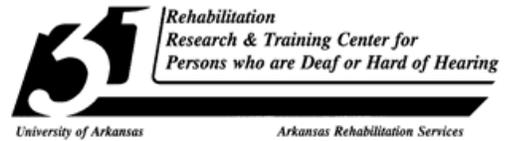




## Selected Proceedings of ALDAcon 2005



### **SURVIVING CANCER**

Presenter: EDNA SHIPLEY-CONNER

**EDNA SHIPLEY-CONNER:** Last year, when I was at the convention in Vermont, I was in chemotherapy at that time for a reoccurring breast cancer. My good friend from the Boston area, Linda Mazola, suggested that we have a workshop at ALDA this year on breast cancer and other cancers, but specifically breast cancer, because there were a large number of us late-deafened adults who come to ALDA year after year who have had breast cancer. We thought it might be a good workshop not only to share experiences but to tell about the access that we had to medical care.

What we're going to do today is let Christine share with you some of the research, some of the information on breast cancer that she has learned through a training program she went through on healthy life styles. She is a certified, healthy lifestyle instructor. Christine will share with you some basic information like what's on my shirt. It says, "One in eight." One in eight of us women will be diagnosed with breast cancer in our lifetime. That rate is a little bit higher in San Francisco Bay area where it's one in nine and inching up towards one in ten. The research has not been able to find out why it's higher in the San Francisco area, even though places like Los Angeles have more smog, more congestion, and that kind of thing.

Christine will share some of that information with you. Then we will talk about our experiences with breast cancer and let you talk about your experiences or ask questions or whatever, after we finish.

**CHRISTINE SEYMOUR:** I work for DCARA, Deaf Counseling, Advocacy and Referral Agency in California because Edna dragged me down from my home in Washington three years ago to do that. Edna was also responsible in her professional capacity of giving me the opportunity to be trained in healthy life styles curriculum, which is women's health related to, we can't say prevention, but early detection and recovery from breast cancer and cervical cancer.

One of the reasons that this topic touches me very deeply is not just because I'm a survivor myself. One thing that's often not talked about when a woman is diagnosed with breast cancer is that chemotherapy itself is highly toxic. Chemotherapy, the life saving drugs that help us recover and destroy the cancer cells in our body, also destroy the hearing cells in our body. As a result of my own chemotherapy, I had a drop of 25 to 35-decibels on my audiogram. I already thought I was deaf. When I returned to work after that experience, I could not lip read my boss anymore. Went back to my oncologist and asked him, "Those drugs that saved my life, did they take my hearing?" He said, "Yes."

I have met a few who went through the treatments with normal hearing before they started and came out with a hearing loss anywhere from mild to profound. So it's another added threat to us if we should get breast cancer that our hearing could be more seriously affected.

Our ALDA East Bay group had a party in August at one of our friends' homes and she invited a new hard of hearing friend of hers from her area to meet us for the party. In the course of conversation, the new woman told those of us sitting at her table that she had just been diagnosed with breast cancer. At that table were five ALDA, A-E-B, female members, four of whom were breast cancer survivors, and Edna, a current fighter. In our chapter alone, but first, that's too many. That's too many out of our group who have had this experience. On the other hand, this woman got a built-in support system not only for her hearing loss but also for breast cancer. She had no idea she was going to find that.

On September 25th, in San Francisco, the Susan Komen race for the cure is taking place. We have signed up as the ALDA East Bay pink ladies and we're going to walk that run to raise money for finding a cure for breast cancer. If anyone is interested in pledging a donation before you leave this afternoon, you are welcome to do that.

Here is some statistical information. Some of it refers to California statistics because that's where I was working when I developed the workshop. Others are nationwide statistics. Breast cancer is the most common cancer for women in the U.S. True or false?

