

# Listening Opportunities for Breast Cancer Patients and Their Supporting Cast

By Carolyn Gwynn Coakley  
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**T**wo nights after having celebrated my forty-eighth birthday, I darkened my bedroom and toppled into bed. As I attempted to get comfortable on my favored side, I felt a dull pain in my left breast as it lay against the mattress. Slowly, I examined my breast. I felt something strange. It was small and hard, and it hurt when I lay on it. Not wanting to believe what my body was telling me, I refused to listen. I shut out the negative message by thinking of a special someone <sup>and</sup> fell asleep.

The next night, I felt the same pain as I lay on my left side. My body said, "Carolyn, you should . . . ." I again chose not to listen to what I didn't want to hear. After all, I had just had a negative mammogram in August . . . nine months ago. I slept restlessly.

The following night there was once again the same pattern: bed . . . left side . . . breast pain . . . inner dialogue. This time, though, I listened to my body telling me something was wrong and my mind telling me I shouldn't wait another day to have a professional exam. I didn't sleep that night.

## **Patient:**

Listen to your body when it tells you something is wrong. Don't deny or ignore its messages.

## **GETTING OTHERS' OPINIONS**

At 10:00 the next morning, I was in my gynecologist's office. With his usual caring ear, Dr. Comfort listened to me express my fear, and with his usual gentle manner, he examined my breast. Watching his face, I saw consternation in his eyes and face lines. I saw his opinion before he spoke it: "Carolyn, there is a lump. I want you to get another opinion." He recommended a doctor and gave me the doctor's card. Then, he hugged me and requested, "Please let me know what he thinks."

## **Patient:**

Listen with all of your senses.

## **Supporting Cast:**

Dr. Susan Love, founding director of the UCLA Breast Center and co-author of Dr. Susan Love's Breast Book, is "determined to get doctors to treat their breast cancer patients as humanely as possible. And she maintains that they won't be able to do so unless they develop listening and empathy skills not ordinarily taught in medical school." Dr. Comfort may be rare, indeed.

Dazed, I left Dr. Comfort's office. Then, I became frantic and raced to my car. The urgency of inner voices engulfed me: "Don't telephone. Go directly to his office. Don't wait another minute." I went directly to the doctor's office.

**Patient:**

As difficult as it may be, this is a time to stop listening to your emotional self and begin listening to the experts . . . and heeding their advice.

It's understandable that you have a feeling of urgency to act immediately, but listen to Dr. Love: "The typical notion is that you're a time bomb and the cancer is going to take over your body unless you do something this moment. Well, that's just not true.

By the time they're diagnosed, most breast cancers have been around for years, which means it's unlikely that anything too dramatic will happen right away. You really do have a few weeks to research the subject, get second opinions, sort out your feelings . . . ."

Try--really try-- to listen to your rational self and have someone go to the medical professional with you. The need for emotional and psychological support begins now.

Dr. Control examined my left breast and decided to perform a fine-needle aspiration. While he was performing the needle biopsy, my heart was speaking loudly, "Please don't let the lump be cancerous, please don't . . . ."

Having completed the procedure, Dr. Control announced, "The lump didn't drain. But, I'm optimistic. . . . While we are waiting for the biopsy results, you are to have a mammogram." I fervently listened to Dr. Control; he was saying what I desperately wanted to hear. I made an appointment to have a mammogram eight days later.

**WAITING . . .**

Over the next eight days, I told family members and friends about the lump. Each reacted similarly--rationally--and asked for more information. No one asked about my feelings. I listened for an invitation to share my fears and anxieties, but no invitation came.

**Supporting Cast:**

Breast cancer patients need to discuss their feelings. Ask them how they feel. Help them express--not suppress--their feelings of fear, shock, anger, betrayal, etc.; deal with them; and then move forward constructively. Realize that **negative thoughts and feelings** are understandable and acceptable. Don't deny, disregard, or evaluate their feelings; rather, listen with understanding.

