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Far From Home

BY SUSAN KREIMER

Patients who travel for treatment now have more places to stay.

When Mikio Yamashiro* needed a stem cell transplant, he wanted to be at the optimal place. “For any given condition, there is a best hospital. I believe very strongly that it’s worthwhile to find that hospital and to go there,” says Yamashiro, 38, whose acute lymphoblastic leukemia, diagnosed in January 2007, is now in remission.

Yamashiro’s research to locate the leader in stem cell transplantation led him to the Fred Hutchinson Cancer Research Center in Seattle. So in June 2007 he left his home in Princeton, New Jersey, and flew to Seattle for high-dose chemotherapy and radiation (known as conditioning treatment) before a stem cell transplant. His wife, 3-year-old daughter, and mother-in-law joined him on the four-month journey.

While excellent care has become available in a growing number of local cancer centers, traveling for treatment may be appropriate in some situations. Patients may opt to travel to a particular center that specializes in their tumor type, to participate in clinical trials granting access to the latest investigational drugs, or to receive a needed procedure that requires a trained specialist.

For cancer patients who seek care in other regions or states, the added stresses of leaving home for treatment are being addressed by hospitals, nonprofits, social workers, and volunteers who provide assistance in areas ranging from emotional support and financial resources to finding affordable housing, which can be the greatest challenge.

In the typical household, if one or both spouses must stop working (most patients need a caregiver to travel along for treatment), income declines dramatically or becomes nonexistent, yet home expenses don’t grind to a halt.

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financial assistance they might qualify for. ”

—Debbie Fraley

“On top of that, there is the cost of living in a new place,” says Debbie Fraley, housing coordinator at the Seattle Cancer Care Alliance, which is linked with Fred Hutchinson. “Our mission as staff is to try to help patients piece together any and all financial assistance they might qualify for.” Fraley says rent, transportation, food, deductibles, copayments, and other uncovered medical bills “can be daunting and devastating.”

Traveling for treatment posed financial challenges for Yamashiro, who had to cover living expenses in two locations—a New Jersey condo and a temporary apartment in Seattle—on disability payments, which were 60 percent of his prior earnings. Luckily, most of their lodging costs were covered by the hospital and the Leukemia & Lymphoma Society through the nonprofit’s Patient Financial Aid program.

It is becoming more common for patients to travel to other states, says Lakshmi Naik, clinical social work supervisor at M.D. Anderson Cancer Center in Houston. “When they are faced with the prospect of a life-threatening disease such as cancer, these patients now get into a survival mode,” she says. “Scared and desperate, they are willing to go to any lengths, even beg or borrow if needed, to find the best treatment or a cure for their disease.”

Affordable Housing

Some cancer centers may have designated “hospitality houses” that offer discounted or free housing.

M.D. Anderson’s department of social work has negotiated rates with nearby lodging facilities, many of which offer a free shuttle to the hospital. For instance, a basic room renting for \$70 per night may cost \$50 plus tax with the discount. Because resources are very limited, M.D. Anderson patients must meet eligibility criteria based on disease, income, region of residence, and other factors.

Limited resources may pose hardships for patients being treated at the Seattle Cancer Care Alliance, where there can be a waiting list for the Pete Gross House, a 70-unit fully furnished apartment building. Monthly rates for the Pete Gross House start at \$43 a night, and treatment can necessitate stays of several weeks to several months.

To address the growing demand, the Pete Gross House will soon be joined by the SCCA House, an 80-room facility expected to open in fall 2009 that is designed to target the needs of those with shorter stays averaging about six weeks. The Alliance offers other housing options to patients, including a nearby residential building with furnished apartments where Yamashiro and his family stayed.

Among the few free places to stay across the nation are the 26 Hope Lodges that the American Cancer Society operates for patients and caregivers traveling for

treatment. Last November, its newest and most expansive Hope Lodge opened near Penn Station in New York City.

In addition to 60 guest suites on 11 floors, the 77,000-square-foot building features communal kitchens, activity rooms, and free laundry facilities. Support services, such as special shared meals and yoga classes, are offered at no cost.