**AUDIENCE MEMBER:** It's true. One in six.

**CHRISTINE SEYMOUR:** Screening with mammograms reduces the number of deaths from breast cancer.

**AUDIENCE MEMBER:** True.

**CHRISTINESEYMOUR:** Some women of color frequently die of breast cancer because they do not get a yearly screening.

**AUDIENCE MEMBER:** True.

**CHRISTINE SEYMOUR:** Finding a lump in your breast means that you have breast cancer.

**AUDIENCE MEMBERS:** True. No.

**EDNA SHIPLEY-CONNER:** No.

**CHRISTINE SEYMOUR:** No. Not all true. Not all lumps that we find is breast cancer. My first scare, well, my second scare, as an adult was a calcification, just a calcium deposit. For some reason, the calcium in my body gathers into a clump in the middle of my breast. The mammogram showed it and they had to pull it out and show it was not breast cancer. When I was 17 years old, I had my first breast biopsy and it was just a benign tumor. It was just a tissue that had grown. There was nothing to it. But two weeks after that surgery, my grandmother had her second breast removed for breast cancer. So we can't leave anything to question. Just because a lump does not mean breast cancer, you need to find out. There is no way for you to know for yourself.

Some facts about breast cancer. Fewer California women are dying from breast cancer. The death rate for breast cancer has decreased 22% since 1988. That's because of the higher level of education, the better outreach that's getting the information out to women for early detection.

Breast cancer deaths declined 13% for African American and Hispanic women in California, which is significant for the first time in this area. Why? Because, generally, the Hispanic and African American women in our area are at a low income level and don't get the information, the exams and the treatment that they need.

More California women ages 40 and older are getting mammograms. That is good news. These are good statistics.

In 1987, only two out of five women reported having a mammogram. By the year 2000, three out of five women reported. As we continue to bring this information to women everywhere, deaf, hard of hearing, hearing, education is the key to early detection and better recovery.

Early detection. The best way to detect cancer is with regular clinical exams, conducted by a health care professional and mammograms. That's two things. That's not just the mammogram. Mammogram can -- it's possible -- miss something. A clinical exam, when doctors use their skills and their special movements around the breast to feel deep inside the tissues, to see if there is something there that's not visible on a mammogram. You don't want to depend on only one medical test. You need to have them both.

Generally, you will get a clinical exam whenever you go in for your yearly GYN appointment. We'll talk more about mammograms.

70% of cancers are diagnosed at an early stage. The rate of late stage cancer is declining. Why? Breast cancer detection programs are educating women. More health insurance programs are covering the mammograms and the exams that are necessary. Low cost and free screening programs are being put in place through local and state health departments so that women of low income can get the mammograms and the breast exams they need to make sure they are cancer free or get treatment early. Breast cancer screening has saved the lives of thousands of women since 1960s.

Diagnosis statistics. Breast cancer is the most common cancer among women. It accounts for nearly one out of three cancers diagnosed in women in the United States and California. Breast cancer is the second leading cause of cancer deaths in women in the United States and California. Only lung cancer causes more deaths in women than breast cancer. If are a smoker, you've got yourself in a doubly dangerous area. In the year 2002, it was projected that 21,325 California women would be diagnosed with breast cancer and 2,275 of those would die. Those are the not encouraging statistics.

Edna's shirt says "one in eight." I walked two Advanced Breast Cancer walks in the last two years and the statistics they show is one woman every three minutes will be diagnosed with breast cancer. Those numbers seem staggering, but the good news is that, because of early detection, so many more cases are being diagnosed. Without early detection, those going undiagnosed face almost certain death later in their lives.

Barriers to detection. The risk of breast cancer increases with age, especially after the age of 50. About 80% of new cancers and about 82% of breast cancer deaths occur in women over 50. Women often don't get the mammograms they need because of no symptoms. They have not found a lump. A mammogram can find a lump as much as two years before you can actually feel it yourself in a self-exam. Don't put off your mammogram. If you don't feel anything, no problem. You don't need to go get this squished. We do.

Women face many cultural and economic barriers to adequate breast cancer screening. That includes mostly hard of hearing or deaf women. Often, the woman will go to the doctor, won't have an interpreter, won't have captioning, and won't hear the talk about breast cancer and say okay, okay, okay. Then, they won't do anything about it. That's what's important about these kinds of education program. More women need to be diligent about discussing breast cancer and mammography with their doctors.

A lack of a doctor's recommendation for a mammogram is a top-ranked barrier for nearly all groups of women. The other barrier is cost. That means a doctor might decide. Doctors were being lazy, were being complacent about making sure that we got back and got our exams. I'm really happy to know since I moved to California, I get notice, just like the dentist office does. In a postcard, in the mail, and in a phone call, I get a message that says, "Your annual mammogram is due" and it reminds me.