There was no invitation, that is, except from my fiance, Tom, who lived in California--over 3000 miles from me in Maryland. His first question was, "How do you feel?" With telephone in hand, I tearfully revealed my fears. He listened and let me know that he understood and shared my feelings.

**Supporting Cast:**

How therapeutic--and vital--it is for the breast cancer patient to have a "sounding board" who provides a supportive communication climate and who reflects empathetic understanding.

**LEARNING RESULTS**

Mammogram day arrived, and with it arrived much apprehension. The technician's words periodically broke through the din of my fear--fear of what the results might show: "This may pinch a little . . . . Hold your breath . . . . Wait here in the dressing area until we see if we need to take more X-rays . . . ."

I closed my eyes, held my body, and prayed that she would not return to say that more X-rays were needed. Moments passed; then, "We need to take a few more X-rays."

When I left the imaging office, I carried my X-rays and the radiologist's report . . . and a feeling of foreboding. Among the words written on the report were, "Biopsy is mandatory."

Stupefied, I drove home; then, I called Dr. Control and read him the report. He, too, had a report--

a report on the needle biopsy: "... Recommend biopsy/frozen section for tissue confirmation." The cytopathologist's report affirmed that I had "suspect or suspicious cells."

Dr. Control then instructed me, "You'll have to have a surgical biopsy. I can perform the surgery on Tuesday of next week. I'll call the local hospital and schedule the biopsy and then call you back shortly." Within minutes, he called to tell me the biopsy had been scheduled, I could drive myself to and from the hospital, and we'd know the results in a few days after the biopsy.

**Patient:**

Know that your body is yours and you have options regarding who treats it and how it is treated. Don't let the physician "squeeze" you out of the medical process; that is, don't allow decisions to be imposed on you. Assert yourself; get him/her to listen to you!

After the telephone conversation, I was bombarded by my mind's chatter. Each message vied for my attention, but I was unable to focus on any one message: "Dr. Control having such an authoritarian manner . . . wanting Tom to be with me . . . Dr. Control making decisions with little input from me . . . wondering what the biopsy would show . . . feeling as if I were outside my body and watching someone else

go through this experience . . .  
needing to feel in control . . . .”

#### SEEKING CONTROL

Suddenly, I focused on “control” and resolved to gain control of what I could still control--my mind. I breathed deeply. . . .

Tuesday arrived, and I was still in control. I drove to the hospital. Others had wanted to go with me, but Dr. Control had told me that I’d be fine to drive . . . . I lived less than a mile from the hospital. I didn’t want to inconvenience anyone.

#### EXPERIENCING INSENSITIVITY

At 12:30, Dr. Control and his operating nurse prepared me for the biopsy. The nurse draped my head so I could not see anything beyond the material wall. Dr. Control gave me a local anesthetic, but my pain during the surgery was nearly unbearable. In anguish, I begged for more anesthesia. Impatient and gruff with me, Dr. Control snapped, “I’ve given you more anesthesia than I’ve given any woman.” His brash claim, however, didn’t stop me from pleading for more.

To try to obliterate the intense pain, I encouraged Dr. Control to talk with me--to tell me what he was doing at various stages of the procedure.

**Patient:**  
According to Dr. Love, listening to your doctor’s reassuring conversation during a biopsy can calm you.

He said little. When he did speak, he flippantly made belittling comment such as, “And in what book did you read that?” and “I know what I am doing.”

**Supporting Cast:**  
Dr. Ethel Siris, professor of clinical medicine at Columbia University College of Physicians and Surgeons says, “If I needed an operation, I’d rather have a brilliant surgeon than someone’s who’s just a great guy.” While some may share **this medical professional’s view**, today’s patients increasingly are demanding both! And, a “great guy” [or “great gal,” the counterpart!] is one who provides emotional support by listening and responding with empathy.

I also tried to blot out the pain by concentrating on the sounds around me. There were scissors snipping and clipping, Dr. Control ordering and breathing, a door opening and closing, bed clothes rustling, instruments clanging, the nurse trying to comfort me with, “You’re doing fine,” the telephone ringing.

**Patient:**  
Listen to the sounds around you. They can assist you in relaxing, gaining control, and understanding your treatment environment.

