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## Healthy Barbs: Activism Confronts Mortality

BARBARA BRENNER (as told by SUZANNE LAMPERT)

*Barbara Brenner, JD, was the Executive Director of Breast Cancer Action (BCA) from 1995–2010. Before that, she was a longtime activist in the anti-war movement and an attorney who, for most of her career, practiced public policy law. After she was diagnosed with breast cancer in 1993 at the age of 41, she took the helm of BCA. Under her leadership, the organization moved into a position of national advocacy—demanding research on the causes and prevention of breast cancer, including the role of industrial pollutants. Barbara started the “Think Before You Pink” campaign, encouraging people to question whether companies that display pink ribbons actually produce products that harm women’s health or generate any funds to fight breast cancer. Her blog, “Healthy Barbs,” challenged readers to critique routine healthcare practices and policies. Barbara received numerous awards, including a Jefferson Award for Public Service in 2007, the Smith College Medal in 2012, and the ACLU-Northern California’s Lola Hanzel Courageous Advocacy Award in 2012. Barbara had a recurrence of breast cancer in 1996. She died of complications associated with amyotrophic lateral sclerosis, ALS, on May 10, 2013.*

**KEYWORDS** *Barbara Brenner, Suzanne Lampert, Breast Cancer Action, Healthy Barbs, lesbian leaders, lesbians fighting disease and disability, lesbians and medical treatment, lesbians coping with illness, lesbian support systems, best medical practices, amyotrophic lateral sclerosis, ALS*

*N.B. As we were preparing to invite Barbara to contribute to this special issue, we learned of her passing. We are very grateful that Suzanne Lampert, Barbara’s partner of 38 years, agreed to be interviewed by Nanette Gartrell for this article in June 2013.*

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Barbara's first serious illness was in 1993. She found a lump during a breast self-exam that turned out to be invasive breast cancer. She had a lumpectomy and six months of chemotherapy—CMF (Cytosan, methotrexate and fluorouracil—5-FU). Then, after a short rest, she had 6 1/2 weeks of radiation, 5 days a week, until she finished treatment in July 1994.

Barbara had a recurrence of breast cancer in 1996. It was in the same breast, so she had a mastectomy because they could not radiate that breast again. There was no follow-up treatment.

In 2010, Barbara was diagnosed with amyotrophic lateral sclerosis (ALS). ALS is a neuromuscular disease that attacks the motor nerve cells and typically progresses rapidly. The muscles gradually weaken, progressing to an inability to move, speak, swallow, and breathe. The cause of ALS is not completely understood, and there is no cure.

Barbara started suspecting that something was wrong in the spring. Her initial symptoms had to do with difficulties talking, breathing, and swallowing. She saw a neurologist during the summer who hypothesized that it could be ALS, or perhaps another neuromuscular disease such as myasthenia gravis. ALS is diagnosed only by ruling out other possibilities but, by November, Barbara had accepted the diagnosis of ALS.

Over the next year, Barbara's physical challenges increased. The change seemed to go slowly, but it was inexorable. She started using a small, portable microphone and amp to make her speech audible, but—as her ability to form words declined (as her tongue lost strength)—she started to communicate with the aid of a text-to-speech program on her tablet computer. She acquired orthotics and started using a cane to help her walk, and then, a few months later, started using a walker. She began eating softer foods, and eventually pureed everything to make it easier to swallow.

In January 2012, Barbara had a feeding tube inserted. This g-tube enabled her to keep nourishing without having to swallow, which was important. But the feeding tube, the mobility aids, and everything else were simply accommodations: there is no treatment for ALS.