In the past, it was always left up to the woman to decide for herself. If you went to the doctor with the flu or a broken leg, the doctor would not ask you, have you had a mammogram lately? They would not look back and check. Now, they are more diligent because we are more diligent. We need to be sure and pay attention. Mark your calendar, have a birthday every year, get your mammogram.

Women who discussed breast cancer screening with their doctors were up to 12 times more likely to receive a mammogram than those who did not. No matter what it's for, if you are like me, you don't go to the doctor unless something hurts or you don't feel good. You don't go because it's time for a mammogram or breast exam or time for a pap smear. If I talk to my doctor about it, then I'm reminded. So any time you go in, you can just say, you know, is there any chance I can get breast cancer or do I need to get this examined? Bring it up your self. Just like our communication, we are responsible to let people know we need communication, as women, we are responsible for our own bodies. We need to take that responsibility and make sure that doctors give us what we need.

Trends and patterns. The chance for getting breast cancer increases with age. For example, age 30 to 40; the chance is 1 in 257. From 40 to 50, 1 in 67. And age 60 to 70, 1 in 28. I'm not sure how those numbers compare to what her 1 in 8 says but the numbers just keep going up.

Uninsured women with breast cancer have a 30 to 50% higher risk of dying than women with private health insurance because of delayed diagnosis. Having no insurance leads to 360 to 600 premature cancer deaths each year. If you don't have health insurance, there are agencies you can contact to get this diagnostic exam without any cost.

When I was doing this workshop in San Jose, California, we had a form to fill out for anybody who came to a workshop. If a woman needed a mammogram, we got her a mammogram, transportation and interpreters if necessary for the doctor care.

Ethnic trends. This is very interesting to me, because I never thought about different cultures being more susceptible to breast cancer or not. Breast cancer seems so random. Who is going to get it and who is not? My grandmother died of breast cancer, but my mother and my sister didn't have a cyst. Then I was diagnosed. Doctors said it was rare for breast cancer to skip a generation.

African American women with breast cancer are more likely to die from the disease at almost every age than women of any other race. The higher rate is related to the percentage of breast cancers being diagnosed at a later stage and less treatable.

Asian Pacific islanders had about a 20% increase in breast cancer from 1988 to 1998. 60% of the breast cancers diagnosed in the Asian/Pacific islander women were early stage. While the numbers of diagnoses went up, they were early stage. Those numbers

are an indication that, with more education, we are getting more early detection. The smaller numbers before probably meant there were late-stage diagnoses.

In 2001, less than half the Asian or Pacific Islander women age 40 and over reported having mammograms. That's the smallest screening rate in all groups. A lot of that is cultural. Asian women have very strong cultural modesty about this. One of the ways that's being addressed is referring the women to a doctor of their own culture to give them more comfort. You can ask for that. If you are Hispanic or Asian, you can ask to have a Hispanic or Asian doctor.

Uninsured Hispanic women are two to three times more likely to have a cancer diagnosed at a later stage making it less treatable. 64% of breast cancers diagnosed in 1998 in Hispanic women were early stage. We are seeing the same pattern. The higher the diagnostic rate means that more often people are being seen by their doctor. That's also a very frightening statistic.

It's telling us how many people really have this cancer. Before when there weren't so many diagnosed and there were so many that we didn't know about, all we learned about were the people who died from it. Now, we are getting statistics about survivors and that rate is going up and up and up.

Living healthy is up to you. Cancer and heart diseases are the two leading causes of death in the U.S. Women can dramatically reduce their risk by making simple changes towards living a healthier lifestyle.

Two important steps are healthy nutrition and physical activity. A way to reduce the risk of death from breast cancer is get your screenings, have early detection. Screening increases a woman's chances of finding breast cancer when it's easier to treat; then the chances of survival are greater.

Mammograms, clinical exams, self-exams. Early detection is your best defense. Early detection improves your chances of survival. When breast cancer is early diagnosed, 96 out of 100 women survive for five years or more. Once the disease has spread to other parts of the body, only 21% survive. Those are staggering statistics. You go from 96 to 21. That's incredible. If you are not getting regular exams, get them. If you know someone, if you've got a daughter or a mother or sister or girlfriend that says, I don't need to go, tell them what you've learned.