When the biopsy was over, Dr. Control told me to get dressed. Shaking, I went into a cubicle in an adjoining room and hurriedly dressed. I wanted desperately to get out of the hospital . . . .

Visibly unnerved, I staggered out of the cubicle and saw Dr. Control walking toward me. There, in the middle of a large, barren room where both of us were standing, Dr. Control insensitively announced, "During the surgery, we sent a frozen section of the lump up to the lab. The pathologist telephoned his initial report: It is malignant." My first thought was, "My world has come crashing down. I'm going to die." Then, my emotions took over; as the tears welled in my eyes and my body became unfeeling, I asked if we could sit down.

I sat down in my dressing cubicle, and Dr. Control sat in a chair near by. He told me that although we would have to wait for the final report, I would have to have either a lumpectomy or mastectomy. His recommendation--beginning with "If you were my wife," was a lumpectomy. He concluded by telling me to come to his office in a week.

### **Patient & Supporting Cast:**

Dr. Love states: "I also think it's vital to treat women like intelligent human beings . . . . [T]he doctor needs to give the patient a lot of information and spend the time that's needed to explain things. Whatever decision is made about treatment should be shared.

"But, unfortunately, the medical profession hasn't done a good job of preparing to work that way--we were all taught to say, 'If I were you, I'd do such and such,' or 'If you were my wife, I'd want you to do such and such,' which is problematic, because the patient is not us, and she's not your wife, either."

If you expect to hear such "If" clauses, you will be better prepared to respond, for example, in this way: "I am a unique individual who wants to consciously share in the decision-making process of my treatment."

### **ACCEPTING RESULTS**

Alone, I left the hospital and drove the short distance home. I was numb . . . not from the biopsy but from the report. I asked myself, "Why didn't you have someone go to the hospital with you?" I knew why: Dr. Control had told me I would be fine to drive alone. But, he had failed to tell me that I

might leave the hospital with the terrifying knowledge that I have cancer.

**Patient:**

Ask a friend or family member to go with you to hospital and doctor appointments as well as initial treatment sessions. You may need a strong shoulder . . . and a caring listener.

At home there was a bouquet of flowers from Tom. They were a beautiful symbol of him, but I needed him to be with me . . . now.

[Three days later] I drove to the airport . . . and Tom.

The appointed day to meet with Dr. Control came quickly. We listened to the results of the final biopsy report: "Infiltrating duct carcinoma of the left breast." I remained in control; I had been prepared for these results by the initial report. And, Tom's being with me made the findings easier to bear.

Without my input, Dr. Control had already reserved an operating room at the hospital--for the following day. He had already reserved a room for me. And, he had already determined that I would have a lumpectomy.

After we left Dr. Control's office, the destructive segments of my mental tape began voicing themselves. I felt as though I were a bottle on a conveyor belt being moved along with no control of my own. Decisions were being made for me--not by me.

**Supporting Cast:**

Seek a breast surgeon who is **both** a competent surgeon and a compassionate human being. Do as one breast cancer patient did: When selecting her breast surgeon, she said, "I'm here to interview you to see if I want you on my team."

Earl Ubell, health editor for Parade Magazine, agrees that patients should find doctors "willing to treat patients as partners . . . . A good doctor places you on the healing team, keeps you informed, answers your questions and encourages you to learn more about what ails you . . . . The physician, the nurse and the technician work for you. You can 'fire' them."

There is much listening--by patient and health professionals--involved here!

**HAVING SURGERY**

Just before I went into the operating room, my mother, sister, brother-in-law, and best friend Susie arrived and greeted me with hugs and kind words. I especially remember my eighty-four-year-old mother saying, "You look so pretty." Smiling and knowing the purpose of the surgery, I thought, "I just want to be pretty again--inside--and soon I will be."

"Do you know where you are?" "What's your name?"

were the next sounds I groggily heard. They were said over and over.

More pleasant sounds followed. I heard Susie explaining, "When she wakes up, I want her to be happy. This will make her laugh."

