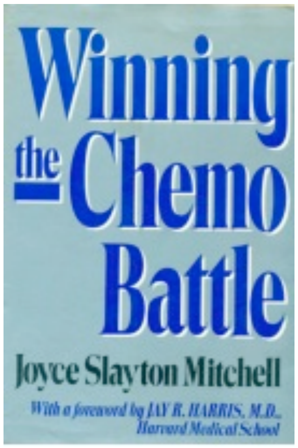
Winning the Chemo Battle

Joyce Slayton Mitchell

With a foreword by JAY R. HARRIS, M.D.,
Harvard Medical School



Here is the only breast cancer book by a "woman on the street," not a celebrity, not a doctor or nurse, not someone thanking their spouse or partner without whom they would never have survived, but one of the thousands of divorced moms with two teenagers in college dealing with breast cancer. This book will be of immense value to cancer patients and their families who have undergone or who are going into chemotherapy. It provides the information and inspiration on coping with a treatment, whose side effects can be as devastating as the disease it is meant to cure. You will laugh out loud and cry along with Joyce Slayton Mitchell for every little vignette and imagined outcome that she describes!

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EBOOK ISBN 978-1-62646-160-4

EBook published by BookLocker.com, Inc., Bradenton, Florida.

Booklocker.com, Inc.
2013

First Edition

To my fellow chemo patients

Let’s agree to win the chemo battle.
That is, to fight for our life, and on the way,
to make the most of what we get.

“So teach us to number our days that we may get a heart of wisdom.”
--Psalm 90:12

Preface

Dear Reader,

Winning the Chemo Battle is a personal account of chemotherapy. If you have had chemotherapy, you will recognize the "truth" in the book, even though your own may be different. If you are about to have chemotherapy, or if a friend or relative or spouse is about to have chemo, you will get an idea of what it's like to go through this treatment by reading about someone else.

Even though this story is about one person, when we think about it, no one takes chemotherapy alone. If you have children, you will be eager to explain to them as much about cancer and crisis and death and living as well as you can. Regardless of the age of your children, you will want to reach out to them and help them understand the implications of cancer in their own family. On the other side of you, you have parents and relatives who have had cancer or other life-threatening diseases, so when you think about where you come from, you realize the kinds of feelings and expectations that your own family history brings to you.

And then, of course, you have a spouse or good friends: your peers who want to be working this crisis out with you. They worry a lot about you, but also worry about themselves and how they would handle a life-threatening disease. Your peers wonder how they would do with a horrendous treatment like chemotherapy, as they watch you go through it.

You are not alone in chemotherapy. You bring a younger generation and an older generation and your peers with you. They all see you differently, will have needs and expectations different from yours, and will give you different kinds of support.

The goal of *Winning the Chemo Battle* is to help you plan and work toward your own quality of life. In other words, the purpose of this book is for you to see creative ways to make the best of what is … even with cancer and the possibility of a shorter life.

Yours with hope,

Joyce Slayton Mitchell

1984

Still Winning – 29 Years Later

When you are in your 40's or 50's and in the throes of dealing with breast cancer and the dreaded chemotherapy that goes with it, you may not have considered that you could be headed for a long healthy recovery that takes you to 80 years old. Not some fragile, scaled down life as a result of cancer and chemo, but as a strong and vigorous life as any other who has not shared your burden of a life-threatening disease.

Let me encourage you by example and say that as I reread these pages many years after having lived and written them, I don't remember when I stopped worrying about recurrence, when I stopped looking for signs that cancer had traveled somewhere else. Getting wholeheartedly back to my family, friends, sports, and fulfilling work was my road to an energetic future.

In the years that followed, cancer and chemo faded to a minimum - annual mammogram reminder - just like everybody else. Back in the swing of healthy eating, regular exercise, favorite sports with my Vermont tennis group and Stowe ski friend, both in our 80s, cancer no longer enters into the conversation, my mind or soul.

As you read these chemotherapy-filled pages, don't lose hope. Know that better days are ahead and that you know someone who is still going strong 29 years later – at 80 years old. My last word to you is that you can do it too. Courage will be key in that dynamic life… and so to you, my dear readers, comes hope for COURAGE!

www. JoyceSlaytonMitchell.com, Asia-American Education, Beijing, 2013

Foreword

Jay R. Harris, MD

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People diagnosed with cancer have commingled fears regarding the disease and its treatment. The emotional response to the diagnosis of “cancer” is perhaps more profound than to that of any other serious illness. This is related both to the disease’s potential for causing suffering and death and to its unpredictable poorly understood behavior. Cancer is an aberration or betrayal of one’s own body.

Given the consequences and fears associated with the disease, physicians and patients have been willing to treat it with strong measures that can have considerable side effects. The first efforts to cure the disease involved surgery, and this is still the major curative therapy used today. For many cancers, an adequate removal of the tumor can result in no further recurrence of the disease. Another form of local treatment is radiation therapy, used either alone or with limited surgery. Radiation therapy attempts to eradicate the tumor before it has a chance to spread. It can avoid the mutilation of radical surgery but can have various side effects. Patients diagnosed with cancer over the past fifty years have typically been confronted by the need for local treatment that is potentially disabling and mutilating.

In the past decade or so, a new method of cancer treatment has emerged. Called systemic therapy, this treatment affects the whole body, not just the local area of cancer.

The most common form of systemic therapy is chemotherapy, in which chemicals are employed to kill cancer cells.

The use of systemic therapy is based on the observation that in many cases local treatment is ineffective because cancer cells have already spread through the bloodstream to other areas of the body. Systemic therapy is given either by mouth or by vein to eradicate cancer cells (or metastases) located elsewhere in the body. Chemotherapy has been shown to have significant impact on a variety of cancers.