The key to early detection is a combination: breast exams and mammogram. Why do we need both a clinical exam and a mammogram? Properly performed, a clinical examination of the breast can detect at least 50% of the lumps that women are unaware of themselves at the age of 40. Mammography has the best sensitivity, 85 to 90% of the women over 50 and in about 75% of the women between 40 and 50. That means that mammography is finding 85 to 90% more cancer than the women are finding with self-exam alone. Mammography is important, even if you don't feel anything.

Clinical breast exam is able to identify 5 to 10% of those that are missed. A mammogram can find 85 to 90% of what you can find and the clinical exam can find 5 to 10% of what the mammogram didn't find. With both in combination, you can be pretty confident that, if there is a cancer there, it will be detected so that you can begin the fight and the recovery.

How often do we need to be screened? Women over 40 should have clinical exam and a mammogram every year and should perform self-breast exams every month. Women 20 to 39 should have a clinical breast exam by a health care professional every three years and should perform a monthly self-breast exam. That is, if there is no cancer history in your family. My daughter is 25. I'm a six-year cancer survivor. She has been having mammograms every year since she was 21 because there is history in her family.

What do we do? Develop good healthy habits, good diet, and exercise. Get the screenings, the doctor's appointments, reduce the need for aggressive treatment through early detection. Now, Edna will conduct her survey here and the three of us will share our experience with our detection, our treatments and our recovery from breast cancer. Thank you.

**EDNA SHIPLEY-CONNER:** I'm going to start with Anne and ask her to tell us when she was diagnosed and how it was detected and the treatment, Anne McLaughlin.

**ANNE MCLAUGHLIN:** Thank you, Edna. I was diagnosed with breast cancer in the late fall of 1992. It was a complete shock. I don't know why. I had had a benign breast tumor on one side, way back in 1973, that was surgically removed. So I always sort of worried about this. There was no cancer at the time. I had a mammogram every year, probably; from the time I was 40. One year, it was fine. The next year, it shows a mass. The doctors were shocked. I was floored. They had just begun stereotactic, needle biopsy.

Anyway, I had that and we waited. I wanted it out yesterday. The doctor was very patient, the surgeon was very patient and he kept stressing that I could take time, that this was very early stage and it was not that much of a danger right away. He gave me the option of a lumpectomy or a mastectomy. At that time, there was some questioning whether lumpectomy was as good as a mastectomy, and I decided I didn't want to play Russian Roulette with it. I was just going to have the mastectomy.

We started out actually between Christmas and the New Year in a brand new facility. It was an optional surgery center and the surgeon did everything to make me comfortable. I walked down the hall to the operating room. He wore funny sneakers that made me giggle before I even got on the operating table. My husband was totally supportive and this room had a chair and a bed where he was able to stay overnight with me. The surgeon kept assuring me I was cured. I didn't need anything else and I didn't have chemo or radiation, just regular visits. And annual mammograms.

Emotionally, I did not recover as well. That took a much longer time. I kept waiting to die until I finally realized that I was forgetting how to live. There was nothing at that time that I could find for deaf or deafened women. I would call the Cancer Society through the relay and ask about support groups. "Oh, well, what can we do?" and that sort of stuff.

I was, at that time, living on the other side of the Bay from Edna. There just was nothing for deaf or late-deafened people in the area that I was in. I just plugged through on my own. I remember just sitting there one day and thinking to myself, you have to fight. Something deep inside me was telling me that I just had to fight to live, to conquer this, or to win over this. And so far, I have. I still have regular mammograms, but that's all. And I hate to say this; I have not had a doctor's examination in about four years.

**EDNA SHIPLEY-CONNER:** I was diagnosed with breast cancer in 1995, three years after Anne. It was from a mammogram. The mammogram showed three small cancerous places and one larger cancer. They strongly recommended mastectomy. They had done a lumpectomy on the larger one. But the other two sites bothered the oncologist and the surgeon both and so both recommended that I have a mastectomy. I had a mastectomy. They removed 31 lymph nodes, which is a large number of lymph nodes. They tested nodes. There was no cancer in the lymph nodes that they tested.

