Cancer Survivorship

Lymphoma Survivor Turns Entrepreneur

Cari Ugent is a good example of the old adage, "When life hands you lemons, make lemonade." Diagnosed with non-Hodgkin's lymphoma at the age of 21 just before her senior year in college, she was in and out of the hospital for 9 years before receiving an allogenic stem cell transplant at the age of 30. "I celebrated my 30th birthday in the hospital," she recalls. During the time between relapses, Cari started a career as a journalist and was awaiting publication of her third book when she received the transplant.

Cari received her transplant at Northwestern Memorial Hospital in Chicago. Her doctors and nurses encouraged her to take daily laps around the hospital, which helped her avoid complications like blood clots and pneumonia that often result from prolonged bed rest. But she found her mobility and independence were limited by the cumbersome intravenous (IV) pole that was her constant companion. "It is there from the moment you step in to the moment you leave," and she found it "was counterproductive to many of the things that I was being encouraged to do that I knew were beneficial for my health."

During her long weeks of recovery, Cari talked to her doctors and nurses about the drawbacks of the standard IV pole, and they shared ideas about how it could be improved for greater patient safety and convenience. "It became a nice pastime to brainstorm how the pole should look," she says, and it gave her a sense of purpose. "The process kept me going."

After her recovery, Cari worked with industrial designers to develop a safer, more convenient IV pole, known as Safepole. The new pole has features that make it attractive to both patients and caregivers, such as a tip-resistant design, an integrated power strip, and a covered dome to prevent tripping and tangling of tubes. Because the pole's design allows patients greater mobility and independence, nurses have more time to attend to other matters. "What is good for the patient, is good for the nurse," Cari says.

Grateful to those who helped her during her illness and recovery and wanting to give back to patients, doctors and nurses, and charities, Cari now shares her story with other survivors and works with organizations such as the Lymphoma Research Foundation of America and the Bone Marrow Transplant Information Network (www. bmtinfonet.org). Safepole is sold directly to hospitals, but individuals can also purchase a pole to be donated to a hospital or clinic, customized with a plaque engraved with the donor's name and inspirational messages or words of wisdom if they wish.

Cari is a healthy cancer survivor and a successful entrepreneur. One key to her success is her own positive attitude. Another is open communication with her doctors, nurses, and other caregivers. They listened to her complaints about the standard IV pole and worked with her to design an improved model. Cari's story shows how important it is for patients to take a proactive role in

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get people to stop thinking that way," Cramer said, because early intervention is key to preserving function.

Primary tumors account for 1% to 3% of cases, with the rest from metastatic disease. Metastases seem to show a preference for the spinal level affected depending on the tissue of origin: cervical for breast; thoracic for breast, lung, prostate, and renal tumors; and lumbosacral for gastrointestinal tumors. Cancer treatments themselves can lead to lytic lesions of vertebrae.

Spinal cord compression presence and extent is diagnosed by spinal radiographs, computed tomograph, magnetic resonance image, bone scan, and myelograms. The strongest indicator for a good prognosis is detection and intervention within 24 hours. Even then, most patients do not regain lost function.

Up to 95% of patients first present with pain, ranging from dull or aching to severe, burning, or shooting. Most have central back pain, which may or may not radiate. Lying down provides no relief. Other early signs and symptoms are weakness; affecting mobility and coordination; and sensory loss to pain, temperature, and light touch. Later, muscle atrophy, paralysis, and bowel and bladder incontinence may ensue. Spinal shock, an extreme outcome with lesions at T6 and above, manifests as autonomic dysreflexia with hypertension, heart rate changes, and respiratory distress.

Caregivers have to decide between palliative care and treatment. Depending on the cause of the spinal cord compression, interventions may include radiation, surgery, and medication, such as high-dose steroids, analgesics, low-molecular-weight heparin, chemotherapy, bisphosphonates, and a bowel regimen. Whereas laminectomy or spinal fusion are not generally used to treat vertebral compression fractures, "kyphoplasty is a big player," Cramer said. Patients "can have immediate relief" of pain. It involves inserting a balloon into one or more collapsed vertebrae and expanding the balloon with a quick-hardening cement to approximate the normal anatomy of the vertebra.

Patients should be immobilized and log-rolled. Monitoring and assessment should focus on sensory (pinprick) and motor function (ataxia), pain, airway maintenance, good circulation to avoid deep-vein thrombosis, and bowel and bladder function. Cramer recommends maintaining urine pH < 7.0 and voiding every 2 to 3 hours or catheterizing as needed. Spinal rehabilitation may be appropriate for some patients.

"Any patient with cancer who complains of new back pain, suspect something is going on," Cramer warned, since early intervention can provide "time with quality" of life.

their own care and for their healthcare providers to listen to their ideas and treat them as partners in their treatment. Commenting on Cari's experience, Karen Haller, vice president, Nursing and Patient Care Services, Johns Hopkins Hospital and associate dean for clinical affairs at the School of Nursing, recommended considering including patient representatives on hospital committees. She wrote, "Patients, especially those who stay in hospitals for long periods, are motivated to solve safety problems. Whenever possible, we should harness their wisdom" (*Johns Hopkins Magazine*. Summer 2006).

For more information on Safepole, visit their Web site www.safepole.net.