Chemotherapy has also produced a whole new set of side effects. Patients and their family and friends need to be prepared to deal with these. In this book, Joyce Slayton Mitchell describes in a compelling and lively manner many of the typical reactions to chemotherapy and some of the coping mechanisms that were useful to her. I believe that it will help patients, their families, and their friends anticipate and cope with the effects of chemotherapy. Certainly, the personal stories will provide laughter and inspiration. I also believe that *Winning the Chemo Battle* will be useful for young health professionals (nurses and physicians) who deal with cancer patients, by helping them understand some of the emotions typical of many such patients.

A caveat regarding the use of any lay book on cancer needs to be mentioned. Such books should not and cannot substitute for effective communication between a patient and his or her team of health professionals. The main thrust of *Winning the Chemo Battle*--and a valuable one—is its description of the emotional response to the treatment that many people share.

Introduction

October 4, 1984

Dear Ned and Elizabeth,

I’m sorry to be writing to tell you the bad news that you have to know. I’ve got breast cancer. Again. And it’s in the same place. I discovered a change in my breast before I went to Paris, but I talked myself into thinking it was a side effect of radiation rather than recurrent cancer. I hate telling you about it because I hate having it.

At least I can say that I’m glad to be writing you now—when you are both happily at your own college, taking courses that interest you, and are places you chose on your own and where you are each taking so much responsibility for financial, academic, and social areas of your life. So at least my children are in place as I start my second round of cancer.

I know how well you handled it when I first had cancer, five years ago. But at that time we were all living together. Now, with each of you in college in California, and your Dad and I divorced and living in different places, I know a family crisis can be more confusing than ever. But do remember that we are still a family when it comes to being there for each other. You both know that, after 24 years of marriage, your dad and I count on each other. Our family is still a team that works together when any one of us needs unusual support.

And you both know that I have my home in place. It’s the first place that’s felt like home to me since I left Vermont, and I’m sure it will be a good place for healing.

And my work is certainly getting in place. Wish I could tend to a little more negotiation of book contracts before surgery. But as Dr. Samuel Hellman (same doctor I had in Boston, who has since moved to Sloan-Kettering hospital--top cancer research institute in the world, where he is Physician-in-chief, which means the big cheese, the top dog) said to me this morning, “You can negotiate those contracts just as well November tenth as October tenth!” So—that’s the end of that idea. Now I know having a mother with cancer is hard on kids. Especially on you, Elizabeth, knowing a daughter’s chances of breast cancer increase if her mother has it. But even increased chances don’t mean you will have it. As you have both learned earlier, I know how to meet this challenge very well—and I expect the same from you.

And Ned, I realize that because of the course you took last quarter on cancer and biology, you know more about cancer than you did before, and that makes it harder on you. The thing I learn most about—as I go along asking and reading—is that so much about cancer is unknown that it’s almost impossible to predict what is going to happen with recurrences, cures, and causes. So I refuse to get scared about “what’s going to happen,” I’m quite sure that no one knows.

What I want each of you to do is to take this as a crisis in life and to notice how you respond to it. Whom do you tell? Whom do you not tell? What do you feel like? What do you want to ask? To know? Whom will you ask? Do you wish you knew more, knew less?

Every crisis, no matter what it is—going through a divorce, getting hurt, losing a dream, having cancer, losing a job or a friend—teaches us about ourselves and strengthens us to handle the next knock that comes our way. There isn't anyone around who doesn't get her share of crisis. If you think there is, it's only because you don't know her well enough.

Personally, I find physical knocks like cancer easier to take than relationship ones. Not that anyone has a choice: that's exactly what a crisis is—no choice—it's just thrown at you. But at least it seems the whole world is on your side with a physical illness like cancer. It's not the same with a "relationship disease" like divorce. Somehow, it's a lot easier for others to understand an illness and somehow more acceptable to be sympathetic. Even though your dad and I were miserable during the last few years of our marriage, we still respect the good years we had together and find it easier, after divorce, to be supportive of one another.

You both know that I intend to do whatever it takes to overcome this crisis, and I plan to see you both at Christmas and to come to California for your spring break, Elizabeth, and to go visit you, Ned, for your birthday in March, just the way we discussed this fall.

I think, too, that it's easier for me, the person with cancer, because I am doing something about it, than it is for the children, spouse, other relatives, and friends of the person. Even though it may be easier for me, I still expect both of you to deal with it constructively, learn and grow from it, as if it were any crisis, apply your reactions to your own life, and not use it for the things you need an excuse for. I notice I’ve already been tempted a couple times to do that. For example, saying I can’t do this or that because I’ve got cancer! Things I didn’t want to do in the first place. Know what I mean?

What I would like most is for you to keep in touch with me with your letters. Nothing is a greater gift from you to me than these letters. Ned, getting your letter today just took me right out of figuring this letter out—to the enjoyment you are getting from your classes and plans for next year in Paris. And, Elizabeth, your letters to me and your artwork are always a wonderful way for us to be in touch.

I’m going to go and cook a chicken, make chicken soup, and have a nice “comfort” dinner with my friends. How I wish you two could also sit down with me and share my chicken dinner!

Courage and love,

Mom

The Chemical Takeover

I was scared all right. Excited scared. The kind of scared that wonders what's going to happen next. The kind of scared that's curious. But also the protected kind of scared—within a structure that's going to take care of you. Not the being-followed-on-a-dark-street-with-no-policeman-in-sight scared.

It was 4:00 P.M. on the first day of my chemotherapy. I figured I could go right to bed and sleep for the worst of it if I made an appointment as late as possible in the day for my first chemo hit. Betsy, my tall, hardworking roommate, a health administrator went with me. Betsy and I, both fresh from Vermont, share many friends, values, and information about each other's lives, the way old friends do. Both in our early fifties and divorced, with children in college, we form a primary support system in our New York City apartment. We're family for each other; we appreciate each other for being there.