I had no follow-up treatment, except for just the treatment of the recovery from the surgery, no hormones, no Tomaxafin, no radiation and no chemotherapy. Then in August three years ago, I was in Texas, taking care of my sister who was dying from lymphoma, and I started having a cough. I went to the doctor when I got home and they gave me allergy medicine. That didn't help. I came to the convention in Las Vegas, stayed in the room sick most of the time, went back home to the doctor and they sent me for an x-ray. I had pneumonia which reoccurred three times within the next four months. During the last month, that four month, fluid began to build up in my left lung. The left side is where I had had the mastectomy. They tested the fluid and found that I had breast cancer cells in the fluid. Then I had a Pt k-scan, a full body scan. I found out that I had stage 4 cancer with cancer zones in numerous places on the bones in my body.

I was in chemotherapy for six months, was in chemotherapy when I was in Vermont last year. Many of you were aware of that. I'm now on a hormone called Aramadex. I will alternate probably for the rest of my life between hormone therapy and chemotherapy to keep it in control because, at that stage, there is no cure.

Now, I will let Christine tell you her experience.

**CHRISTINE SEYMORE:** I mentioned when we were talking about the statistics that, it was in October of 1995 that they found the calcium deposit in my breast. At that time, it was a mammogram that showed a lump. I went through the frightening, oh, my God, I might have cancer.

I called a friend and I said, "Oh, my God, why is this happening to me?" I was trying to be really strong. I said, "God gives us lessons to learn so we can pass on that strength to others, but why did he give me this?" And my friend said to me, "God does not have our time to make our circumstances. He doesn't do this stuff to us. He is there to help us through it."

Those will probably be the most important words that anyone has said to me. That time, it was benign. Because I had that, the doctor wanted me to have mammograms every six months for the next two years to make sure they could not find anything else. I was just out of the shower, felt an itch, and felt a little plump. Can't be. About two weeks later, I was drying myself off in the shower. Something's there. My mammogram was already scheduled for the next week. When I went in there, I told them, "There is something up here, make sure when you get that picture. Get all the way up there because I want to make sure that there is nothing there." That's what I wanted to make sure. I didn't want to make sure I had cancer. I wanted to make sure that there was nothing there, assuming it was exactly the last one that there would be nothing and I would go on with my life.

My doctor knows I'm deaf. He knows that I can't lip read, so when I went to his office, he handed me the chart and it says, "cancer, a high possibility." And I was just stunned. He said, "We're going to do a needle biopsy." I lay there and I let them do the biopsy and prayed all the way through the needle going in and out. When it was all done, they said, "We have five days before we get the results of this test." I walked out and I looked at the nurse and I said, "I didn't expect that. She said, "You did great." Most women cry. I didn't get one step out of the door before I burst into tears. I could hardly walk to my car. To add insult to injury, our telephone company was on strike at that time and my computer was on a dial-up line. I had no way to call my mother or call anybody and tell them what was wrong with me. I'm sitting in the car; crying and I can't even drive. When I finally did stop crying, I went to work.

I got myself to work, walked in the door and said, "I might have cancer" and I walked out the door. I went to my girlfriend's house because I didn't want my mom to see what I looked like. Fortunately, my girlfriend was home. We went the five-day wait and I went back to the doctor's office with my girlfriend this time to help me make sure that I understood everything. He showed me the chart again because I can't hear him and it says, "carcinoma, a high probability." They still didn't know. He gave me all of my surgery choices, lumpectomy, mastectomy and all of this. My girlfriend listened to it all. I have to give my doctor a lot of credit for this. He showed her all the pictures, went through the book. Then he said, "Now, you two go out and talk about all this and come back this afternoon when you are ready with your questions."

So my girlfriend and I went to lunch and she went through everything with me. She did a good job of getting the information. I went back and I told the doctor that I would have a lumpectomy, not a mastectomy because they didn't know for sure yet that it was cancer

and I could not go to sleep not knowing if I was going to wake up with a breast or not. If I was going to have a mastectomy, I needed to know that ahead of time. There was a possibility I would not need that. As it turned out, I didn't have to have a mastectomy.

