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### Live Your Life Out Loud

Susan M. Love <sup>a</sup>

<sup>a</sup> Santa Monica, California, USA

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## Live Your Life Out Loud

SUSAN M. LOVE

*Santa Monica, California, USA*

*Susan Love, MD, MBA, has dedicated her professional life to the eradication of breast cancer. Author of the bestselling Dr. Susan Love's Breast Book, Dr. Susan Love's Menopause and Hormone Book, and Live a Little, Susan is Chief Visionary Officer of the Dr. Susan Love Research Foundation where she oversees an active research program centered on breast cancer cause and prevention. Susan co-founded the National Breast Cancer Coalition in the early 1990s, and she served on President Clinton's National Cancer Advisory Board from 1998–2004. Her recent projects include recruiting 377,000 women for the Love Army of Women, an Internet program that partners women and scientists to accelerate breast cancer research; and the online Health of Women Study designed to identify the cause of breast cancer. A recipient of six honorary doctorate degrees, Susan is Clinical Professor of Surgery at the David Geffen School of Medicine at the University of California, Los Angeles. In June of 2012, Susan was diagnosed with acute myelogenous leukemia and was treated with an allogenic stem cell transplant.*

**KEYWORDS** *Dr. Susan Love, Dr. Susan Love Research Foundation, Love Army of Women, lesbian leaders, lesbians fighting disease and disability, lesbians and medical treatment, lesbians coping with illness, lesbian support systems, best medical practices, leukemia, breast cancer*

*N. B. Susan Love was interviewed for this article by Nanette Gartrell and Esther Rothblum.*

In 2011 and 2012, I had some arthritis and auto-immune problems for which I was treated by a rheumatologist. My rheumatologist announced that she

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Address correspondence to Susan M. Love, 2811 Wilshire Boulevard, Suite 500, Santa Monica, CA 90403. E-mail: [slove@dslrf.org](mailto:slove@dslrf.org); [www.actwithlove.org](http://www.actwithlove.org)

was retiring, so I made an appointment to see her on Thursday, June 7, 2012, in order to get a referral to a new doctor. I was feeling fine—I'd gone for a 5-mile run the night before—and as usual she drew a lot of blood. The lab called my rheumatologist to tell her that my white blood count showed that I had 20% blasts. Blasts are baby white cells that you don't usually have in your blood. But if you have leukemic cells filling up your bone marrow, it shows up as blasts in the blood stream. My rheumatologist called my primary care doctor, who called me to say, "I have shocking news for you." There is no good way to tell people that they have a serious disease, so you just have to tell them. She told me to come back to UCLA right away so they could do a bone marrow biopsy and make a diagnosis. I drove back to UCLA, all the time thinking, "Blasts, now what are blasts again?"

Although I'm a surgeon and an expert in cancer, the one kind of cancer that never involves surgery is cancer of the blood. Blood cancers are the only cancers that I've never dealt with in my professional career, and therefore knew the least about.

Helen, my wife (who is also a surgeon), was out of town, and my daughter was back east for the summer, so I was alone when I had my bone marrow biopsy. The hematologist's bedside manner was somewhat lacking, and I finally said, "What's the most likely diagnosis?" He said, "AML of course." That is Acute Myelogenous Leukemia, the most aggressive kind. He told me that it takes a while to read the bone marrow biopsy, and I wouldn't get results until Monday. I said, "Bullshit. You're a hematologist. You can look at it yourself. Go look at them and call me."

Helen arrived in time to go with me to meet this guy the next day. He told us that I had an unusual type of AML that had only been reported before in eight women. It was located on my X chromosome (gene 13). He said, "We need to bring you in, give you chemo, then do a bone marrow transplant. By the way, I'm going on vacation."

I went home and reached out to all my friends who are hematologists and oncologists, one of whom was a lesbian hem-onc doctor, Lisa Weissmann, in Boston. UCLA is close to home, but I wanted to know if there were any other hospitals I should consider. They all said, "You know, you can get the chemo at UCLA, but if you're going to be a candidate for a bone marrow transplant, you really should go to City of Hope in Los Angeles." We went there for a second opinion, and I really liked the doctor we saw. He was just the opposite of the first guy. He was very knowledgeable, but also he was our age, experienced, and had good judgment. For all these reasons and the fact that they do a lot of bone marrow transplants at City of Hope, we decided to have the treatment there.

