

TOPIC OF THE MONTH FOR FEBRUARY 2008
(REVISED FEBRUARY 2010)

UNDERSTANDING HOW RHEUMATOID ARTHRITIS AFFECTS COACH
WHITE

Rheumatoid arthritis is an auto-immune disease, inherited at birth and usually undetected until some event serves as catalyst to amplify its activity level. Related to lupus and sickle cell anemia, it is a blood disease (not a bone or joint-specific disorder) that makes the body fight itself. There is no cure; the medications advertised are chemotherapy options to slow the progression of deterioration and come with serious side effects. Rheumatoid is systemic (affects the total body), parallel (attacks matching body areas), and non-environmental (shows no variation because of rainy or cold weather). It is called an "arthritis" because the bones ultimately pay the greatest price.

The disease attacks the soft tissue surrounding joints, causing internal inflammation and swelling. For most people, this also means high concentrations of pain and stiffness in the affected joints. Like white blood cells congregate at a cut to fight infection, rheumatoid enzymes daily seek areas of overuse or discomfort. Their mission is to cut that part off from the rest of the body. As inflammation increases, the sedimentation rate within the blood cells rises. A high sed rate means that the "good stuff" in red blood cells settles quickly to the bottom of the cell, preventing healthy blood from carrying enough oxygen to the body or transporting waste materials to the elimination system. Managing this inflammation requires energy conservation (rest), movement therapy (exercise, moist heat, topical creams), and frequent blood tests. There are more than one hundred variations of the disease, and it affects everyone differently.

Sudden onset of rheumatoid arthritis happened for me on October 19, 1999. When I awoke, my legs would not work. I could haul myself to a standing position, but the muscles would not move the bones. There was no overwhelming pain, and my legs felt normal ---- no lack of sensation, no numbness, no coldness. To move, I had to lift with my arms or swivel my heels a few inches at a time. Getting from the bedroom to the bathroom took five minutes. The effort left me exhausted.

Looking back, I know now that I had been displaying symptoms of rheumatoid arthritis for many years. Because I was physically strong and drove myself to excel, I ignored the fatigue and the

extended times for completing tasks. From previous experience, people assumed I could always carry a large share of the workload at a high rate of productivity. The hardest adjustment for me has been forcing myself not to fight the disease. That means I must rest frequently, stop immediately when symptoms arise, and say "no" without giving explanations. My habit of forcing my body to do what my brain wanted was literally killing me.

Describing rheumatoid to others without the disease is challenging. It has no "off" switch. Once the rheumatoid enzymes are in "high gear" to protect the body, that response mechanism lasts for days or weeks after the cause or threat has been removed. When a radiator has a hole, filling it with water is a temporary solution; it will soon overheat again. I can rest for days after a flare up, leave home feeling fine, and reach total exhaustion within an hour. For me, loss of movement in arms or legs is one recurring symptom. If I throw footballs for hours, two or three days later my right arm will hang useless. If I type for hours, I will soon lose function in my right wrist. When I sit in a restricted position for several hours, my left knee (already non-bendable for more than two years) will swell internally. Anticipating these cause-and-effect patterns, I can minimize response by limiting the offensive actions. Below are some "rules" I try not to break, despite their impact on others.

- I do not keyboard, except to prepare business documents and hand-outs. I do not access the internet. I will never be available by e-mail.
- When I do "office" work, I sit on the floor with both legs flat and the work on the floor between my legs.
- Whatever I am reading must lie on a flat surface. To keep a book open, I use a flat weight.
- Anything I need to carry goes on wheels. Books and papers travel in square, wheeled file cases. Grocery bags, trash bags, laundry, luggage, clothes on hangers, and all other objects ride on the seat and handles of my rollator (large walker on wheels). Mail, keys, and valuables go in the basket under the seat.
- I do not do stairs or curbs. I must locate elevators or ramps. I avoid uneven pavement and artificial turf.
- I do not sit on low or soft furniture, chairs with restrictive arms, molded chairs, seats that are low in back and high in front, or other surfaces from which I would have trouble standing. Because the left leg does not bend, I stretch it out on a second chair. I take my rollator to stores, restaurants, and private homes.
- I use only handicapped bathroom facilities, with a tall toilet and hand rails. This affects where I sleep.

