep. I managed to sleep for five hours and sleep apnea was not detected.



However, the sleep study detected periodic limb movements: 60 per hour. Peter Fotinakes, MD, of St. Joseph's, evaluated my sleep study and recommended that I consult a neurologist to consider the use of a medication for Parkinson's disease to control the limb movement. The periodic limb movements had prevented relaxation of the muscles in my left leg and hip and, consequently, had exacerbated the pain at night. Stephen Waldman, MD, at St. Jude's, prescribed Mirapex (1 mg) to control the limb movements and Zanaflex (2 mg) to calm the muscle spasms.

The medications brought 4 to 5 hours of solid sleep before pain in my leg and hip would wake me up. I was happy to be making so much progress, but I told Dr. Shanfield that I still didn't feel like I was getting enough sleep. He agreed and ordered a TENS (transcutaneous electrical nerve stimulation) unit. Now when I wake up with pain in the middle of the night, I attach its electrodes to my left hip and knee. I set the stimulus to a comfortable level and usually I am back to sleep in ten

minutes. The stimulus of the TENS unit blocks the “pain message” from getting to the brain.

The result is that I now sleep 7½ to 8 hours a night. My energy level has improved, and I no longer feel fog-headed all day. I’ve noticed that I’m getting much more benefit from my pool exercises. The night pain hasn’t gone away; the TENS unit just lets me sleep through it. To minimize the onset of more pain, I use the power wheelchair often to reduce standing and walking.

The treatment plan I follow works for me, and the periodic limb movements may have nothing to do with the late effects of polio. I caution polio survivors reading this that my condition is particular to me, but we need to share our experiences so others can find different ways to deal with pain and fatigue. What is important in my story is that Dr. Shanfield followed a

Letter to the Editor

“I just received my copy of *Post-Polio Health* and I’d like to add my comments about ventilator users who need a colonoscopy. If they cannot lie down without the ventilator, then the procedure will be difficult, possibly risky and will generate anxiety. My approach is to use the ventilator during and after the procedure so the person is less anxious so less sedating medication is needed, speeding the procedure. Arrangements have to be made in advance with the institution (I agree that the procedure must be in-hospital.), and it is preferable to have the patient’s physician make all contacts, set up the ventilator with respiratory therapy and monitor the patient post procedure.

“The bigger problem is when an upper endoscopy is needed and the person uses a nasal or face mask. In that case, I use negative pressure ventilation pre-procedure, so it is not being tried for the first time during the procedure. I also use ventilators for CVT scans and MRIs in the same way, with provisions for longer tubing for those procedures.”

Norma M.T. Braun, MD, St. Luke’s-Roosevelt Hospitals
New York, New York

scientific method to treat my pain. He thought my problem might be breathing-related sleep apnea, but the data of the sleep study did not support his original conjecture and the results guided him in successfully resolving my pain and fatigue. ●

New Books

Paralysis Resource Guide (2003) is a colorful, comprehensive, 310-page, spiral-bound resource by Sam Maddox. Contact the Christopher and Dana Reeve Paralysis Resource Center (www.paralysis.org, 800-539-7309 toll-free).

I’d offer you my seat ... but it’s taken, is a soft-cover 72-page book by Ralph M. Scott of Alabama, that candidly shares his life story with numerous anecdotes that exhibit his observational abilities, his sense of humor and his faith. Send \$4.00 to John N. Clayton, Does God Exist?, 1555 Echo Valley Drive, Niles, Michigan 49120.

The following books are available from Barnes and Noble and Borders, or on www.Amazon.com.

Broken Yesterdays, is a memoir by the late Joseph William Meagher, focusing mainly on the years he spent in the late 1920s and early 1930s at the St. Charles Hospital School in Port Jefferson, Long Island, New York.

Voices from the Edge: Narratives about the Americans with Disabilities Act, is compelling fiction and nonfiction by the disabled. Edited by Ruth O’Brien, Professor, John Jay College of Criminal Justice, and Chair of Political Science MA/PhD Program, Graduate Center, City University of New York.