

Cancer CAREpoint is all about non-medical care for cancer patients

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When Bernice and George Bajada attended a fundraiser in July 2013 for the newly formed Cancer CAREpoint nonprofit, it was to support a good cause. It was an enjoyable afternoon party in the elegant Atherton gardens of high tech notables Carol Bartz and Bill Marr, and the Bajadas were pleased to be there and to donate.

"We went to the benefit in Atherton, never thinking we would be cancer patients," says Bernice.

It wasn't long after that, George says, when his arm started getting numb and tingling, and he thought he had a pinched nerve.

In fact, he says, "I had a tumor the size of a golf ball-and-a-half wrapping itself around my spinal cord. I had a 7½-hour operation, and I'm lucky I have no paralysis."

Radiation followed and chemotherapy was considered, but George's blood count was good enough to skip it.

"There were no signs of cancer, and everybody was so excited," he recalls. "They had one more test, and when they got my bone marrow they found I had multiple myeloma cancer."

The Almaden couple turned to Cancer CAREpoint, which Bernice says, has helped them physically, spiritually, psychologically and emotionally.

"There has been tremendous support by all the caregivers there. There's a great deal of hope that one receives in going through this process. It's not as scary and negative as it could be," she says. "It's an amazing, compassionate, caring program which anyone going on this journey could benefit from."

Cancer CAREpoint--with CARE standing for counseling, assistance, resources and education--was formed in 2010 by local community leaders Gay Crawford, Bill Piche and Dave Henderson. They recognized there was a need for non-medical support services for cancer patients that was not being met in Silicon Valley.

Prior to opening, they did extensive research and held many, many focus groups with current and past cancer patients, caregivers and others working in cancer-related areas.

Jan Willoughby, a Cancer CAREpoint board member, recalls, when Crawford and Piche called to see if she would be interested in joining this nonprofit, she had "no choice. I had the understanding, belief and knowledge that this was a need unmet in our community."

Willoughby has been touched by cancer many times. She dealt with it when it hit her husband twice, her mother, sister-in-law, father-in-law, stepfather and several close friends.

Then, she says, "When my daughter was diagnosed, I stopped my life and moved in with her."

Willoughby's daughter lives near Sacramento and has two boys who were 2 and 4 at the time.

At the end of May 2014, Willoughby says, her daughter will reach her five-year anniversary being cancer free.

"All these experiences gave me a background and understanding of how you can complement medicine with nutrition, exercise, massage--whatever it is that can make a person feel better," says the Los Gatos resident.

Willoughby served on the Cancer CAREpoint steering committee that hosted focus groups of more than 200 current and past cancer patients, caregivers and others involved in work related to cancer.

The groups helped determine the services Cancer CAREpoint would provide and its mission statement: "Cancer CAREpoint is dedicated to transforming support for cancer patients, families and caregivers in Silicon Valley through personalized one-on-one counseling, assistance, resources and education."

All services are free, and programs include nutrition seminars, massage therapy, guided imagery, yoga for cancer survivorship, healing partners for breast cancer, networking groups, stress reduction classes and more.

Allison Jones Thompson, who started her term as president of the Cancer CAREpoint board in January, says, "It's hard to find someone who has not been touched by cancer."

The Los Gatos resident lost her father to lung cancer when she was in high school, which resulted in her choosing a career in the health field, eventually working with the National Brain Tumor Foundation.

"I've referred people to Cancer CAREpoint and I've seen the direct outcome," Thompson says. "When you're dealing with a cancer diagnosis, everything is about the medicine and the disease and finding the best treatment.

She says that Cancer CAREpoint allows patients and family members and caregivers to focus on the person who so often gets lost in the cancer journey.

"By focusing on the whole person, we empower them to be stronger, and they come through treatments and the journey stronger."

Rob Tufel, executive director of Cancer CAREpoint, says when he first learned of it, he found the group's mission exciting.

"When someone is diagnosed with cancer, their whole world turns upside down," he says. "They have to figure out how to deal with the reality of the medical world, treatments, learn a new language and doctor visits. Then there is the reality of the non-medical impact of cancer--How does this impact my family? Can I still work? What about income? Do I have to eat different foods? How do I prepare for surgery?"

Tufel says Cancer CAREpoint is really a complement to the medical care patients are getting.

"Obviously, the doctors and nurses don't have the time to offer these kinds of services, but we can offer that emotional piece. We have support groups; we have practical nutrition classes, educational series,

therapeutic massage and we just started a wig bank. We have both the practical and emotional side of things."

Since officially opening its new office in October 2013, Tufel says Cancer CAREpoint has served some 500 clients.

"For us, a client is anyone impacted by cancer--a patient, a caregiver, family members."

The agency has been seeing about 50 new clients a month, and Tufel says that number is bound to increase.