Betsy left work early and met me in the general waiting room on the fourth floor at the Sloan-Kettering outpatient hospital. I pretended it was nothing, like going to the dentist. I tried to appear cool, reading the *New York Times* as I figured out how to act next. An awful lot of people were there, and almost all had someone with them. Some had no hair; many were women with wigs; some read; others were visiting with their neighbors. Most were older people, a few middle-aged like me, a very few young adults. The outstanding thing about the room, besides the people in it, were the exquisite flower arrangements. They reminded me of the extraordinary flowers in the Great Hall of The

Metropolitan Museum. Not ordinary tulips, daffodils, and roses, they ere exotic, tropical-looking flowers, three or four arranged in green bottles, in several spots around the room.

When I arrived on the fourth floor and asked for the chemo unit, I learned that I had to qualify for entry. First, I had to check in. Next, I took a number from a baker-shop ticket machine and waited until my number was shouted over a loudspeaker so loudly that everyone in the room jumped from the jolt of the noise! Then I got to go in for a finger stick. After that, I was called to weight in (in kilograms, which shows you how scientific they are) and to have my temperature and blood pressure measured. When I passed all of these tests (and sometimes you don't, especially on the white blood cell count), the loudspeaker again blared my name. Once more everyone in the crowded waiting room was startled by the obtrusive noise: people with hearing aids automatically reached for they volume controls. I hurried to the doctor's office. Dr. Minelli wrote my chemical prescription, and I asked him a hundred questions. He explained that he would drip (infuse slowly through a tube) an antinausea drug and give me a prescription for an antinausea suppository, which I should insert as soon as I got home. He made an appointment for a month later and sent me on to the chemo unit. I qualified. I was allowed to enter the holy of holies, the inner sanctum of the fourth floor—the chemo unit.

First I looked for a seat and place to put my coat in a very small room without windows. It was full of people whose faces expressed a little more seriousness than those did in the outer room. In this serious little room, with its few magazines, no exotic flower arrangements, a wheelchair or two hovering at the edges, I first met Connie, the chemo-unit receptionist.

I handed her my prescription, which she filed in her big black notebook. (Later I learned that when anyone forgets or loses a prescription, she always finds it in time to give the orders.) Connie is a glamorous-looking, trendy, high-fashion black woman who schedules everyone's chemotherapy. It didn't take me long to learn that she's the boss. All the chemo nurses, pharmacists, doctors, and patients to through Connie. No one gets anywhere or anything until Connie says so. Right in back of her is the open window on the pharmacy, through which she yells like a waitress to a short-order cook as she calls out, "Two Adiamycin, one Cytoxan, and three 5-FUs to go!" She knows and calls everyone by name. And she's funny.

After my first visit she asked, "How you doing?"

"The last hit was too hard on me," I replied.

"Sorry it must have been the wrong stuff; I'll see what I can do," was her flip response. It brought a smile to all the chemo patients, who listen to Connie for their waiting-room entertainment. When I asked her how soon I'd be called, she would go through the stacks of prescriptions, stalk out back through the chemo stations, return, and give me an accurate estimate. Connie often has candy on her desk for all of us who want it. I never once had a chemo hit without her being there. If I worked at Sloan-Kettering and had a nutrition program or a patient workshop and wanted folks to come, I'd sell her first on the program to get the people there. If I wanted to reach all of the chemo patients with a message, I'd do it through Connie. My idea of communications between hospital and patients starts with Connie. The whole Sloan-Kettering chemo unit revolves around the boss of the chemo unit—Connie.

My first chemo nurse, Ms. Gentry, walked past Connie's desk and announced my name. She was British and the head nurse of the unit. I learned that all the nurses had special training and had received a chemotherapy certificate for this job. The unit had twenty comfortable chairs set up in private little cubbyholes A curtain could be drawn around each chair and nurse's table, where the chemo-certified nurse always had a special platter of chemicals, designed just for me. There was a drip stand at each cubbyhole. Some chairs had one arm on them and looked like a school desk; others were like the big TV lounge chairs that many Americans buy the man in the house on Father's Day (except in sophisticated New York City, of course) or like a dentist's or barber's chair. Those lounging chairs are for the long drips, those lasting an hour or more. But my first hit, for some reason, was in a regular chair even though my drip was to last an hour. I sat right on the edge listening to every word the nurse was telling me; trying to figure out every detail that was going on. There was no way I could have relaxed and slept even if I had been in that big lounging chair! Besides, I hadn't yet learned the dangers of this nice friendly nurse and comfortable-chair chemo unit.

The nurse introduced herself; I introduced Betsy, who sat in a chair in the little cubbyhole right beside me. As it turned out, all three big hits brought a different friend into that chair. With a friend beside me, I felt as if another person's body were taking in the chemicals with me, diluting the poison so that I wouldn't get any more than I could tolerate.

The nurse started her procedure by giving me a booklet, *Chemotherapy and You: A Guide to Self-Help during Treatment,* to take home. It contained a list of chemicals and their possible side effects. She told me that chemotherapy is simply the use of drugs or medications to treat cancer. It can consist of one drug or of a group of drugs that work together. She said there are three ways to administer chemotherapy. In the oral method the drugs enter the bloodstream through the lining of the stomach or upper intestines when taken by mouth. In the intramuscular (IM) method, they are injected into a muscle in order to be slowly absorbed into the bloodstream. In the most common, the intravenous (IV, or drip), method they are injected or infused into a vein, in order to be absorbed very fast. When I jokingly said I preferred the oral, she didn't give me that choice. "How you take the drug is part of the doctor's prescription," she explained to me. "Cytoxan, for example, can be given either through a drip or orally. Chances are you will get the stronger dosage in your first three months through the drip, and the lower dosages will come later through pills you take at home."