**Patient:**

Listen to whatever makes you laugh. Laughter stimulates the body's immune system, which fights off cancer cells.

I heard my sister asking, "What's that on her eyes? Has she been crying?" I heard Tom whispering, "I love you." I heard my mother requesting, "We should go now; she needs her rest." I could hear them, and I could smile in response, but I couldn't speak.

The day before I left the hospital, Dr. Control stopped by and reported: "The tissue surrounding the lump is clean." The little voice inside said, "The cancer is gone! I am again pretty inside!"

Seven days after the lumpectomy, Dr. Control removed most of the stitches and then consulted with Tom and me. He reported, "Your binders are fine. However, a total of five of the removed sixteen lymph nodes showed cancer cells. You will have to have chemotherapy and radiation."

Crash! A quavering voice inside said, "The cancer is not gone!"

**BECOMING MORE INFORMED**

That afternoon, I preoccupied myself with more reading--reading about binders (hormone receptors), lymph nodes, chemotherapy, radiation, side effects of cancer treatments, and cancer stages and statistics. Tom read with me, and we our learnings.

**Patient:**

Take time to research cancer and cancer treatment options, including lumpectomy, mastectomy, chemotherapy, radiation treatment, and hormone therapy (such as tamoxifen, which may prevent breast-cancer recurrence). While you may feel a sense of urgency to make quick treatment decisions, becoming self-educated can ease the fear of the unknown and provide a means of control through informed treatment decisions. Read and listen! As Dr. Love says, "Knowledge is power!"

My neighbor, a doctor at the National Cancer Institute (NCI), added medical books to our reading collection, explained relevant sections to us, and answered many of our questions.

He encouraged me to explore the possibility of becoming a subject in an NCI study, and he recommended--as did numerous authors we had read--that I have an

oncologist (a cancer specialist) oversee my treatment. The following day, I made an appointment with a recommended oncologist.

#### ENCOUNTERING INTIMIDATION

A week later (and three days after Tom had returned to California), my friend Betty went with me to see Dr. Control and later the oncologist. Dr. Control removed the remaining stitches. Then, while I was still on the office cot and nude from the waist up, he told me we should begin the chemotherapy.

After I had told him I had an appointment with an oncologist that afternoon, he erupted.irate, he yelled, "Why are you going to an oncologist? I've spent more time consulting with you than I have in ages with any other patient, and then you go to an oncologist who is absolutely unnecessary." I don't think I'll ever forget those intimidating moments; I felt like a naked little girl being scolded by a wicked stepfather because I had challenged his authority.

#### BECOMING A PARTNER

The climate in the office of Dr. Understanding, the oncologist, was much more supportive. After having studied my medical records, Dr. Understanding carefully and clearly described the status of my health. He then presented me with treatment options.

He welcomed my questions, and he credibly answered them. He was kind, patient, and open. When I mentioned the possibility of being in an NCI research study,

he said he'd gladly explore the availability of a study for me if I would like for him to. I replied, "Please do." I left Dr. Understanding's office with a feeling of confidence and control, for I was now a participating partner in the decision-making.

#### **Patient:**

You may want to consider tape-recording office visits or taking notes or having a friend take notes so that you can later review what was said.

#### **Patient:**

As of August, 1991, fifteen states require by law that any woman diagnosed with breast cancer have all her options outlined by her physician.

If your physician does not describe your options to you, ask him/her to do so; then, listen and make notes as he/she presents them. Also, ask questions, and listen to the doctor's responses.

The following day, Dr. Understanding called. He had learned that because I had already had a lumpectomy, I did not qualify for the current NCI research protocol. He would, though, be quite willing to give me the same drugs in the same degree as being given to subjects in the present study if I so desired. He suggested that I

consider my treatment options and then let him know my decision.

**Supporting Cast:**

Seek a competent--and understanding--oncologist. The person overseeing your cancer treatment should take caring personally, be available for you, and be sensitive to your concerns. Dr. Sam Broder, director of the National Cancer Institute reminds us, "Treatment is an individual choice, and doctors have to make women understand what all their options are. And what is also very clear is that no woman should feel that her point of view is irrelevant."