There is only one drug, riluzole, that is approved for the treatment of ALS: it is supposed to delay progression for about six months. Barbara took it for a number of months and then developed a liver problem that required her to discontinue it. By that time, she was in a clinical trial that is commonly known as the Dex Trial. (That trial was later stopped because the results were not positive.)<sup>1</sup>

While Barbara was in the clinical trial, a device called a “diaphragm pacer” was approved for people with ALS. These devices have been used extensively for people with spinal cord injuries to help them breathe. The terms of the Dex Trial were that Barbara could not start any other medications or therapies while she was in the trial. Barbara was being treated at California Pacific Medical Center (CPMC) at the time, and she fought with her doctors and the Food and Drug Administration (FDA) about whether she could get

the diaphragm pacer while she was in the clinical trial, arguing that this mechanical device could not possibly interfere with drug effects. She has a blog on this subject entitled “FDA to ALS Patients: Fuck You.” (I suggested that she change the title, but she would not.)

CPMC stalled about pursuing a pacer for Barbara: it was new, they had no experience with it, and it would take her out of the Dex Trial. By the time the clinical trial was over and she could get the pacer, she could not pass the lung capacity test required to qualify her for it. She had missed the window of opportunity.<sup>2</sup> Barbara’s negative experience with the pacer process at CPMC prompted her to change her medical care to the University of California, San Francisco (UCSF). By that time, the doctors at UCSF said that they were concerned about putting somebody in her condition under a general anesthetic. They were not sure how she would recover from anesthesia, or even if she could recover. So she decided against the pacer. I think she felt that if she had been approved for it six months earlier, she would have done it. We have a friend whose brother had ALS at about the same time Barbara did, and he was able to obtain a diaphragm pacer. He took a long time to recover from the anesthesia and surgery, and he and his family were never sure that the pacer was that helpful. But there are other people in the ALS community with whom Barbara communicated online who found it very helpful.

## SOCIAL SUPPORT

At the time of Barbara’s first cancer diagnosis, when her treatment included chemotherapy and radiation, I was still working. Friends offered all sorts of assistance. We also reached out for support and asked friends if they could help us out. We were in our forties, when a lot of our friends were still working full time, but we identified friends who might have flexible schedules. For example, we did not want Barbara to be left alone all day, especially because we did not know how she would feel on any particular day, so we set up a schedule of people who would come every day to help with lunch and sit with her for part of the day.

One thing we noticed is that it’s very different when people say, “If there’s anything I can do for you, please don’t hesitate to ask,” as opposed to saying, “I want to do this for you,” or just doing it for you—like bringing you food, or saying, “Can I take you there?” It’s very kind when people say, “Don’t hesitate to ask,” but you still have to ask. Whereas if people say, “Let me do this for you,” then you just have to say “yes” or “no,” and that’s much easier.

I took Barbara to most of her chemotherapy appointments. The only time I was not available was when my mother was dying, so somebody else took her then. When Barbara had daily radiation, women in our community of friends took her to treatments. That was very important to us—this

intentional community of friends who kept an eye on Barbara during the day and took her to appointments. Most of these people are lesbians.

Here's something else that I think is really interesting. At that time Barbara and I had been together for about 18 years. A few years prior to her diagnosis, we had had a big 15th anniversary party with about 120 people at our house, including my parents and a lot of friends. But it was not until my mother was in the waiting room with me during Barbara's cancer surgery, and a number of women friends—some lesbian, some not—joined us there, that my mother realized we had a very strong support community. In contrast, when my father had had surgery for lymphoma a couple of years earlier, I had gone to Los Angeles to sit with my mother; nobody else came except my older sister who was visiting from out of town. None of my parents' friends came, and no other family members came. I found that kind of odd. I could not figure out whether the difference was an artifact of generational differences or the need that we had had to form our intentional community.

Barbara's second episode of cancer was just a one-day outpatient procedure (mastectomy), with about a week of follow-up. Several women came with us to the surgery center and sat with me during the procedure. Our greatest need for support during that episode was in pain management—deciding whether to stay ahead of the pain by using Vicodin, or to stay ahead of the nausea by avoiding Vicodin. We spoke with friends who are medical professionals and got helpful advice.