Next, Ms. Gentry read which chemicals were prescribed for me, showed them to me in the book, and then circled each drug I was getting. At the same time, she pointed out the particular container of each chemical on her tray. First was the red syringe with the Adriamycin. Oh yes, that's the one that causes total hair loss, nausea, vomiting, lowered blood counts, red urine, and mouth sores. Bur the little book didn't mention the worst side effect of all, heart failure. (I knew that only because Dr. Minelli had said to me when first reviewing my record, "I'll prescribe Adriamycin if I can talk Dr. Hellman into it." "Why will you have to persuade him?" I innocently asked. "Because one of its side effects is heart failure," he said. "Heart failure!" I shot back. "Talk *him* into it? It's my heart you're talking about!" Needless to say, he convinced us both.) The clear-looking liquid on the drip stand was Cytoxan. The list of its side effects read, "Nausea, vomiting, hair loss, lowered blood counts, blood in urine, loss of appetite." Then there was the bottle with the water “chaser” and, finally, the other syringe, containing 5 F-U. I read, “Nausea, vomiting, diarrhea, lower blood counts, mouth sores, loss of coordination, skin darkening, hair loss.” The chemo nurse talked about what was going on and answered questions the whole time I was there—just over an hour. As it was my first round of therapy, she never left my side. Ms. Gentry appeared very competent and professional, and I was as relaxed as a scared chemo patient can be. She pointed out that although some people have this or that reaction, others suffer absolutely no side effects.

After this flood of information, the first of many hunts was on for the perfect vein on the back of my right hand.

“Why do you use the back of my hand?” I asked.

“We start as far out on your extremities as possible in case the vein breaks down; then we have some place to go further up your wrist and arm. In that way, if we have to make a second puncture, the drugs won’t leak from the first.”

“In case the vein breaks down?” I asked.

“Yes, with continual use, especially when you’re on chemo each week, the fragile veins sometimes don’t hold up for carrying the drugs. Or the needle goes through the other side of the vein, and we have to find another one. We always test with water to be sure the vein will carry the drug properly.”

Ms. Gentry went on, “In your case, we use only the right hand, because the lymph nodes were removed on your left side. With a lymph system, your immune system is lowered in your left arm, and so we avoid using needles because of the possibilities of creating an infection on that side.” Oh yes, I remembered that from post surgery classes. When I made a fist while a rubber band constricted my upper arm, several good possibilities presented themselves. The first time was the best time. The experienced nurse easily found my fresh, new hand vein. One tiny prick, a piece of tape, and a lot of conversation about what she was looking for, and it was all over. She injected a shot of water into the taped needle on my hand to test her route, then proceeded to the first chemical.

Cytoxan, a clear colored liquid, dripped from a bottle hanging on the drip stand in front of me through the plastic tubing and into the needle on my hand. Ohhhhhhhhh—strange feeling in my nose—cold---the Cytoxan looks like vodka, feels like the first fresh horseradish of the season in Vermont, opening every nose and sinus passage. I can hear my father at our Easter table saying, "Good for what ails you; it clears out your head!" Only this time it won't go away! My nose feels exposed, way inside. The Adriamycin is red, like a danger sign. Will she inject it from the syringe? Why are two chemicals in syringes instead of in bottles? Oh, good: she injects it in the needle already taped to the back of my hand, and I get all four drugs in one needle. Phew. That's a help. How can people be scared of a tiny little needle when they've got a great big life-threatening cancer and when this is the only opportunity for knocking those cancer cells dead? Easy.

For the last one, another syringe was injected, but 5-FU was a nothing experience. No color, no Cytoxan-like response in my nose and head. Nothing. Just as easy as the water chaser that hopefully cleaned out my veins, washing away the heavy chemicals. I said my thank-yous, good-byes, and that-wasn't-so-bad. Then Betsy and I left.

We splurged and took a cab home. I could have walked. But being scared cautious now, I had all antennae out to see what was going on in my body. How would I respond? Did I feel light-headed? Weak? Slowed down? Thirsty? Drowsy? Wide awake? What were those chemicals doing in my body as I walked out of Sloan-Kettering?

I felt good. Not exuberant high-energy, but good.

Several friends called when I got home by 7 P.M. and a church friend came by with Chinese take-out food for Betsy and herself, in case I had a problem with cooking smells. I started drinking my quota of water and liquids right away to flush out those killer drugs as soon as possible—as I had been told. Betsy stood close by but could see I was moving very much on my own steam, so she didn't hover. I watched Dan Rather. I was very aware of my body and was happy that I felt so good. At seven-thirty I decided to eat with my friends, mostly the bland rice. After all, I wasn't feeling a bit queasy. So we sat down, joyful that it had been so easy—nothing like what I had heard. Besides, Chinese food was my favorite. In fact, I was ravenous. By then I had decided that rice would be the perfect food to sop up all those drugs running around in my body and to diminish any possible side effects. So, I ate more than usual. Any why not a few vegetables? And why not try the wonton? Everyone was in a good mood. My friends were glad that I'd accepted the chemo treatment after all and were happy with the thought that I would be getting the best cancer treatment in the world. Soon, though, I began to feel a little odd, and I was the first to leave the table. Although unable to describe what the odd feeling was exactly, I was very sure that it wasn't normal. But I was glad to feel a little sleepy. I went to bed at nine o'clock with a slight feeling of a chemical buildup—whatever that is—in my body, something like tight skin all over my body, with my flesh and liquids expanding within that skin.

I dozed off and then opened my eyes. I saw the clock. It was 11 P.M., six hours after my first hit. All of a sudden, VA VA VOOM! The chemical takeover: my feet hit the floor, I bounded into the bathroom, flipped up the seat just in time to explode like a time bomb into the toilet. Betsy, whose room is closest to the bathroom, had heard me coming. Her cool hand was on my hot head, just as my mother's hand had been during all that car sickness when I was three, four, and five years old, and just as, later the hand of Bill, my former husband, had been whenever I had three martinis. But there—loving hands on my sick forehead—the similarities ended. I threw up, retched, vomited, heaved, and retched some more and just couldn't stop. My body felt bloated in every direction, my skin stretched and punctured as if I'd thrown up through each pore of my body. I couldn't stop. Every grain of rice, every sip of water, that horrendous wonton taste made me shudder to my soul, and I got sicker and sicker as I knelt there. Finally, staggering up, I reached for the green plastic basin that I'd brought home from Sloan-Kettering surgery, to take to my room. I glanced at the mirror on my way out and saw a red, puffy face with a rash just as if I had the measles. I staggered back to bed, thanking Betsy for being there.