If you have to have a transplant, you need a place where they do so many that everybody on the team is used to it. At City of Hope, the nurses have been there 20 years, as have the people who clean the floor.

Because the treatment involves wiping out your bone marrow so you have no immune cells and blood clotting cells, if you fall down, you could bleed to death. Also, if you get an infection, you could die because you just don't have any way to fight it. So, everybody's wearing a mask and gloves, and it's really important that everybody's working together with the same routine. When you're in a more general hospital, you don't have that same level of expertise. You might have a good doctor, but you need the whole team to be trained to perfection.

That's one of the things I would tell anyone with my diagnosis: find a doctor and a team that you trust. Do your research, get your questions answered, make your decision, and then just go with it. Don't second guess it. If you start second guessing everything, you can make yourself crazy.

The problem with my kind of leukemia is that you have to be treated right away. Most people are symptomatic, get diagnosed, and are admitted to the hospital. They may not even have the time to do the research. Because I didn't have any symptoms, I had ten days. We had to make our decisions very quickly.

My family was really terrific. They have always been very supportive of us. When we found out I had leukemia, my sisters and brother all signed up to be donors, but they were not all matches. My baby sister Betsy, who is 12 years younger than me and lives in Mexico, was a perfect match. My brother was a half match, and the sister right behind me was not a match at all. Which does not surprise me because she's an artist, and we are completely different physically, temperamentally, and in every other way. The funny thing about Betsy being the match is that when she was growing up, we always told her when we wanted her to do something for us that she was "too little." Then she would say, "I can do it," and go do it for us. It was really nice that this time Betsy wasn't too little. She was incredibly happy that she was the match.

As far as my work was concerned (Dr. Susan Love Research Foundation), I told my board that I would be out for about six months. I had a very good executive director and they carried on very effectively while I was out.

This is how AML is treated. First they give you chemotherapy to kill the leukemic cells. Depending on how you respond and your age and your physical condition, either they give you more chemotherapy, like 4 or 5 cycles, or they give you a bone marrow transplant. Chemo is just poison and the way it works is by poisoning cells that are dividing rapidly. The reason you lose your hair is because your hair is dividing rapidly. Chemo also interferes with making blood cells. You have this factory in your bone marrow that's making red blood cells, white blood cells, and platelets. Chemo interferes with this factory when it's used to treat any kind of cancer.

In my case, they wiped out the cancer cells in my bone marrow, and then we waited for the normal cells to come back. Mine did not come back

very well, so I was in the hospital for seven weeks. I was not feeling that bad, but I had no white cells and my platelets were low, so I could not go out into the world.

We have a tradition in our family, partly from living in Mexico, that if somebody's sick, you always have a family member in the hospital with them. My brother and sister each took a 24-hour shift every week. Then my 25-year-old daughter was there at night, and my wife during the day.

My doctors did not want to give me more chemo because my normal blood cells did not come back after the first chemo. Since I had a perfect match in Betsy, they decided to go straight to the transplant. They let me go home for two weeks—basically for mental health—on industrial-strength antibiotics.

For the transplant, they give you chemotherapy again, but this time, the goal of the chemotherapy is not to kill the cancer cells, but to annihilate your bone marrow. Then they give you new bone marrow—Betsy's, in my case—and there's a place for these stem cells to go.

I had the transplant on August 29. They took the stem cells out of Betsy and put them into me through an IV. While that was happening, everyone sang "happy birthday" to me. My sister and brother sang the Spanish—"Las mañanitas"—the version we sing in Mexico.

You know, your blood type changes to that of the donor's during a transplant. If I had gotten my brother's cells, then my blood chromosomes would be XY, and the rest of me would be XX!

For the first two weeks after the transplant, you have virtually no blood cells. Then my sister's marrow started making cells. It is as if these new cells are armed, if there are any of my leukemic cells still in hiding after they wiped out my bone marrow, my sister's cells would recognize them as foreign and kill them.