When Barbara was diagnosed with ALS in November 2010, she stopped working almost immediately. Initially, she thought she would continue to take the bus downtown to have lunch with friends, but soon she felt that walking was like wading through molasses. Things were just getting harder, although she did not start using walking assistance until May of the following year. But she had a pretty active social schedule with people who would come to visit her. She did not like to have people over for meals because she did not want them to watch her gag or have trouble swallowing, but they would talk or play table top games.

For the first two years, Barbara could manage pretty well by herself at home during the day. She could prepare her own food to take by mouth or through the tube. She could shower, dress herself, and get to the bathroom. But in October 2012, we discussed whether she would like to have somebody she knew, or did not know, come in to help her with some of the tasks of daily living. We eventually hired somebody to help her shower and dress in the morning, prepare her first meal, and then leave food out for her afternoon meal. Later, we had a hospice volunteer come to spend time during the day if I was out. Then in early 2013, when she was no longer ambulatory, we engaged hired help eight hours a day during the week to help her get started in the morning and provide whatever other assistance she required with meals and other needs during the day, and two hours a

day on the weekends, just to help her shower and dress. Also, friends often came to sit with her on Sundays while I went hiking.

The Internet was very helpful in soliciting help from our friends. We used the Internet site “Lotsa Helping Hands” to get rides to and from the airport while we were still traveling by air, and sometimes to find people to stay with Barbara when we did not have a hospice volunteer or hired help.

The original impetus for getting somebody to help Barbara shower and dress was so that I could maintain my schedule of going to the gym early in the morning. I always tell people my social network is in the locker room. It was important to both of us that I not be confined to the house. Years ago, Barbara and I worked in the same office and commuted to that office in Santa Rosa together (a one-hour drive each way), so we were together 24 hours a day. During that time, we learned about the importance of autonomy and support networks outside of our relationship.

The Internet and the iPad were Barbara’s portals to the world. They enabled her to publish her blog, send birthday cards, correspond with a wide circle of friends, and send e-mails to my friends saying things like, “Take care of Susie.” They also brought her all sorts of news and a social network that included ALS groups and all of her other contacts. With these tools, Barbara was able to be very interactive all the way up until the end.

## ACTIVISM

Barbara increased her activism with every health challenge. Together we fought Proposition 6 on the California ballot in 1976 (an initiative to ban lesbian, gay, bisexual, and transgender [LGBT] people from working in public schools). Barbara was on the board of the American Civil Liberties Union (ACLU) for a number of years, first the local and then the national board. She was a lawyer at the time.

When Barbara was diagnosed with cancer, she decided that she wanted to stop doing law. She wanted to morph from activity that involved arguing to activity that involved community building and cooperation, especially around women’s health. While she was in treatment, an editorial appeared in the *San Francisco Chronicle* about whether research dollars should be devoted to basic science or to breast cancer research specifically. Barbara wrote a letter to the editor about this piece, and it was seen by the woman who was chair of the board of directors of Breast Cancer Action (BCA). That organization had been started by women with breast cancer who had a political outlook. The chair of this board contacted the *Chronicle* to find out how she might get in touch with Barbara and invited her to come to a board meeting. When someone nominated Barbara for membership on the board, another board member objected because Barbara was a lesbian. The other board members asked how that member knew that Barbara was a lesbian.

“Well, she has very short hair and she was wearing boots,” they were told. Somebody pointed out that maybe Barbara’s short hair had to do with her chemotherapy. That person may or may not have pointed out that there were other lesbians on the board already. Ultimately, they accepted Barbara for board membership and then, very soon after that, she became the chair of the board.

When BCA started looking for a full-time executive director, the board asked Barbara if she would take that job. It was a pretty small organization at that time, with a budget of less than \$200,000 a year. As she considered it, somebody outside the organization pointed out to her that if she became the executive director, she could take the organization in whatever direction she wanted. Barbara took that job in 1995, just two years after she was diagnosed with breast cancer.

Barbara started reading books about the political and social history of breast cancer activism, such as Sharon Batt’s *Patient No More* and Ellen Leopold’s *A Darker Ribbon*, and that reading enabled her to become a knowledgeable cancer activist who knew a lot about the science. She took some workshops at what is now called “CompassPoint” in order to acquire skills that enabled her to become an executive director.