My chemo sickness had seriously begun. I found and inserted the prescribed antinausea suppository, remembering how I'd used suppositories with both children when they were sick babies. I thought of Ned when he'd been sick from his toxic asthma medicine. I thought of my mother and her excruciating migraine headaches when I was a little girl. I thought of being in labor with both children and unable to ever get comfortable.

The antinausea stuff made me drowsy and weaker. Oh no. I could feel the buildup coming again. I tried lying on my side, my stomach, my back. Nothing worked. What was happening to me? Restless, but trying to stabilize my body with willpower, I was overcome again by the feeling of the time bomb going off as I ran down the hall to the toilet, retching for what seemed ages. Groaning, I staggered back to bed. Oh, I thought, if only I can find a comfortable position. I feel so weak I can't relax. I don't have the strength to figure it out. I toss and turn. What's happening? I feel the buildup again. Its 1 A.M. I can't hold it in. I can't relax. I can't stabilize.

I grabbed the green basin and ran, throwing up before I got to the toilet. Oh, that rice: there's more in my stomach—those Chinese-sauce tastes repulse me. How could I have been so dumb as to eat anything? Oh Lord, let me stop retching so that I can just stand up and get back to bed.

Why isn't there relief after throwing up? Why don't I feel better? There's nothing in my stomach to come up. Why can't I find a good position in bed? Close your eyes—try to relax. How did I do it with childbirth pains? What were those relaxing exercises I learned? This is worse: there's no relaxing in between. There must be a way to let go. What is this tension, this constant buildup?" Oh no, back to the bathroom. It's 2 A.M. Betsy won't have any sleep tonight, and she needs her rest for her job.

"Betsy, how can I keep throwing up? I can't stop retching. Don't get up with me next time. Look at my skin—its so red and puffy." Ohhhhhhh, get back in bed, when will it be over? Do the cancer cells feel all of this? Are they getting wiped out along with me? Why don't I feel better after I throw up? Why can't I handle this better? It's 4

A.M., then 5, 6, 7 and 8 A.M. I am throwing up on the hour. “Betsy, don’t you have to go now? You’ve brought your work home for the morning? Oh, that’s wonderful!”

How can I keep throwing up? I’ve used these suppositories every four hours. They seem to make me weak and just as nauseous. Not again! At 9 A.M. a shorter retching; another at 10 A.M. Will it ever stop? 11 A.M. I’ll just stay here. I’m not going into the bathroom again. I can’t make it again. I’m practically crawling back to bed. Betsy even has to take my arm. I’m absolutely exhausted. What do people do who are alone with this? I’ll close my eyes; I don’t feel the buildup. My stomach is so sore. I’m so hot, I’m so miserable. I drift off. It’s been twelve hours. Oh, thank, God. P-E-A-C-E at last. I hear Betsy on the phone. “Hard night—she’s resting” I quickly snatch my green basin; just a little spit. It’s over. Chemo Hit No. 1.

Thank God for Betsy. We came to share an apartment because she came down from Vermont a year after me to take on the biggest private home health agency in the country, as vice-president of New York City’s Visiting Nurses Service. But before all of that she herself was a nurse. She’s my resource for figuring everything out, my primary source of medical information. “What is this drug, and what is that? What does Cytoxan do? Have you heard of 5 F-U? Will you find out about Adriamycin? Does it really hurt your heart? Why do I crave sugar? Why is my face red? Why is my whole body hot? How can you stand these chemical smells in our apartment? Did Bill, Elizabeth, Ned call? What did you tell them? Do we have any apples? Or canned fruit? Who’s in the living room? What time is it? Do you think ginger ale would be good for me? Oh, Betsy, thank you for holding my head! Can you close my window? The chemical smells are still coming in! What time will you be home? What is Methotrexate? Cytoxan? Is

Prednisone the same thing used for tennis elbow? What's the difference between dripping in Cytoxan and taking it orally? Why can everything be oral? Can you imagine, Betsy, they prescribed an oral antinausea when they know I can't stop throwing up? Is it hot in here? Is it cold in here? Do we have any potatoes, pasta, oatmeal? Are there any visiting nurses who teach relaxation techniques? Are there any nutrition nurses especially for cancer? I know the VNS has the best hospice program in the Big Apple, but I hope I'm not yet ready to ask for that!"

I'm so weak my stomach hurts. How can I recover? The sooner I get some food in my stomach, the sooner I'll be able to stabilize. I sleep an hour, then another hour. My clock reads 1 P.M. and then 2. Then it's 5 P.M. Twenty-four hours has passed since my hit. Oh, I'm so weak and miserable. Maybe a little banana will help. That's what they feed sick babies in New Guinea: ripe banana, easy on the stomach. Oh, it's so sore. I'm so thirsty. I can't possibly drink anything and won't be able to flush out those chemicals in my bladder, my liver, my kidneys, and where else did they say? Oh, God.

It's now been forty-eight hours. Maybe an ounce of ginger ale. When Ned was a little boy and taking powerful medicine, his doctor said, "Just an ounce of liquid to see if it stays down." Oh, Ned I never realized how your body felt on that asthma medicine every four hours for years. Did I comfort you enough? Is this how you felt? Was I patient with you? Oh, God that tastes good. Feels as if I could drink two ounces. Better not.

