



Surviving Cancer with Care

City of Hope patients discover ongoing healing with a human touch.

» CANCER TREATMENT—THE THING THAT CAN SAVE YOUR LIFE—OFTEN FEELS LIKE DEATH ITSELF. » CANCER SURVIVORS HAVE ENDURED CHEMOTHERAPY, PAINFUL TESTS AND SOMETIME HARSH MEDICATIONS. BUT THEY ALSO HAVE DEALT WITH FAMILY STRAINS, DISRUPTIVE JOB SITUATIONS, SPIRITUAL CRISES AND EVERYDAY EMOTIONAL STRESS.

Understanding that patients in the 21st century need more than just state-of-the-art physical care, medical facilities across the country have been raising the banner of "supportive care," offering patients a wide variety of services, referrals and information along with an attitude that a patient is more than a series of blood panels and X-rays.

"Supportive care' has been ebbing and flowing as a movement, but the City of Hope has taken to it like a flame," says Natalie Schnaitmann, director of operations for the new Sheri & Les Biller Patient and Family Resource Center, a key ingredient in the newly designated Supportive Care Management division at the Duarte campus.

One of the few cancer centers nationwide with a dedicated clinical and research approach to supportive care, City of Hope has been known for its day-to-day humanistic touch and follow-up programs that include the Center for Cancer Survivorship, which began in 2003.

Now, opening mid-summer, the patient and family resource center will be a "one-stop empowerment zone," says Schnaitmann, describing the centrally located space where all new

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patients will go right after checking in.

Newcomers will fill out a questionnaire, deemed "How Can We Help You and Your Family?" so medical teams can be on top of a patient's unique concerns, such as insurance questions, transportation problems and religious needs. This profile will go directly into the medical records, says Schnaitmann, so caregivers will see the patient as a human being with a history, abilities and needs. On the backend, data collected from the questionnaires will be studied to educate the rest of the world about cancer patients in general, he notes.

At the resource center, patients will find educational materials, workshop information, support group listings, music therapy schedules, private consultation rooms and computer-guided research. Services can be practical (How do I find an elevator?) to more specific (What is going to happen to my job while I'm in here?).

While the new center will make it easier for new patients and medical staff to work together, current survivors have already experienced many supportive care aspects at City of Hope. Aid from social workers, psychologists, psychiatrists, chaplains, nutritionists, rehab specialists and counselors has always been an active component—but now all will be under one official umbrella division, says Schnaitmann.

Still, many former patients say the supportive care they experienced at City of Hope was first and foremost the professional and personal attitude they found from simple staff interaction.

"I remember watching how they handled the woman next to me who was dying," says Carol Ramnarine from Santa Clarita who was treated for multiple myeloma two-and-a-half years ago. "She was sharing a room, but they didn't move her, they moved others around her so she'd have a private environment. They were bright, attentive and really provided her and her family such dignity."

As the first multiple myeloma patient in the world to undergo total marrow irradiation, Ramnarine remembers having to lie still under a humming and buzzing machine with only her thoughts to keep her company.

"It was the last 27 minutes I found the most difficult," she wrote about the experiences later. "The staff kept me motivated and resolved. I remember even singing to them one of Peter, Paul and Mary's folk songs, off key and with a dry throat. They were terrific, tolerating almost anything from me to complete our mission."

During her treatment, Ramnarine wanted to walk outside in the Japanese Gardens, but it was closed. "A volunteer made arrangements to open the gardens and escort us there," she says. "How cool is that?"

Indeed, Gustavo Perez of Mission Viejo describes himself as in "full panic mode" when he arrived at City of Hope with a leukemia diagnosis four-and-a-half years ago. A firefighter for 19 years, Perez "stumbled into discovering" his disease during a routine physical while applying for a new hazardous materials position.

What helped Perez through the year-long ordeal of medication and waiting for a bone marrow donor was knowing that "everything there was in one place, one facility," he says. "I didn't have the stress and anxiety of having to go somewhere else for a test or schedule something."

Because he was a work comp patient (he most likely contracted the disease through his line of work), Perez was pleased that it was a "non-issue to the folks at City of Hope. Others would have balked at taking me in."

"But more importantly," he continues, "their understanding of what I was going through was so great. They have a complete understanding of everything you might need and want."

Isolated for almost a month after the bone marrow transplant, Perez says he had roundthe-clock care and was monitored continually.

"They kept checking my vitals, sleep patterns, comfort levels, you name it," he says.

Five months after he was discharged, Perez, an avid surfer, explained to his doctor during a follow-up visit his need to get back on his board. "He realized this was important to me, so he told me to give it a shot," says Perez. "So I did and it did wonders for my spirits."

Altogether, Perez says, "there is an air to the whole place that while there are no guarantees, [they] will use every resource available to help you get rid of [the disease]. And [they] will make sure you stay sane through it and after it."

Following the Patient

Keeping an eye on survivors is the goal of the Center for Cancer Survivorship, which tracks the effects of treatment on the thousands of young cancer patients from the early 1970s to today.