When I went in for the surgery, I had a whole room full of people with me. It was so wonderful. I had eight people on the day of surgery there with me. One friend signed and helped me through all the questions and everything that we had to do. I went into the surgery with this prayer in my hand that said, "Dear God, help me remove and let me not forget that nothing is going to happen today that you or I can't handle together." I chanted that all the way until they put me under anesthesia. When I woke up, my friend was on the right side of me and I saw him signing, "Cancer, true." He was interpreting what the doctor was saying to me. Then I looked up and my daughter came charging at me crying, "Mom, Mom" and that's all I remember. I went back to sleep.

I went through four rounds of chemotherapy every three weeks for four months and then I had 35 radiation treatments for seven weeks. I went through hell for seven months. I was not able to work. I was not able to think. I was not able to read. I could not speak a sentence and remember what I was going to say by the time I got halfway through it. I called my experience, my chemo coma. That was the time when I understood that there was absolutely no one, no one in the presence of my life but God that was going to help me get this through. Through the process of all this treatment and trusting that God was going to take care of me one way or the other, I learned the difference between grief and self-pity. I no longer asked, "Why does this happen to me?" I simply said, "I don't have my life and I can't wait until it gets back." I was grieving the loss of life, as I knew it and I cried for most of those seven months.

When I finally was in recovery, my whole life, my world came wide open. On March 25, 1999, they said, "You are cancer free. Go on with your life." I just jumped up and down. I was so excited. My life has not been the same since that day. A person asked me later, when they had their own serious diagnosis, if I was afraid I was going to die? In all honesty, I was never afraid I would die. I was afraid that I would live and not get well. But we do. We do get well and we get stronger and our faith gets stronger and life gets much more meaningful.

**EDNA SHIPLEY-CONNER:** Christine covered her access to communication during that time. Anne, could you tell us what access you had at that time through communication with your doctor?

**ANNE MCLAUGHLIN:** I had no access except that the doctors were very patient and looking straight at me. My personal physician at that time had worked with deaf people in Wisconsin when he was an intern. It was just sheer accident that he became our family doctor. He told my sons that he found it easy to communicate with me. Only when my husband was dying and I saw the doctor talking to Don did I realize how much he changed his speech to communicate with me. I had no trouble understanding him.

When I had the biopsy, they asked me if I needed an interpreter and I took that to mean, did I sign. I didn't sign very much. So I said no. Later, I ran into one of the technicians and she said, "Oh, I remember how hard it was for us to get through to you because you were laying face down and you could not hear us." This woman had a foreign accent and she was complaining about getting through to me. I had no interpreters or anything in the hospital. I don't remember having any great problem understanding hospital personnel.

Biggest thing I had a problem with was I could not find any kind of a support group that had interpreters. Of course, C.A.R.T. really didn't exist then.

**EDNA SHIPLEY-CONNER:** I had a fairly different experience. I had full access to interpreters during the diagnosis, during this surgery and when I was going to the oncologist after I had the surgery.

One thing I didn't tell you earlier was that, in April of this year, because my body was so damaged by chemotherapy, I had pneumonia in one lung and two blood clots in the other one. And that experience in a hospital was quite different. While I had interpreters when the doctor was in the room, I did not have interpreters for the nurses. And because I speak well, they could not believe I was deaf. I had signs posted in my room. It was on my chart. I would tell them, please write for me. They would stand there and just keep talking.

It was very difficult for me, very frustrating. It was difficult for my children to see the nurses not paying attention to what I was saying. Afterwards, we were discussing it and if I had been a Hispanic person or a person from an Asian country, and speaking a different language, they would have known not to try to talk to me. But because my voice sounds normal, they just stood there and kept talking.

I became angry several times. One time, somebody tried to talk loud in my ear. Well, that's very painful for me. And I screamed. I screamed. I said, "Do not talk in my ear. That hurts!" So that was quite a different experience from what I was used to having when I would go to the clinic or when I would go to the doctor. When I have chemotherapy treatments, even though I'm sitting there in a chair with an I.V. in for two or three hours, the interpreter stays with me. I've been fortunate about that. But the hospital experience was very traumatic for all of us.