**OPTING FOR CHEMOTHERAPY**

The next day, I went to Dr. Understanding's office and gave him my decision. I would begin chemotherapy the following Monday.

On Monday morning, I awakened with immense fear of the unknown. Then, Carlotta called me. A Reach to Recovery breast cancer survivor had asked her to contact me because I wanted to meet someone "like me." That someone was Carlotta. Except for the times when we first learned we had cancer, our health situations were almost identical. She was already in her third cycle of chemotherapy. She had been where I was; she understood my feelings that morning.

**Patient:**

Reach out to other breast cancer patients who are undergoing similar experiences. Only they truly understand. Talking with and listening to them can give you a sense of shared problems and of comradeship because what is happening to you is also happening to them.

Accompanied by my sister Shirley, I went to Dr. Understanding's office, where the doctor told me what I would have done that day. I then met his nurse, Ms. Gentle, and sat down in the chair whose contour I would grow to know well.

As my tension grew, I closed my eyes and barely breathed. I heard the water run and knew my sister was dampening a cloth to put on my forehead during the treatment; I had read earlier that a damp cloth helped relax some patients. Next, I heard Ms. Gentle prepare the needed implements to draw my blood . . . the pop of a vial of blood being removed. . . the churning sound of a machine . . . the ripping of paper that recorded my blood count . . . the opening of containers . . . the pouring of chemicals into another vial . . . Ms. Gentle's soft, comforting voice showing concern and explaining her actions: "Are you okay?" and "I'm attaching this second vial to the same syringe to which I attached the other so I

won't have to puncture your vein twice." I sensed the toxic chemicals entering my body . . . and I knew my body would never again be the same. Ms. Gentle removed the needle, laid a piece of cotton on my violated vein, and placed a Snoop bandaid on my arm. I opened my eyes and breathed deeply.

Home again, I completed my first dose of chemo--the oral portion. Sounds accompanied this task, too: water dashing into a glass, cap popping off pill container, pills knocking each other in competition to be the first four to reach my hand, and gulps as the water guided the pills down my throat.

#### FEELING SICK AND ALONE

Saturday, the day after my sister had gone home, was the lowest cancer treatment day I experienced. I was so nauseous I could hardly get out of bed, prepare my breakfast, or eat my breakfast so that I could take the oral chemotherapy. After I ate, I began crying--uncontrollably--because I didn't think I could walk three feet to the sink where my pills were waiting for me. Suddenly, I couldn't imagine living alone for the next six months--the length of my chemotherapy. I didn't know what to do.

At that moment, Carlotta called. I explained the helplessness I was feeling. As always, she listened and understood. She invited me to go to an I Can Cope cancer support group meeting on Monday night. Feeling that "help" was on its way, I began to feel hopeful. I gained my compo-

sure, invoked my strength, and walked to the sink . . . and the pills.

Then, Tom called. He had gotten a plane ticket and would be with me on Monday.

#### REACHING OUT

Monday arrived. I met Tom at the airport, and we went directly to the I Can Cope meeting. There, we met Carlotta--the lady behind the sustaining telephone voice--as well as other cancer patients.

And, there, I gained understanding and strength as I listened to my companions in disease give of themselves. They shared information such as how to stop smoking and where to get wigs. They shared coping strategies including taking long, vigorous showers while imaging the "scrubbing" of the cancer cells from the body; meditating to reduce stress created by the mind's hurtful chatter; and keeping a journal to get in touch with one's own thoughts and feelings.

#### Patient:

Consider joining a breast cancer support group. It can be a source of emotional support, inspiration, and up-to-date information. And, it may even contribute to your longevity! A widely heralded Stanford University School of Medicine study revealed that participation in a support group by women with advanced, metastatic cancer improves their chances of survival. Although not for everyone, one patient noted, "My support group is a lifeline to my future."

They shared openness, sincerity, caring, and understanding and, they reached out to one another . . . and to me. And, with genuine ease, I reached back to them. I had self-seekingly gone to the meeting to receive support; I left the meeting knowing that true support is both received and given.