Two and a half days after my first hit. Oatmeal. That's what I want. Oatmeal will be perfect. I remember how good that oatmeal was every Vermont winter morning. My dad always made the oatmeal. He had more ideas about how to make perfect oatmeal. I don’t remember ever meeting anyone else so into oatmeal. Just before he went to bed, he would fix the oatmeal in the double boiler and set it on the register of our coal furnace. Even when the furnace was turned down as far as possible, enough heat came out of the register to cook the cereal. I’d be the first one up, and I remember that thick crust on top of the pot: I’d roll it back, putting my spoon underneath to dish out the soft part so as not to get any of the top crust. We even had a special way to eat it, learned from my grandfather. First, put the oatmeal into the hot bowl. Then make a little well in the center and fill it with maple syrup.. Next, pour heavy cream (of course nowadays I use milk) on the outside edge of the dish, just enough so it doesn’t go over the top of the oatmeal and touch the syrup. If the consistency of the oatmeal is perfect, it floats in the milk and swirls all in one piece in the bowl. Finally, with the first bite make a little channel between the maple syrup and the milk and let the milk flow in the center, while the syrup flows out. I can just see it now. Oh boy! I’m going to survive this inhumane treatment. Hmmmmm. Oatmeal.

Fight to Win!

My doctor comes in and out of here so fast that it’s impossible to ask him anything.

Just his running in and out makes me forget the questions I was going to ask him anyway! I remember the black woman in my exercise and talk-it-over class at Sloan-Kettering who said this to me. She was always crying. One day in class she told the group that she couldn’t tell anyone at work where she was. She said when people go to the hospital they usually write their address on the bulletin board and everyone sends them cards or calls. But if you end up at Sloan-Kettering, everyone knows you have cancer, which, like leprosy, scares everyone off—they write you off as dead—you could lose your job—and in the meantime no support will be coming to her from the workplace.

I walked by this woman’s room one morning and, peeking in, found that she was still crying. A visiting friend was sitting by her bed, crying with her. I stepped in and asked if I could help. Knowing I asked millions of questions in class, she asked me how I got the doctor to answer my questions. Trying to get a smile out of her, I acted out a little scene. “First of all,” I said. “write out all of your questions on a piece of paper before he gets here. Now, let’s figure this out together. Let’s start with your exercise rope over there. Get your friend to take your rope and stand right in back of this chair. Now, when the doctor comes running in here, you get his attention by smiling at him as if you didn't have any questions. Just as he relaxes, you jump out of bed and push him back in this chair, your friend will run around the back and quickly drop the rope around him and tie him there. Next, you relax, take out your list, and say, 'Listen here, Doc. I've got this list of questions. And we're going to stay right here until I understand everything on my list. So if you want to say it in a way nobody but a medic can understand, that's okay with me—I've got all week for you to figure out how to answer my questions until I understand.'"

The "control over the doctor" image soon had my tearful classmate and her friend in stitches. Then she shook her head and said, "I don't know how you do it. How can you be a fighter when you've got cancer?" I lowered my voice and whispered, "I'll tell you a secret: I was a fighter before I got cancer. Weren't you?"

"Yeah, but . . . "

Yeah but nothing. Think of your own history. Think of all those black women fighting for their lives. Think of Sojourner Truth, right on our U.S. postage stamps. They're all fighters. What's more important than fighting for your life? How else can we win our chemo battle, if we don't fight back? Isn't it only natural to fight for our lives? How much do we have to think about it? Are some of us so discouraged that fighting doesn't seem enough? So we sometimes think that our own personal fight isn't worth the effort to go up against this dreaded deadly disease? What more do we need to be encouraged enough to fight?

After all, we’ve read the stories about how cancer victims who have been pronounced as good as dead fight back, and the next thing you know the doctors are saying a miracle happened and the cancer is in remission. And we’ve read the scientific evidence that research shows that cancer patients who have a fighting spirit and who don’t accept a negative verdict are far more likely to improve than those who stoically accept feelings of helplessness and hopelessness.

Let’s say you agree. You do want to fight back. Then the big questions are, how can we fight cancer? How can we win? What does it mean to win the chemo battle? How can we win if our remission doesn’t last? How can we win when we’re dying? The first important step in winning the chemo battle is to accept the premise that winning doesn’t mean living forever, or even living the normal range of years. Winning means the process of fighting for life in a life-threatening situation. As soon as we begin to fight, we take control; we change the quality of our life, regardless of whether we know where the cancer is or is not in our body. We take control by choosing to take action in our daily life with the sickness and the horrendous side effects of chemotherapy. We ask each other for ways to ease the side effects. We learn to notice when we feel well enough for action. Our own agenda means exercise, our job, getting together with friends, reading, writing a letter, making a phone call—using our moment of energy to reach out to someone special, to acknowledge our encouraging friends. Taking advantage of the good moments of our life, that is the fight. Fighting gives us control, and control changes our condition of stress into a condition of healing. Going in the direction of rushing the good moments, however few, is winning.

Sound easy? Just get right in there and do what you most love to do—even as short as the time may be? There's a catch! You've got to know what you're going to do to make the most of your good moments. How to use the energy, for however short a time, to do what feels best for you. How to take over and not let the dreadful fact of cancer ruin the time you do have to enjoy life. After all, the answers aren't there for us with cancer. That's one of the most scary factors: there are so many unknowns. To think that even the front page of the *New York Times* in 1986 has to state, "Breast cancer continues to strike women with undiminished force and still baffles science. . . .What causes breast cancer and what can be done to prevent it—remains unanswered."

Those of you who have been through the treatment for cancer, or have been with friends and relatives who have, will have learned that you won't get every question answered, because there are no final answers. We won't get all the information we want, because it doesn't all exist, to make sound decisions or to feel on top of the situation. We won't get control by knowing everything, so we have to look somewhere else for control. That somewhere else has to be in the realm of what we do know. We do know how we feel right now. Take away the anxiety of not knowing, take away the fear of death, take away the dread of our disease, take away the guilty feeling for having cancer, take away the side effects of chemotherapy, and every single one of us has some time. Turning that time into actively seeking the good things in life—no matter how short—is where we can each find our personal answers and help our chemo family and friends find theirs.