The center helps survivors identify possible complications, which often arise from previous cancer treatments (more than 80 percent of former child patients develop complications, frequently long-term), as well as provides advice on improving their daily lives.

Overall, the news for cancer survivors looks promising, says Smita Bhatia, the center's medical director. "The five-year survival rate of people diagnosed with cancer is 66 percent, up from about 51 percent in the late 1970s."

Still, defeating cancer, she says, means survivors can potentially face other medical problems, including osteoporosis, developmental issues, cardiovascular problems and, of all things, other cancers.

The program invites survivors to come in annually for an array of personalized tests (based on their specific cancer and treatment) and general discussions on how life as a survivor is going for them. How is your diet? Any problems with moodiness? Are you getting regular physicals? In the end, each survivor receives an individualized booklet that outlines personalized heathcare recommendations and where to find outside help.

"I was impressed with my very own notebook," says Toni Mynes, a 42-year-old cancer survivor from Brea who came for treatment in 1979 for Hodgkin's disease.

Making the journey for the clinical tests was emotionally hard for Mynes, who hadn't been back to the facility since she was young. She recalls sitting by the large fountain at the entrance, working up her courage.

"I had to remind myself that I'm not a patient here anymore," she says "Driving out there was really different because this time I was in the driver's seat and it wasn't my mom."

The day-long endeavor, however, became for Mynes a "fun experience that I appreciated very much," she says. She ended up joking with the EKG technician and sharing an emotional moment with her phlebotomist.

"Even though the people were different, they were the same," Mynes says. "They treated you like you were the center of attention. I meant something."

"Other large cancer centers offer some kind of follow-up care, but we take it to a new level by incorporating across disciplines," says Wendy Landier, clinical director. "We want to champion their rights to know what specifically happened back then, what could happen in the future and what they can do about it."

For Mynes and family, City of Hope certainly lived up to its name, despite the fear, pain and anger that Mynes recalls of her youth.

"I don't ever want to relive those days, but I am most grateful that I'm cured," she says. "When I walked in there when I was 13 and 14 years old, I was the only person who mattered to them. I was the center. They understood everything that was going on with me inside and that, with my faith and family, gave me hope."

WORKING FOR WELLNESS

From beakers and test tubes to epigenetics and robotics, City of Hope's Beckman Research Institute celebrates 25 years.

Many people think City of Hope is only a cancer treatment institution, but that's only one slice of the pie.

Look at the buildings on the 112-acre Duarte campus and you'll find a remarkably equal distribution: One-third is for patient treatment, another third accommodates the accredited City of Hope Graduate School of Biological Sciences and the last third houses the Beckman Research Institute, one of the country's top biomedical research facilities.

Founded in 1951, the research facility was endowed in 1983 by Arnold and Mabel Beckman, becoming the first of only five Beckman institutes in the United States. Throughout its history, the institute has a long success list of medications and procedures that target not only cancer but also diabetes and HIV/AIDS.

The institute was responsible for synthetic insulin and A1C monitoring for diabetics in addition to the development of such well-established cancer drugs as Herceptin, Avastin and Rituxan.

The institute is a researcher's dream model: the ability to experiment, conduct clinical trials and share information with colleagues—all without academic restraints.

Also, having lab facilities so physically close to actual patients creates a dynamic of researchers working toward a specific end in mind—discovering practical applications for people suffering from discovers

"Bone marrow transplants are our specialty," says Arthur Riggs, who directed the institute from 2006–2007 and is still active in research today.

Right now, researchers are working on improvements to the bone
marrow transplant process that
would mean less radiation exposure
for patients, says Riggs. Research is
being done on procedures involving
antibodies—not chemotherapy—
that would knock out the immune
system or deliver radiation directly
to the bone marrow.

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"Another elegant program" says Riggs "is one that reeducates a person's white blood cells to attack brain tumors." Tumors have a way of masking their existence to the immune system, he explains, adding that this training, in essence, would give white blood cells "night vision goggles."

Advances in surgery also can be found at the institute, one of the first to use robots for operations. More precise than the human hand, robots are used almost routinely with prostate cancer patients today, says Riggs. "Prostate cancer patients have recovered dramatically better with robotic surgery," he adds.

Finally, the institute has invested much time and energy exploring the nature of epigenetics, a branch of biology that investigates how changes in the way DNA strands are wrapped and coiled affect whether genes are silent or active.

"Chromosomes can be decorated with this additional information not found in genes," explains Riggs, who was part of the City of Hope team in 1975 and continues to study how DNA packaging can be associated with cancer, developmental abnormalities, diabetes and aging.

Today, clinical trials with epigenetics are taking place with leukemia and lymphoma patients, and Riggs says the benefits of these trials go beyond a potential patent for City of Hope.

"We have very strong statistics that show that people who participate have better outcomes, even those in the control group," he says. "I think it's because of the care they are given by their doctors. These patients are helping us learn how to do things better for future generations."