"We know in Silicon Valley about 10,000 people a year are diagnosed with cancer, so there really is a great need."

Client Sian Sanders has dealt with cancer twice.

"I was initially diagnosed with stage 3 colon cancer in March 2011 and dealt with it, but it came back as stage four in my liver in June 2012," says the Rose Garden resident.

Sanders says her second diagnosis coincided with the point when Cancer CAREpoint was really getting off the ground.

"It wasn't there the first time around for me. We just battered down the hatches and got on with it. I did as I was told," she recalls.

"When it came back the second time, I knew I needed more support than the oncologist could give me. He would look after my tumors, but I needed more than that. I needed to talk to someone and have someone listen to me and point me in the right direction for anything not medical related."

She took advantage of everything--massage, image therapy, nutrition classes and also the collage art class.

"They offered everything and they offered a safe place where you could go and get advice," she says.

She's still involved, but she says she's starting to take on a role as a volunteer, rather than a patient.

Sanders says of all the help and support she got from Cancer CAREpoint, the one thing that stands out is the support they have given her children, three teenagers, two of whom have been going to the teen group.

"It's given my kids a much greater understanding and made it easier to talk about everything," she says.

Volunteers are crucial to Cancer CAREpoint and what allows it to continue offering services at no charge.

Mike Culcasi, a Willow Glen resident, volunteers at the reception desk.

"When they walk in the door, I want it to be a positive and warm experience for the people who avail themselves of the services," he says. "I make them know people are happy to see them when they walk in."

Lorien Nearing, who leads some of the yoga classes at Cancer CAREpoint, has been a volunteer there since it started.

"Gay Crawford came to Breathe Los Gatos where I was teaching a cancer class. She told me about the programs they were looking to offer, and we agreed it would make a good partnership.

Nearing now volunteers her time at two yoga classes a week, one at the Breathe Los Gatos studio and the other at Cancer CAREpoint.

"Working with cancer patients is not like anything else," she says. "There is no ego trip going on whatsoever. They're just open, so open and willing, and you see such a huge difference in their attitudes from class to class and week to week. The change is enormous."

"I teach a lot of different yoga for cancer programs, and one of the things I love about Cancer CAREpoint is whenever they're offering something new, they step back and say, 'How can we serve our patients first and foremost?' "

Cynthia McDonald, a certified clinical and medical hypnotherapist, volunteers her services for one-on-one guided imagery to clients to help them reduce stress and anxiety. She also leads a meditation group and does workshops on living with uncertainty and the unknown.

She's also a cancer survivor. "I was diagnosed at age 30 and now I'm 59. None of this existed then. I went through the medical treatments and I had nothing available to help me process what was going on with me," she says.

"The shaking of your life when you receive the diagnosis is so unexpected. The medical community does everything they can, but they're not geared toward non-medical needs."

McDonald felt she had a calling to get personally involved helping people with cancer, so she left her high tech corporate job and spent 10 years earning her doctorate and certifications.

"I sit one-on-one and spend an hour and a half with every person, and I customize the imagery for them." She says that it's most effective when she's using imagery coming from the person that is meaningful to them.

"Some people come in and are just diagnosed and they're extremely anxious and fearful, and we use imagery to empower them so they have the capacity to let go and relax. To let them know they haven't lost that ability, even if their world is turned upside down.

Another use is for insomnia. "I joke I put people to sleep with my voice, but imagery has helped people to wean off sleep medication and helped them with insomnia issues."

She says guided imagery is also effective to help people prepare mentally for the surgery they're going to face.

"Even the physicians will say, 'I don't know what you did, but they bled less, they needed less pain medication and they were discharged earlier.' "

McDonald says guided imagery is also used to help prepare for chemotherapy, radiation and many more treatments.

"I customize their application and I do a session for them with soft music. I use my voice to paint the picture for them that we discussed, and I invite them to go into their imagery as deeply as they can," she says.

At the end of the session she burns a CD with their imagery, and they can take it with them as a tool and use it anytime they want. They can play it at night before bed, play it during chemotherapy or right before radiation treatments.

"I helped one man get through neck radiation treatments. He was claustrophobic and he had to wear a tight mask."

Although McDonald, Nearing, Culcasi and others volunteer their expertise and time, Cancer CAREpoint still requires funding. All services are offered free. Tufel points out that it doesn't matter where clients are getting their medical care or what their insurance status is.

Their primary funding is from donors in the community who want to see this type of local resource, but as they grow, they are reaching out to corporations like Xilinx, which he says, has been generous. They will also be reaching out to foundations and more donors to help support programs.

"We're local, we're filling a need that hasn't been met in the past and we rely on the community for support, both in kind and financial," he says, adding, "We're always looking for volunteers and we're always looking for donors."

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