**Patient:**

Give of yourself to other breast cancer patients. You can share thoughts and feelings, serve as a "sounding board," empathize, and be sources of strength, nurturing, understanding, hope, and healing for one another.

**EXITING CHEMOTHERAPY**

The remainder of my chemotherapy treatment was not too eventful. Oh, I was tired, I had a metal taste in my mouth, my stomach always seemed to have a pit in it, my hair thinned . . . . And, I hated those injections on Day 1 and Day 8 of each 28-day cycle and those pills the first fourteen days of each cycle, but each time I went to see Ms. Gentle or took a pill, I knew I was one day closer to the end of chemotherapy.

On December 15, 1991, I took my last pill, and on December 20, I saw Dr. Understanding for the last time. That day, I gave Ms. Gentle--who never once hurt me or bruised my arm--a stuffed lamb to symbolize her gentleness. And, I gave Dr. Under-

standing a copy of my book, Listening, with this inscription: "May you always continue to listen with understanding to your patients." I then walked out of the building and obeyed my inner voice's command, "Go ahead and shout!" I wonder if everyone in Silver Spring, Maryland, heard me!

**Patient:**

If you have a medical professional who listens effectively, let him/her know how much you appreciate his/her listening to you!

**ENTERING RADIATION**

I began my radiation treatment in California, where Tom and I lived after we had been married the day after Christmas.

Tom and I first met my radiation therapist, Dr. Where-Is-He?, in early January. During our initial consultation, which began 52 minutes after the scheduled time, he said little except "Any questions?"

I wasn't afraid as I began my radiation therapy. I had accompanied Carlotta during a treatment session; also, I had read a great deal about radiation.

The three technicians who worked with me were competent and cordial. Particularly pleasant was Mr. Soothing. Before the first session, he familiarized me with the procedures I would follow.

During the next 33 days (excluding weekends), I became well acquainted with the procedures and the sounds that accompanied them: my gown rustling as it was

removed from and later returned to my personalized "mailbox" slot; the door of the dressing cubicle sticking as I opened and closed it; the gurgling aquarium, brewing coffee, and turning pages in the waiting room; the relaxing voices of the technicians as they called my name, conversed with me, explained what they were doing during the treatment, announced, "Here we go," and spoke the parting words of "See you tomorrow [or Monday]"; and the buzzing machine as I received less than a minute of radiation.

#### **Supporting Cast:**

Little is written or said about the impact that technicians (like Ms. Gentle and Mr. Soothing) have on the breast cancer patient even though they usually spend more time with the patient than do the surgeon, oncologist, or radiation therapist. Through my experiences as a breast cancer patient, I found the technicians' emotional and psychological support--often given through listening with concern--to be invaluable in helping me feel at ease during treatment sessions.

Throughout the 33 days of radiation therapy, the only noticeable side effect was that I daily grew more and more weary. Repeatedly, I asked myself, "Will I ever be perky and energetic again?" Carlotta told me that one month after having completed her radiation therapy, she had had

ninety percent of her "old energy" back. I was eager to be able to say the same!

February 27, 1992, arrived at last, and I had my final radiation treatment. My heart was happy, but my body was too tired to shout as I left the building. I did, though, let out a weak, "Hooray. The radiation is over." I wonder if anyone in Santa Rosa, California, heard me?

#### **BEGINNING ANEW**

When I arrived home that day, I experienced--as I so often had during the past ten months--the value of having supportive family members and friends. I looked at the fresh flowers Tom had given me, and I read the inspiring note Carlotta had written me:

"I truly believe in fate and although we met under the most difficult and stressful times, we have made it through the worst of it. I'm so happy that all is over for you. Now's the time to heal (mind, body, and soul). Try to forget . . . you now have a new future . . . a new beginning . . . Learn to live again!"

I listened to the love being spoken by Tom through the flowers and Carlotta through the note . . . and I am still listening . . . as I daily take two tamoxifen pills.

#### **Patient & Supporting Cast:**

Listen from the heart.

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