From the pre-transplant chemotherapy, I had a severe neuropathy. I had horrible nerve pains in my legs, so they gave me a lot of narcotics—so much that I have no memory of the 3–4 weeks after the transplant. Which is probably good, because I've heard lots of stories about how much pain I was in. I'm just as happy I don't remember that period. I was basically almost anesthetized, but I always had a family member there. It was a very stressful time for them watching me go through all of that.

Once the transplant has taken enough to give you a sufficient blood count, you can go home, but you are still on a lot of drugs. These are protective drugs—antibiotics and anti-viral drugs. I also took immunosuppressants so my sister's cells wouldn't attack mine in what is called "graft-versus-host disease." The first 100 days are critical in determining whether the transplant is going to work. I was pretty much stuck at home. I couldn't go out without a mask and gloves. We really had to watch for infections.

The recovery is slow. When I first got home, I was so tired that I didn't even want to read. I just listened to the radio. By the end of the 100 days, we had a party in Santa Barbara where my sister and brother live. Betsy flew up from Mexico so we could celebrate these 100 days on the Feast of Our Lady of Guadalupe. My family has always been close, but my having leukemia has even made us closer.

In January 2013, I started going back to work. Initially I was so tired that I could only work for two or three hours. But gradually I got more energy. Now, a year after my diagnosis, I am completely back to my old routine. My staff at the Dr. Susan Love Research Foundation really stepped up to the plate and carried on while I was out—so much so that when I first got back to work, I was having trouble figuring out what to do (laughing). They were so good at running the foundation without me that I had to figure out my role again!

Today, there's no sign of leukemia, and I have a normal blood count. Of course it could come back at any time. But at least for the moment, all is well. And this kind of leukemia is so aggressive that if you make it to two years, you're pretty much going to make it.

#### ADVICE FOR OTHERS WITH SIMILAR DIAGNOSES

1. When you're deciding on doctors or treatments, always have an advocate with you who will ask the questions you're afraid to ask. Tape record appointments so you don't forget anything. If the doctor doesn't like the questions being asked or your tape recording the meetings—tough! That person is the wrong doctor for you.
2. People really want to help, but you need to tell them what to do. If you do not, they will do what they would like done if they were in your shoes, and sometimes that's exactly the wrong thing. For example, Helen hates to eat alone, so it was not going to work for people to bring food to the house. I said, "Tell people you want to go out to dinner." She did, and three or four nights a week she went out to dinner with different people. That was really helpful for her because she could not stay in the hospital all the time. Besides, we had done enough of that during our surgical residencies.
3. For the thousands of hours of boredom in the hospital, we watched movies and old TV shows like "I Love Lucy" that we loved when we were kids. Before I went to the hospital, I told people to recommend funny movies and books, so I had lots of fun things to distract me when I needed it.
4. While you are going through the chemo and transplant, it's really about putting one foot in front of the other. I have run three marathons, and it reminded me of that. You just say, "Okay, 26.2 miles: we'll put this foot and then we'll put that foot." If you can stay in the present and just know

that this is your job for this moment, that's important. I should also say that I am genetically blessed because in my family, we are happy people. There's a lot I do not worry about that other people do. I am lucky that I have this positive brain chemistry.

5. You also need an advocate when you are in the hospital. Helen and Katie served as that for me. They would tell the staff that I was still in pain, or whatever, because I could not do it. When the doctors came, I regressed to being a good little girl wanting to keep them happy. I would be screaming all night with pain and then they would come in and say, "How are you?" And I would say, "Oh, fine." Helen and Katie would jump up and say, "No she's not!" When you are that sick, it's not uncommon to regress to a place of wanting your doctors and nurses to like you and take good care of you and not be mad at you for complaining. It's really important to have a spouse or friend or family member there to be your advocate when you need something that you cannot or will not ask for.