One thing that distinguished her from other activists was the civil liberties framework that she had acquired through her work at the ACLU as an intern while still in graduate school, at the ACLU of Southern California’s Women’s Rights Project in 1975, at a summer legal internship at the ACLU of Northern California in 1979, and through the public policy lens she had refined during her legal career. Even before she was on the BCA board, she had a civil liberties and civil rights framework for thinking about social issues. Her legal background also enabled her to ask a lot of questions and challenge authority. Consequently, BCA was probably the first breast cancer organization not to accept money from pharmaceutical companies or any other sources that contributed to or profited from breast cancer. Apparently she was the only—or one of the only—activist(s) who was not paid by pharmaceutical companies to attend conferences or workshops. Not surprisingly, she was also one of the only people to stand up and ask penetrating questions at the scientific sessions. Under her leadership, BCA formulated its mission statement into a three-pronged platform: providing information to anyone who needs it, pushing for research into the causes of breast cancer and the environmental links to breast cancer, and advocating for less toxic and more effective treatments.

Barbara was on the grant review panel for the breast cancer research program of the Department of Defense a couple of times. She was on the California Breast Cancer Research Council. She was really frustrated with the research process, partly with people doing the same work over and over because there was no coordination. No one knew how much money was going into breast cancer research because there was no reporting system.

Also, companies were not required to publish the results of failed trials (clinical trials that showed no improvement). Sometimes she was so outspoken in her criticism of the powers in the breast cancer industry that I feared for her life.

After her ALS diagnosis, she created the blog “Healthy Barbs” to talk about creative ways to live with illness. Being a lesbian gave her insight into how people who are not 100% in the mainstream population might be marginalized in any kind of system. Barbara was never a person who was too shy to ask for what she needed or wanted, but she understood that some people might be inhibited in asking for partners to be present or to have access to information. At the same time, she never believed that lesbians have different health problems from those of other women. For this reason, she eventually stopped supporting groups, such as the Lesbian Health Research Center at UCSF, that distinguished lesbian health from women’s health. Our lesbian community provided tremendous support to Barbara during her illnesses, but that’s different from thinking that lesbians have intrinsically different health issues.

## SPIRITUALITY

Barbara had planned to retire from BCA when she turned 60, in 2011, and one of the things she planned to do in retirement was study Torah. We had never been particularly religious, but when Barbara was in treatment for cancer, we observed the Sabbath every week by lighting candles, and saying the blessings over bread and wine. Over the years, we began to attend Jewish services on the High Holidays, settling on the Mendocino Coast Jewish Community (MCJC) as our religious community of choice.

Our Sabbath observance lapsed over the years between cancer and ALS, but resumed once Barbara had accepted the ALS diagnosis. She began to listen to CDs of modern interpretations of the morning prayers, and had monthly counseling sessions with a rabbi from the Jewish Healing Center. The addition of Torah study, with our friend Jane, to her daily or weekly routine gave them a chance to consider carefully the stories and messages of the five books and discuss their implications for the ways we live our lives today.

Each year at Rosh Hashanah, the rabbi at MCJC asks three members of the community to deliver a teaching about something meaningful to them. In 2010—pre-diagnosis, but during the testing period—she invited Barbara to speak, and Barbara talked about living with uncertainty. The next year, Rabbi Holub asked Barbara to deliver a teaching during the Yom Kippur service, and Barbara spoke (through her iPad) about the *Mi’She’Berach*, which is the prayer we say for anyone who needs healing. And, in 2012, again invited to speak at the Yom Kippur service, Barbara and her iPad talked about the prayer called *Unataneh Tokef*, which contains the lines, “On Rosh Hashanah



it is written; on Yom Kippur it is sealed, who shall live and who shall die . . .” These three talks (posted on her blog) traced the course of Barbara’s spirituality as they reflected the course of her physical health. I believe that the turn toward spirituality helped her face the unknown calmly, gracefully, and bravely.

