

A CANCER SURVIVOR STORY: ALMA DENESHI

1. Where were born and raised? (Hometown)

I was born and raised most of my life in Riverside, but I lived in Oceanside for quite some time until I got cancer.

2. Where is home now?

I live in San Ysidro now with my ex-husband and our daughter. I moved in with him after things got tough on my own. I was living in Oceanside when I lost my job at T-G-I-Fridays as a Restaurant Manager during my recovery from having a brain aneurism. During that same time, right after open brain surgery to remove the tumor, I got my first cancer diagnosis. I had breast cancer on the right side. I was still on government assistance, but my disability funds eventually ran out. I tried to hold several other jobs, but I kept getting fired for not remembering things. After open brain surgery, I just wasn't the same.

3. Please share with readers your history of cancer.

My sister, my mom, my aunt, uncle and two sets of grandmas all died of cancer. I am the only one in my family alive after a cancer diagnosis, not to mention three! I was diagnosed with the brain aneurism in 2005. In January 2006, while still recovering from open brain surgery, I was diagnosed with breast cancer for the first time. Later it returned in my breast, and after than I got cervical cancer. When I went for my mammogram the first time, I got a call from a doctor asking me to come in for a follow-up visit. I had a coworker take me, because I wasn't able to drive yet. He told me I had cancer. I said, "Okay. Thank you" and I hurried out of his office. I just thought that cancer was a common and curable as the flu. When I lost my job and we received an eviction notice from our landlord, my daughter called my X to let him know I was unable to pay our rent. My daughter was 12 years old at that time I had the aneurism, and then a few months later I got the breast cancer. She went to live with her grandparents for a few years while I moved in with her father in San Ysidro. I was not simply able to care for her. I needed my own caretaker, but no one was available to stay home with me for long to help with keep up my household and care for my personal needs. I had a few caretakers volunteer, some of them who were my employees, who came by a few times to clean, make me some food, and do my laundry. But that dwindled over time, which is understandable. For the most part, I was on my own dealing with the aftermath of my brain surgery, all while trying to comprehend what cancer even was. Because of my brain injury, my cognitive skills weren't great. I have short term memory loss, which made remembering the advice from my oncologist difficult. Once I accepted the truth about my illness, the doctors and nurses went over and over the information for me, patiently repeating everything. They really helped to make sure I was aware of my body and the surgical procedures. I am happy my doctor sat down with me to make sure I was aware of the seriousness about my cancer diagnosis.

4. How did you first get involved in the health field?

My breast cancer came back in the same breast, and I was diagnosed at the same time with cervical cancer. The three cancer incidences were after the brain aneurism. I was a general manager for T-G-I-Fridays at the time I was diagnosed with the first cancer. I was diagnosed with the second and third cancers at the same time after I had stopped working. I had to take time off for radiation treatments for the breast cancer. I contracted viral meningitis when I was going through treatment, which really put me out of work for a few months. I told my oncologist that I was no longer working. They had stopped my radiation treatment because of my viral meningitis. If I had had bacterial, I wouldn't have survived. My oncologist let me cry for a bit before she said, "Instead of crying, put your anger and sadness into something positive." That was great advice. She was on the board to directors for the American Cancer Society (ACS), and she told me that I can get involved as a volunteer with the organization. That's how I started in the health field. I am still volunteering for the San Diego regional office, and now I have my own office.

5. What is your favorite part about your role in the field of public health?

Information sharing interests me most about the field of public health, and is an important part of my role as an ACS volunteer. I am the only Spanish speaking ACS volunteer in San Diego. When someone calls the 1-800-number with inquiries, or to exchange cancer experiences with survivors, volunteers call them back to ask if calling the 1-800-number to speak us helped them answer their questions. If we were not able to help them, we try to find out why by volunteering our time in the public health community to get those people the help or information they need. During these 'call-backs', I often learn of cancer patients lacking health insurance. I work as an ACS volunteer and partner with public health professionals in the San Diego community to provide an information avenue to spread cancer prevention and awareness information to people affected by cancer. I will soon be preparing and delivering presentations to the local community to promote access to health care. By informing the community about the Affordable Care Act (ACA) health care enrollment process and assisting those who need health insurance to enroll in a plan that's right for them, it's my chance to make a difference in my community in my new position with Blue Shield as a Certified Enrollment Counselor (CEC).