I remember a Sunday afternoon when I looked out to a very blue sky. Sunday was always the day when I began to recover enough from a Thursday hit to think I was going to live until the next one. Finally stabilizing my stomach with part of a banana and my latest concoction of liquids, I thought about going out. A friend was visiting and asked if I felt like taking a little walk. I groaned but listened to what she had in mind. "On Ninetieth Street and Fifth Avenue, just a few blocks away, is a beautiful building, the National Academy of Design, and there's a fascinating show today of American landscapes," she said. "I think you'd love looking at those paintings; they're very much like those of the Hudson River School you liked at the National Gallery." I perked up, decided to give it a try, got dressed, walked slowly up the hill to Third Avenue, then up to Lexington and on to Park, and crossed Madison. There, on Fifth Avenue, was the loveliest-looking building I'd seen in a long time. The beauty of it thrilled me so. As I stood there taking it all in, I clearly remembered my first look at the Taj Mahal. Not that the buildings were the same, not that it was one of the wonders of the world, but my response was the same. That exhilarating experience of seeing a spectacular design in a building was the same. The wonder of a "something" that lifted me out of myself was the same. Once inside this very small gallery, I saw an exquisite winding staircase and chandelier that took me by surprise. I slowly walked up the elegant stairs, stopping often to gather my strength and to take in an art world—the most wonderful change from the medical world I could imagine. When I got back home, I looked at the clock and saw that I'd been gone for ninety minutes. I was astounded—all of that beauty and new perspective in just an hour and a half. It turned my life around. I knew that to be surprised by beauty was one important reason to live. It was worth side effects that I hate. Worth chemotherapy toward which I direct my anger, instead of cancer. Worth getting better for. Worth the fight.

Isn’t it amazing that ninety minutes made the ordeal of chemo worthwhile? What kind of an agenda can you bring to your life that shows the fight in you? Figuring out an agenda means we first have to figure out our values. In career development workshops for college students, I have often used an exercise to help them rank their values. I’d ask the students, “If you had one year, one month, one day to live, how would you live it?” I always used the question for students in the process of choosing their careers. I never thought I’d be living out that exercise because I had cancer. The lucky chemo patients have given their values and priorities some thought before they got cancer, before they started on chemo. Understanding ones values is hard for a lot of mothers who have spent most of their lives with shoulds about husband and children. Often, they don’t see their own priorities, without the shoulds. It’s not unusual for them to decide they should spend their time with their teenagers, or take a trip with their husband, when they really want to get away from the family or go visit their sister or a friend on their own. Mothers just aren’t used to saying what they want. When they get cancer or a life-threatening disease is perhaps the first time that some women and men give themselves permission to ask, “What is my agenda?”

I met a woman in her early thirties at Sloan-Kettering who told me she had to be on chemo the rest of her life. Smiling, she said, “But I don’t mind. I never knew my priorities until I got cancer, and I’ve turned my whole life around now, knowing what I want to do most and doing it. I think cancer is good for people. They get their priorities straight!” I was, to put it mildly, shocked, and I thought, some of us with cancer already knew our priorities. I had been through a divorce after twenty-four years of marriage and already had my priorities straight, and didn’t need cancer to check them out.

I also met a man of about the same age who was told he had less than a year to live and who had no idea how he wanted to spend it. He had a young child and a wife whom he had been about to divorce before the diagnosis. He was sure he didn't want to be with them. He wasn't sure what he wanted to do. He gave up his work but missed it. He loved to play golf but didn't dare get out on the course, because he was afraid he'd have a seizure. Working out an agenda isn't automatic, as we can quickly see when we ask our friends, "How would you live your last year, month, day?" Now ask yourself, "How do I want to spend a one-, two-, or three-hour period of feeling better than usual? How will I fill my good moments? How will I make my life count, no matter how short?"

Another man, a well-known writer, has a wife who is dedicated to making the most of their time together, doing everything she can to ensure that they have as many good moments as possible. When his cancer was first diagnosed, he was told he would never leave the hospital. By the time he had obtained a second opinion, he'd already had enough good moments to make him want to fight for his life. He and his wife take very slow walks to their favorite restaurants and often meet one friend there—any more than one is too many. "We usually have one course—a soup, or dessert and coffee, or small salad—and that's it," she says. "But it's the feeling of being where we like to be, for as short a time as it feels okay, that counts. Looking at him, most people think he doesn't have any 'good time,' but he does and so do I. We have freed ourselves from the consequences of what will happen next with cancer, and we do have thrilling moments of life, laughter, friendly faces-not just scared, worried, and feeling-sorry-for-us faces. At this point, we both consider our good times a miracle, each day we fight for his life."

One woman I talked to had a hard time saying no to all the people who wanted to come and visit her at home. Finally, she found an assertive way to say that a half- hour with one friend when she felt up to it was how she wanted to spend her time. Knowing that she would see only whom she wanted to see within a time limit and that her friends understood, she began to enjoy her "up" time.

One's sense of time varies, from a few good minutes when we try to stabilize after a big hit to a couple of weeks before the next one. I decided to go for the big time—long weekends—if I ever recovered from the big hits. My first trip was in January to Key West, a perfect place for me. Without a single hair on my head: with that pale, white sickly-looking scalp (very unlike the healthy tanned heads of men with naturally bald heads); without a prosthetic breast, because I hadn't been out of surgery for long, I fit right in with all the characters who roam the streets of Key West. I had a straw hat but often went without it just to get a little sun. No one batted an eye, though. I swam in the pool in my T-shirt, but how I ever got myself seven miles out at sea on a snorkeling boat is beyond me. I was the one trying to stabilize her body. And I'm the one who always got seasick, or carsick, or just any little motion sick. My friend had never been to Key West before and wanted to snorkel. Not until the boat kept going and going and going did I realize that we wouldn't be standing in the water; we'd be in water way over my five feet. That meant my life would depend on my swimming with my left arm. I looked around at the others on the boat with their snorkel and fins and suddenly noticed that they were all aged twenty, twenty-one, twenty-two, or twenty-five tops. I was the only single-breasted mother with fins on board. God! I thought. What am I doing here? I don't even care about looking at fish in an aquarium.