The Manhattan facility functions at more than 90 percent capacity, says Lindsay Edgar, manager of guest and volunteer programs. The ACS works with medical centers to identify nonlocal patients with the greatest need on a first-come, first-served basis. To be considered, prospective guests must submit a special form signed by their social worker or doctor.

When the lodge is full, staff and volunteers refer patients to other options in Manhattan such as Miracle House. Established in 1990 to address the AIDS crisis, Miracle House now accepts patients with cancer and other critical conditions for its five, three-bedroom apartments in a modern high rise that has a sports club and Olympic-size indoor pool.

Each unit is equipped with a kitchen, dining room, living room, free high-speed Internet access, television, air conditioning, and 24-hour security. More than 150 volunteers assist with apartment renovations, food drives, and fundraising events.

For \$50 per night including tax, the patient and caregiver get one bedroom and share common areas in the apartment with other clients. (A second bedroom costs an additional \$50 per night.) Patients are required to have a caregiver at least 18 years of age. Miracle House covers breakfast Monday through Friday, dinner Tuesday through Thursday, and brunch on Saturday at a nearby diner. Meals for Miracle House residents are at set times, encouraging families to socialize.

Support becomes more critical for patients spending weeks or months away from familiar turf. Cheerful staff and volunteers at Miracle House go a long way to make their guests feel comfortable and upbeat.

“I want them to think about coming to New York for the treatment—that’s the main reason—but they also need to go and have fun,” says Majo Prazenec, client services coordinator, who suggests activities for residents. Miracle House has been able to obtain free passes to venues such as the Guggenheim Museum and the Museum of Modern Art, as well as discounts to Broadway shows.



Susie Wade, with her daughter Deloris Wade Ball, at Miracle House in New York City. Photo by Ryan Ashby.

Back and Forth

Susie Wade, 75, of Lancaster, South Carolina, was diagnosed with mesothelioma in July 2006, a decade after retiring from 26 years at a textile plant that manufactured bed linens. Wade began treatment near her home in the Atlanta area, where three of four daughters live. Doctors originally estimated she would live “six weeks to six months.”

The search for a second opinion led Wade’s youngest daughter, Teresa Wade, to an oncologist in New York City. The prognosis—and Susie Wade’s spirits—brightened in March 2007 when she consulted with the oncologist and decided to become his patient. Teresa has covered nearly all the travel and housing costs.

The path to extending her life hasn’t been easy. She endured 24 rounds of chemotherapy, three surgeries, and one radiation treatment, as well as various scans, fluid taps, blood drawings, and medications too numerous to count. Sometimes it’s hard to tell what exhausts her more—the treatment or flying back and forth, she says.

During each visit, one of Wade’s four daughters stays with her at Miracle House. “The vital care she receives from her doctor and the home-away-from-home atmosphere that Miracle House provides are the reasons we keep returning to NYC,” says daughter Deloris Wade Ball of Decatur, Georgia, her caregiver on a recent trip.

Helen Domenico, 76, of Cheyenne, Wyoming, received chemotherapy treatments near her home, but her oncologist conferred with her second oncologist at M.D. Anderson, where she underwent surgery for peritoneal cancer in 2001. She flies back to Houston for checkups, and in May and June, she returned for six weeks of radiation after a recurrence because she preferred to continue her care at M.D. Anderson.

Employees at Jesse H. Jones Rotary House International—connected to M.D. Anderson via an enclosed skywalk—welcomed her back with a smile. Domenico’s two-bedroom suite at the Marriott-operated, M.D. Anderson-owned full-service hotel, which caters exclusively to M.D. Anderson patients and their families, cost her \$225 per night not counting tax (room rates vary from \$98 to \$315 per night).

“I feel it’s worth it, and my family feels that it’s worth it,” says Domenico, a widow with four stepchildren and one biological child. “I get excellent care here. They know the latest in cancer care. I’m able to take advantage of anything new that’s coming out.”

As for Mikio Yamashiro*, he returned home after the stem cell transplant and is having his health monitored by a local physician. He and his wife, Kazuko, believe the trip to a leading transplant hospital was well worth it.

(*notes that name has been changed to protect interview subject's privacy)