6. Can you recall an experience that has influenced your role as a cancer prevention and support outreach volunteer?

I work primarily with Spanish-speaking San Diegans residing in San Ysidro who tell me they are illegal immigrants from Mexico. Many callers lack access to health care insurance and fear that clinics will request proof of U.S. citizenship. Hearing their desperation and frustration is my motivation to do all I can to help meet their needs. I usually start by informing them about the community health clinics and free public healthcare options that are locally available, and that clinics do not need proof of citizenship. I didn't have health insurance either when I was diagnosed with cancer, so I can relate to these individuals. One time, another woman also named Alma, had called the ACS 1-800-number. She had been recorded onto my volunteer call-back list. It

touched me that she was diagnosed with the same cancer, and that we both had the same name. I self-identified with her. I called the number and a man answered the phone. I asked, "Hello. May I please speak with Alma?" he replied, "What do you need?!" He sounded very angry. I told him I was a volunteer for the American Cancer Society. "She's not here!" I let him know that I can call back later. He said, "No. You won't." Then he started yelling at me some more when I politely asked why not. He said, "We do not have any health insurance, we are not legal here in the US." He went on to inform me of the rest of his situation; he worked under the table at a restaurant and was barely supporting his family, Alma has four daughters, she never had a mammogram until she was diagnosed with her breast cancer, they do not know the laws of this country, nor speak the language, and his source of transportation was not reliable. He was unable to take her to any doctor to treat her cancer, and she die died Christmas. I spoke with him to calm his anger and ease his pain, relating to his situation with a story about the loss of my mother. I told him that this was a time for him to grieve, and that anger, sadness, and emotional grieving is a process he has to go through and overcome. He shared his feelings with me, and that he was not mad at me but at his situation. I asked him if he was religious, and he was. We were both Catholics, so I asked him if he wanted to pray. I got his address and sent him a Relay for Life Invitation, and I know he got it because it was not returned. I called him back several times, but his phone was disconnected. I learned that Hispanics don't like to word "cancer" and that if I stayed true to my big mouth, or my ability to 'tell it like it is,' people tend to respond with more willingness to accept my help. It saves lives if people get their preventive healthcare exams. I explain that in ways that less acculturated Hispanics can understand.

7. Have you made any contributions that have impacted the cancer survivor community?

In 2009, I started volunteering with the ACS. In 2010, I became the Hospitality Chair for the cancer awareness fundraiser event, Relay for Life, hosted by the American Cancer Society and held in a number of locations around the San Diego region. In 2011, I started tabling at health fairs and educating people on the importance of getting cancer screening exams before you feel sick. I attend health fairs to share information with Spanish-speaking Latinos in two regions of San Diego, Chula Vista and San Ysidro, putting to good use my strengths in speaking the Spanish language to engage and empower the Hispanic community. I became a Survivor Chair for the Relay for Life event in San Ysidro. I told the ACS volunteer committee that I wanted to deliver the educations in both English and Spanish. I am proud to share that I was the first volunteer from the San Diego regional office to ever to deliver health education at the event in both languages. Considering the size of the South San Diego Hispanic population, I am very proud of this accomplishment. In 2013, I unexpectedly won the spirit award as the winner for the year for my work in the Hispanic community. I find this award to be a reflection of my kept promise to that man on the phone, Alma's husband. I was going to help spread the word that help is available and prevention is possible.

Back in November of 2013, I am blessed that I was approached by a doctor at a Sharp Healthcare provider conference. When I introduce myself to the community, I am first a foremost always a cancer survivor. During opening meet-and-greets at this conference, I said “Hi, I’m Alma, and I am a three-time cancer survivor.” Then I said I was an ACS volunteer. After the conference, Dr. Feinstein, who I met there, approached me with an idea. He suggested that I start my own cancer support group. I had already thought of that, but access to a large enough meeting space was my issue. Dr. Feinstein offered me the space at his office to host a cancer support group. After accepting his offer in person with excitement, he said to me, “I wish we had more people like you out there on our side.” I host a cancer support group that meets every third Wednesday of the month at his San Ysidro office. Our cancer support group is called *Vamos a Chalar*. I created my support group specifically to increase access to support groups for San Diego’s Spanish-speaking Hispanics affected by cancer. I chose that name to be different. Most of the support groups in San Diego are for English-speakers, and are simply called ‘cancer support group’ or ‘prostate support group’, without a real name for it. ‘Vamos a Chalar’ means ‘let’s chat’ in Spanish. I wanted to name it something distinctly memorable and culturally inviting.

My favorite contribution, I began a project called *Princess for a day*. I had always wanted to do something for cancer survivors. I wasn't working, but was volunteering and networking, and my relationships with community leaders. I met a woman named Emma last October of 2013, at a Promotores conference. There we talked about my story. Emma and I related to one other in that our parents both had cancer. I mentioned I had always wanted to do an event for women who are breast cancer survivors, but my being without an income meant I really needed assistance putting on this kind of an event. “Why do you think you can’t do it while you aren’t working for an income? I know what we can do!” She and I got together and set an event date for October, but I said no because other events for cancer are popular that month. I suggested we set the date for Valentine’s Day because it is a day for love and relationships, a day I can recall feeling sad every year. Going through cancer, and losing your nipples, makes enjoying holidays like Valentine’s Day harder. Valentine’s Day especially made me feel less attractive and self-confident about my looks because parts of my body had been cut off, and I am sure other female cancer survivors feel similarly. I explained this to her, and Emma agreed. Valentine’s Day, last February 13th, we held an event at the San Diego Country Club. This event is dear to my heart.

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