Nor surprisingly, this exhausting experience had its consequences: my most dramatic cancer dream. I went to bed early, feeling low on energy and down after a day of too much sun, seasickness, and exercise. In my dream, I woke up, went into the bathroom, and looked into the mirror. My eyebrows had grown six to eight inches long, down over my face. I could see a small space on my forehead between where my hairline was supposed to be and this long, curly growth of eyebrow hair, which looked absolutely bizarre. I didn't know what to do: Should I cut them? Should I have a friend cut them? Should I call the doctor? Would they grow again if I cut them? My kids saw me, and at the same moment there was an automobile accident outside. A man had run over someone with a truck. I watched them pull the body out from under the truck; then everyone turned and looked at me and, seeing my weird eyebrows and no hair, started to chase me. I was in Vermont. It was winter, and the sidewalks were very icy. I had on my L. L. Bean boots but couldn't get enough traction to run fast. I tried to grab the rail at the iron bridge to pull me along and go faster and to get better traction. But it was too icy even with my good rubber tread. I started slipping and slipping. I could picture my boots trying to grab the ice, but it was no good; I couldn't get a firm hold and was helplessly slipping . . .

What a relief to wake up! What kinds of anxiety do we live with in our unconscious? How symbolic is hair, anyway? Maybe I wasn't getting away with looking like "one of the crowd" in Key West, after all.

My dream was just a dream. I knew what I was after in the real Key West. Having been there two years earlier without cancer, I knew what I wanted: eating fresh fish, having everything be within walking distance, reading on a beautiful beach, seeing tropical flowers and palms, seeing the sunset. It was all there. Being in warm, sunny Key West was wonderful; it gave me a real chance to recover, to gather my strength for the second phase.

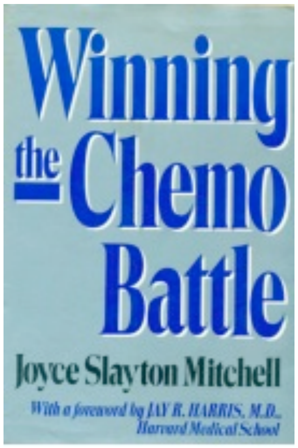
And then there was that long Vermont ski weekend when the first big hits were all over. I was still on chemo, not drinking even a beer after skiing, but that Vermont weekend was nevertheless heavenly. I was testing again, wondering if my knees and legs would still work, wondering if my left arm would work. Could I push with my left ski pole? Carry my skis, poles, and boots to the lift? I was testing to see if life was still worth living. Testing to see if chemo was worth the agony. Testing to find out if I could really do my agenda.

I remember that Vermont friends who had heard about my chemotherapy ordeal expected me to look half-dead. So when they saw me in my ski clothes, they were surprised to see a person who was so healthy, ruddy, and vigorous—even without hair. Friendly Fidel, a Hardwick boy I grew up with, now the handsome man in charge of a Stowe chair lift, came running out of his little hut to give me a big kiss and say, “I heard you were skiing!” He just stood looking at me, nodding his head, eyes sparkling, and said, “ I can’t believe you’re here.” I could tell by Fidel’s expressiveness that he, like others who knew me, changed his perception from “Poor Joyce, she’s got cancer again,” after they saw me.

Those were the good, big times in my chemo program. The shorter times were good, too. The walks, the letters, the phone calls, the oatmeal, the first thing that settled in my stomach, the new day without hyper smells, the forgetting that my body was loaded with poisons and the remembering that chemo was going after and killing those intrusive, unwanted, undeserved cancer cells. Looking at life rather than fearing death is what it's all about.

The trick is to know what you want, and to go after the smallest corner of that want: the most ordinary taste, smell, sight, sound, or touch of life. Clearing the mind of disappointments of the past, worries about the future, and fear of death is necessary before we can immerse ourselves in life. We can't enjoy the moment if we're hanging on to guilt, worrying what's going to become of us, and fearing that we won't be here for our next birthday or the children's next Christmas. Even when we have no idea if another good moment will come, we can still learn to ease out all thoughts of past nausea, of the blown vein, of the repugnant smells of the world storming into our nose through Cytoxan.

You can do it! I recovered from my last chemo hit enough to enjoy this perfectly baked potato. Crisp on the outside, steaming hot and soft enough to mash with butter on the inside, and that cool sour cream with chives dabbed in the middle. Now just hand me that burgundy pepper mill I found in Paris, and the memories of France come flooding in. Remember that upper-class neighborhood café, right near the Parc Monceau? The one with the two older ladies all dressed up and wearing lots of makeup and huge straw hats, their perfectly coiffed poodles sitting in their laps eating from the table, too? Look, friends, . . . I'm winning.



Here is the only breast cancer book by a "woman on the street," not a celebrity, not a doctor or nurse, not someone thanking their spouse or partner without whom they would never have survived, but one of the thousands of divorced moms with two teenagers in college dealing with breast cancer. This book will be of immense value to cancer patients and their families who have undergone or who are going into chemotherapy. It provides the information and inspiration on coping with a treatment, whose side effects can be as devastating as the disease it is meant to cure. You will laugh out loud and cry along with Joyce Slayton Mitchell for every little vignette and imagined outcome that she describes!

Winning
the
Chemo Battle

by Joyce Slayton Mitchell