## RESILIENCE

Barbara understood from her own experiences that we all encounter illness differently, that we all experience challenges differently, and we have to do what’s right for us. No matter what cancer treatment people decided on, Barbara felt that it was the right decision. That was huge.

On her blog, Barbara shared information about her own strategies. A nurse at CPMC told us that Barbara was the most proactive patient with ALS he had ever seen.

I cannot even tell you how impressed I was with Barbara’s ability to cope with this disease. She was able to wake up every morning and say, “Okay, now, who am I today? What can I still do today that I could do yesterday, and what can I no longer do today that I could do yesterday?” Sometimes this assessment showed up on our Caring Bridge site ([caringbridge.org](http://caringbridge.org)) in the form of a can/cannot list. I was so impressed with Barbara’s ability to live within that ever-narrowing framework. She would say, “Now, how am I going to deal with this new challenge? How am I going to make this new adaptation?” She *never* got depressed.

Barbara had more of a problem-solving personality than a victim personality. In her ALS online communications, she might offer advice about how to deal with different situations that arose day by day. What happens when you cannot button your buttons anymore? What happens when you cannot tie your shoes anymore?

Very soon after Barbara was diagnosed, there was an Op-Ed in the *New York Times* by a man with ALS who said that when he could not tie his shoes anymore, he was going to end his life. At the time, I thought, “That guy is dying of ALS, and Barbara is living with ALS.” That was a key difference. She really lived with it until the last week, when she had just had enough.

In the course of her illnesses, Barbara’s career underwent metamorphoses from lawyer to executive director to health activist. She evolved from a student of social sciences to a person who could understand all the science of breast cancer and breast cancer treatment, as well as someone who could manage a non-profit, which required constant attention to both program and process, working with board members and staff in the service of BCA’s mission. These were skill sets Barbara acquired after she was first diagnosed with breast cancer. She also became an expert—a counselor—when people called to say, “I have this diagnosis, what should I do?”

She had an amazing ability to listen to people who called with questions about their illnesses. I do not know if that is a skill that lawyers develop, but she had it. When I sat Shiva—when I opened the house to people every evening for a week after we buried Barbara—a lot of people talked about how helpful she had been to people who had called her with questions about their cancer.

Barbara was a person of great passion and courage. During the course of her ALS, there was a much quieter growth when she just had to think every day about who she was, what she could do, and how she was going to get through that day and that week. That was a much more personal experience for her. At the end of her life, when she no longer wanted to think about the can/cannot list, she posted a list of things she was thankful for in her life. And, in her final blog post, she wrote (in part):

I have met amazing people both in person and on-line. Everyone I have come in contact with has had something unique to offer the world. The world is a better place because these people are or were in it. Some of these people I have mentored (and you know who you are), others have taught me. What I know about all of these people is that I have been blessed to know them, and that they will succeed at what they set their hearts and minds to do.

## NOTES

1. The trial was stopped soon after it had gone “open label,” which means that all who participated fully in the trial could get the drug, regardless of whether they had been on the drug or the placebo during the trial period. During the open label period, Barbara received the drug but soon noticed a sharp decline in function and stopped taking the drug immediately. Of course, we cannot know whether there was any relationship between the drug and the decline. We later learned that she had been on the placebo during the trial.

2. ALS usually starts in the extremities, but Barbara had bulbar onset, which means that the neuromuscular symptoms started in her throat. Her abilities to speak, swallow, and push air were compromised before she lost lung capacity.

## CONTRIBUTOR

Suzanne Lampert met Barbara when they were graduate students at Princeton University’s Woodrow Wilson School of Public and International Affairs. Until 2010, Suzanne was a city planning consultant whose career focused on the economics of land use and public policy. For many years she was a member of the board of directors of Equal Rights Advocates, a non-profit law firm that works to protect and expand economic and educational access and opportunities for women and girls, serving as chair of that board from 1992 through 1998.