**CHRISTINE SEYMOUR:** After my initial surgery when they introduced me to the oncologist who would take care of my treatments, I asked my sister-in-law if she would go with me and help whenever I could not lip read the doctors. I can read her lips very, very well and she is in the medical profession. My mother, who is hard of hearing, e-mailed me saying, "I'm picking you up to take you to the doctor." I said, "Mom, Carolyn is going for me." She said, "No. I'm taking you."

Mom was terrified. She felt helpless. She felt what she could do was listen to the doctor for me, but my mother can't hear. So we went to the doctor's office. I had my sister-in-law, my mother and the doctor there and the doctor is talking to me and I'm doing okay answering his questions. Whenever I didn't understand, I looked at my sister-in-law and my mother butted in and I had two of them talking to me at the same time. "Wait, wait. Mom, let her." Then my mom started answering the doctor's questions without letting me even hear what they were saying. I was just so upset. I mean they are talking about my life here. Finally, I just said, "Stop. This appointment is over. Here is my interpreter's card. Can we please reschedule this?"

My mother didn't realize she was causing me more pain than she was helping me. I had interpreters from that moment on. I had interpreters in the surgery. I had interpreters like Edna said for chemotherapy. I sat there for four hours and the interpreter sat there for four hours. I had them for every checkup, every exam, everywhere all the way through.

Prior to that, I never asked for interpreters at a doctors' offices because it was always cold, flu, a headache, something that was real easy for me to communicate about. From that day on, I will never go without an interpreter.

The important thing to recognize is that when our family is involved, they are too emotionally involved. You might find that they will only tell you what they want you to know and not all of it so they don't scare you. If you have a serious diagnosis, make sure you get communication access. Interpreters, captioners, whatever it is, access. So you don't have to go through what I went through with my mom.

**EDNA SHIPLEY-CONNER:** The one thing I want to us to cover is what kind of life change happened after cancer, if any?

**AUDIENCE MEMBER:** That's a good question. When this hit me, I sat around waiting to die and I started thinking about what life was all about. Many other things -- many of the things that had bothered me in the past, trivial things, I'm too critical, not a joiner. They were meaningless. In the final analysis of life, as Christine said, we only have our relationship with God and the life that we had. I found that I had a long way to go to really being what I should be. I just wanted a different outlook in life. Shortly before this diagnosis, I had driven myself to finish getting my bachelor's degree because I had not gotten it due to my hearing loss when I was 21. Nobody thought I was capable of doing all this driving and getting it but I did. I look back on this and I thought, it was nice.

But that's not what life is all about. I began to argue with friends more. It seemed like I felt alone. I had friends coming out of the woodwork, friends I had known 30 to 40 years ago. And this continued. My husband became terminally ill with cancer as I was getting over my cancer, or getting over it emotionally. When I think of the 1990s, I think cancer. He did not survive. He passed away in 1998. I had the support from friends. Edna started a support group in San Jose. It was just wonderful. There was a group of women who shared a lot of things about faith. We were at the same point. We came together

with friendship and we really bonded and that was wonderful. I thought that was the changing point.

You go back to being what you were in a way. I was too critical, still complain a lot. But life has a different meaning. Life is never the same after cancer. It's like the realization that there are time limits and how are you going to use that time? What are you going to do?

**CHRISTINE SEYMOUR:** I always hated the clichés that life takes on a new meaning, life becomes more meaningful. I thought it was just a cliché. But the day that a doctor told me that you are cancer free, get on with your life, my life began. My life began more than anything else. I didn't mention that my diagnosis of cancer came 17 months after I had become profoundly deaf.

The faith that I acquired that I talked about, using God to help me through all the treatments and the recovery, was stronger than anything I had ever experienced. The fear that I used to have of trying new things was gone. If I could face this, if I could survive this, I could survive anything. Now, I approach the rest of my life the way that I approach the cancer treatment. As long as I'm doing good things with my life, everything that I need will be provided. And I faced some pretty serious challenges. I lost my job because of discrimination. I moved to a new place. All the fear of change is just so small today that I have had more opportunities in the last six years in my life than I had in the first -- I'm not going to tell you how long. It's because I survived. When I do fundraising for breast cancer causes, "Yeah, we survived." Survival does not mean that we got cancer and got over it. It means that we fought the fight and we won. When I feel that fight, it comes alive to me every time I face a challenge and I'm thrilled to have it. I'm a different person than I was before I went through that.