## GROWTH EXPERIENCES

Having a serious disease really does focus you on living each day. You just never know what's going to happen when you wake up on any particular day. I certainly did not. I woke up a year ago thinking I was having a regular day, and by the time I went to bed, I had learned that I had a life-threatening disease. These days, I try to be much more focused on the present and appreciate the moment. In the past, I would be so focused on where I was going and the goal that I would not pay attention to the trip.

Another change in my life is that I drink the expensive wine now. After all, what are we saving those expensive bottles for? In other words, I do not put off doing things.

Also, I look around when I go for a run. I am back to running five miles, and I actually pay more attention. "Oh the flowers are blooming," I think to myself, as opposed to, "I have to run five miles, and I want to run it in this amount of time, then I've got to do this, and then do that."

These days, I am reading more books, practicing the piano, and paying more attention to people. I travel a lot. I used to just fly in and out of a city. Now I think about who I know there, and I reach out to spend some time with them. Because you realize that you do not have these opportunities all the time, and you would feel terrible if you missed them.

At work, I do not put up with the small stuff. I am impatient and my work is very important to me. It has to be. Our goal is to figure out the cause of breast cancer.

Something else that I often spoke about but now understand viscerally is the collateral damage of chemotherapy—whether it's numb feet, or chemo brain, or secondary cancers from the treatment for the first cancer, or heart

disease caused by the chemo. As physicians, we tend to dismiss or ignore the collateral damage, because we are looking at living patients and comparing them to those who have died. We think, “You’re lucky to be alive.” But as a patient, you compare yourself before to yourself now, and you’ve lost a lot. I actually said to one of my doctors, “You don’t care that I have numb feet, do you?” He said, “No.”

I now realize that we need to do a lot better at avoiding collateral damage from cancer treatment. I have had a big problem with peripheral neuropathy, and I am still taking drugs for it. Just last week there was this really interesting article in *Nature* about adrenergic nerves near a place in the bone marrow where stem cells hide out. What the article suggested is that we should give drugs to *protect* those nerves during chemotherapy, to improve the bone marrow response. But we should also do it because that could reduce the incidence of peripheral neuropathy.

With our Army of Women involving 370,000 volunteers, and our Health of Women cohort study we are going to try to document this collateral damage. Collateral damage is not recorded in the medical records. Doctors often do not document the side effects that people are having, unless they are so bad that you have to be hospitalized. Everyday problems are pretty much ignored. And drug companies do not find them because they do not always look for them and when they do their clinical trials, you cannot be on other drugs or have other diseases. In these very pure populations, the collateral damage is not as apparent. Meanwhile you have so many people living with significant side effects that have a huge effect on their lives. Nobody’s studying them systematically in order to figure out how to prevent them. Yes, you are lucky to be alive, but you are not back to normal.

## CONCLUDING COMMENTS

One thing that helped me get through all of this is being a surgeon—training as a surgeon when I did. When I went to medical school there were still quotas for women. I was the first woman general surgeon on the staff of Beth Israel Hospital in Boston. In some ways, I have always been in somewhat of an outsider position. Even when I was little, my family would tease me that I would say, “I can do it. I’ll do it my own self.” I have this “I-can-do-it” determination, whether it’s training in an all-male field, running a marathon, or fighting cancer. When I was out of it and hallucinating in the hospital, they told me that I was still trying to do things myself that I should not have been doing!

I decided a long time ago that it’s not worth worrying all the time about what people will think of me as a lesbian. It’s easier just to be out and then let people deal with it. You were the one, Nanette, who said to me long ago when Helen and I first got together that every time you do not come out,



you get another nick on your soul. I believe that. Since then, I have always been very out professionally and personally. Also, when you have a kid, you really have to be out.

During my treatment, I did not ever feel that I was treated differently because I am a lesbian. Helen and I are fairly prominent as a couple, and as my wife, and also a surgeon, Helen was always treated as my significant other by everybody at the hospital. In my room, we had pictures of our family, our wedding, and all of that. One of the things they did at City of Hope was that the nurses and nursing assistants always asked about the people in my pictures. They really made an effort to see me as a person.

If you live your life out loud—"here I am, take it or leave it!"—then that's one less thing you have to deal with. Life throws enough at you without having to worry about hiding who you are.