- Standing still in one place is much more damaging than walking. I do not wait in lines, stay behind a podium when speaking, or stand at spectator events.
- I use only "fuzzy" pens for writing.
- Driving long distances is possible if all limbs are relaxed. I plan travel to avoid inclement weather and peak traffic periods, often driving all night. I rely on the use of cruise control, and I get off the highway when I encounter traffic jams. I avoid passenger seats.
- Clothing must fit without binding or restrictions.
- Wherever I go, I take leverage aids and pillows.

Since October of 1999, I have lost the ability to walk five other times. These episodes follow prolonged periods of excessive physical overuse. Like the first episode, these symptoms usually subside after one week. For the past three years, mobility has been poor in September and October. In early September 2007, my right leg would not stay upright in a car seat, much less control the automobile pedals. To eliminate this rheumatoid response, I gave up driving for two months. I went out once each week for mail and groceries. Wishing not to get this far behind again, I will no longer assume responsibility for summer camp equipment, and I will cut back on campus visits in July and August.

In April of 2000, the rheumatologist "inventoried" my body by taking detailed X-rays of all joints. I was shocked when she told me the bone structure in my wrists had disintegrated and could no longer protect the soft tissue connections to my hands. I had never had pain or stiffness in my wrists. During 1999, my hands had become claw-like and very painful, and I had lost the ability to move my fingers independently. I could not grip pens or silverware, push thumb against index finger to pick up items, or spread either hand out on a flat surface. To keep my fingers from curling involuntarily into rigid balls, I had been sleeping with my hands tucked into the waistband of my pajamas, palms flat across my stomach. Over time I forced my hands to return almost to normal by wearing wrist braces and special gloves, applying moist heat several times each day, and exercising my fingers. My luggage and my vehicles are full of "toys" that I use daily to minimize stress on my wrists and maximize utility of my hands. I will never again have hand strength. I have developed strategies to prevent my wrists from tightening and closing down my hands. I keyboard as little as possible and avoid tasks which require the wrists to twist or sustain pressure. I "hug" packages to me, shunning plastic bags. Assuming my fingers could work the keys, I can never again play a musical instrument, even with a neck strap. I open doors, turn faucets, and drive left-handed. The following simple tasks still present serious challenges.

- Combing hair requires gripping with a twisted wrist while pulling, plus picking up and opening bobby pins.
- Depressing the buttons on aerosol cans often takes more force than I can deliver with one finger or hand. I have mastered "pop top" cans but not pull rings on juice containers. Large round lids on large round containers (glass jars, laundry detergent) defy even the best mobility aids.
- Handling laundry requires six to ten "grips" on every article, plus the added water weight.
- Making change, turning pages, filing papers, and folding clothes take an inordinate amount of time.
- Unless I can pull myself upright from a grab bar or door frame or someone's hand, every time I arise from the ground or a chair I am resting my weight on bent wrists. Using the rolator to enhance leg mobility also requires gripping and pushing down on bent wrists. (Having the big "Gear" table at practices gives me a platform for sitting, speaking, and leading stretches.)

From the beginning, I chose not to take the chemotherapy drugs you see advertised on television. There is no cure for rheumatoid arthritis. What the drugs promise is retarding the speed of deterioration for six or seven years. The damage was already done when I was diagnosed. Most of these drugs require injection at a doctor's office or refrigeration if self-injected. They cost \$1400-\$1600 every two weeks. My itinerant lifestyle would not match such chemical dependence. I manage the symptoms of the disease. Through exercise, I retained flexibility and overcame the long list of tasks I could not perform in 1999. The knees and the wrists can never improve, but I remain functional without drugs. For the most part, I am also pain free.

The most recent challenge was the development of pulmonary embolisms (blood clots in the lungs). In May of 2009, I was hospitalized because my pulmonary artery (vessel that takes blood to the lungs to pick up oxygen) was 90% blocked by clots and both lungs were covered with clots. I had experienced months of lung congestion and fatigue. Because my lungs were unhealthy, my rheumatoid enzymes had found a way to eliminate them! I had no idea how limited my supply of oxygen really was, and I was still running clinics. I had to take blood thinners so that the clots would dissolve. A CAT scan in December 2009 verified that the clots were gone. I will never again take breathing for granted.