**EDNA SHIPLEY-CONNER:** Because that first experience and diagnosis was not very traumatic for me, the only thing that really changed was every morning, when I get up; I have to look for my boob. Having a prosthesis was the biggest change that happened from that beginning cancer. We'll wait and see what changes happen after this reoccurrence of cancer. I have grieved so hard over my hearing loss and I had learned to get out of that grieving state and learned so much from that experience that, when I had breast cancer, I went through a really, very brief grief process. I understood what I was going through. I was diagnosed. I went back to work the next day. I happened to be working with Pam Snedigar where we were selling Christmas trees to raise money for DCARA. Pam listened to me all that day. She encouraged me. She was my right hand that day.

I was raised a fundamental Christian. It's funny how some things come back to you, even though you may not believe that way anymore. I went through a ritual every evening before I went to bed the three days before surgery. What I did was I put a very nice lotion on my breast and I talked to it. I told it how much I was going to miss it. And what joy it had brought me, both in my relationship with my husband and feeding my

babies. That's about the only thing I did those three days of talking to my breast before surgery, and I was ready. I've never shared that publicly before. But I thought that it might be helpful for anyone who, in future, may be diagnosed with breast cancer and anticipates a mastectomy. It's a way to prepare your self.

Now, we have a few minutes for questions or comments from the audience. I know some of you have gone through similar experiences.

**AUDIENCE MEMBER:** I'm Margot. First of all, I'm a breast cancer survivor and I feel all survivors have the responsibility to go on and encourage other women. Being a hearing person, I have gone through similar experiences ANYWAY. When you get that diagnosis, all you see is the mouth moving. You don't hear anything. You need somebody there regardless if you are hearing or non-hearing because you can't just go into a state of dream. You don't hear anything. You are in shock so you need somebody. If you call the Cancer Society, they can pair you up with somebody who is hearing or non-hearing. They know what you are going through because they have gone through the same experience.

**AUDIENCE MEMBER:** I am the daughter of my recently deceased mother and she was a survivor of breast cancer for four years. She made the decision not to have chemo. Instead, she used a lot of support from friends and radiation. Over the years, we noticed that she would have reoccurrences of the cancer, about each ten years. It was kind of a cycle that would happen over this 40-year period. She still refused to have the chemotherapy. She would survive and survive and, on the third occurrence of this ten-year cycle, the last one, she didn't make it because of her cancer in her pancreas.

She was very nervous about death, naturally. She asked me kind of out of the blue one month, right before she passed away, "Do you think I'm a loser in this fight against cancer?" I came out with, I guess, the right answer. I said, "You are still a winner in my opinion because you beat it for so long." Look at a baseball series. If they win three and lose one, they are still considered winners. I think you have to look at it with that kind of sentiment. I think she passed away as a winner.

**AUDIENCE MEMBER:** I also am a cancer survivor. Thirty years ago, after my dad passed away, I found a lump. I went to the doctor. The doctor said, "You have cancer." So They removed half the breast and then decided to take me back to the operating room and take the whole thing off. I have that completely off. A year later, I had reconstructive surgery. I have an implant in and I'm really happy with it. After that, after having the surgery, I had chemo.

**EDNA SHIPLEY-CONNER:** thank you, for sharing that with us and thank you for sharing that information about your very brave mother.

**AUDIENCE MEMBER:** Yes, I think she never complained at all; even to her death, she didn't complain at all about the pain. I know she was in a lot of pain but she would never have been able to tell. She was a very brave woman.

**EDNA SHIPLEY-CONNER:** Okay, thank you for being a very good audience.

Edna Shipley-Conner is Program Developer for the Deaf Counseling, Advocacy, & Referral Agency (DCARA) in the San Francisco Bay Area where she developed DCARA's Deafened Adult Program and facilitated it for over 15 years. She is active at most ALDAcons working with newcomers and received the I. King Jordan award from ALDA in 1998 for her contributions to deafened people. Edna has received the Tom Fluret Award, an award for volunteer services, from DCARA for her work with ALDA and the Deaf Senior Housing Project. She is the ALDA Inc Region IV Director and also an avid MF player."