

# BUSTING LOOSE

# Cancer Survivors Tell You What Your Doctor Won't



## **CHERYL SWANSON**

#### **BUSTING LOOSE**

# © 2009 by Cheryl Swanson ISBN 978-1-934841-74-7

#### Cover art and design © April Martinez

All rights reserved. Except for use in review, the reproduction or utilization of this work in whole or in part in any form by any electronic, mechanical or other means now known or hereafter invented, is prohibited without the written permission of the author or publisher.

"Zumaya Publications" and the heron logo are trademarks of Zumaya Publications LLC, Austin TX. Look for us online at http://www.zumayapublications.com

Library of Congress Cataloging-in-Publication Data

Swanson, Cheryl, 1952-

Busting loose: cancer survivors tell you what your doctor won't / by Cheryl Swanson.

p. cm.

ISBN 978-1-934841-74-7 (alk. paper)

1. Breast--Cancer--Popular works. I. Title.

RC280.B8S85 2009

616.99'449--dc22

2009036496

# This book is dedicated to the memory of

### **Arthur Mauritz Swanson**

"Life is life, fight for it."

— Mother Teresa

## TABLE OF CONTENTS

Introduction		
PART I DIAGNOSIS: BRACE YOURSELF		
Kill Fear before it Kills You	1	
Plan for the Best, not the Worst	5	
Myths and Old Wives' Tales	9	
Ignorance and Poverty Are Carcinogens	13	
The True Value of Mammograms	17	
Best Doctor in the World, Please Apply	19	
Part Scientist, Part Alchemist		
and Part Shaman	21	
Wild Women and Bad Girls:		
It's So Good to be Bad	27	
Nothing Wrong with Nuts	31	
Macho Never Means Mucho	35	
Cancer Idiots: How to Handle Them	37	
Life Partners	41	
Cancer Confidantes	47	
Stop Asking: "Why me?"	51	
Turn Off the Effing TV!	53	
Write Yourself Well	55	
Tame Career and Personal Stress	59	
Do You Have the Life Instinct?	63	
Dangerous Cultural Taboos	67	

Kissing Momma's Boo-Boo	71		
Breaking the Chain	73		
My Sister, My Mother, Myself	77		
Passing a Milestone	81		
PART II TREATMENT: ENTERING THE LABYRINTH			
Tests and More Tests	83		
Slow and Steady Wins the Race	87		
Medical Dis-Appointments	91		
Become an Expert on Your Disease	95		
Hospital Hell	99		
Lumpectomy or Mastectomy?	101		
Get a Second Opinion	105		
You and Your Breast Surgeon	109		
Prophylactic Mastectomy	111		
Immediate Breast Reconstruction	113		
Plastic Surgery Choices	117		
Sentinel Node Biopsy	121		
Medical Errors: Don't Be a Victim	125		
Ignore the Survival Statistics	131		
Thrive on Risk	133		
Clinical Trials	135		
No Such Thing as Incurable	137		
Stay Abreast of New Therapies	139		
Get the Most out of your HMO	143		
Flip-a-Coin Medical Treatment	147		
Cancer Support Groups	151		
Only Dread Life One Day at a Time	155		

	Make it Stop Hurting	157	
	Pain Without Suffering	161	
	How Not to Pay the Bill	165	
	Uninsured? Get Help With Medical Expenses	169	
	Know Your Employment Rights	173	
	The Best Treatment Facilities	177	
	The Long-Term Benefits of Chemotherapy	181	
	Big Advances in Hormonal Therapies	185	
	How To Outlive Your Oncologist	189	
	I Just Need to Lie Down	195	
	Listen to Your Body	199	
	Alternative Therapies	203	
	Hawaiian Approaches to Disease	207	
	Just Say "No!"	211	
	Go Cold Turkey On Stress	215	
	Cry All Your Tears	219	
PART III RECOVERY: LESSONS LEARNED			
	Get Used to Feeling Out of Control	225	
	Where in Hell Can I Find a Bathing Suit?	227	
	Break a Sweat, Not your Bones	231	
	Sex Thieves	235	
	Hormone Replacement Therapy	239	
	Eat Like a Bad Girl and Still Get Healthy	241	
	Rethink Pink	245	
	Ending Cancer in the Community	247	
	Attila the Hun, I'm Home	251	
	Fall in Love Again	255	

Organic Healing	259
Prevail Against Recurrence	261
Push the Limits	265
Motherhood After Cancer	269
Cleanse Your Memory	273
Keep the Faith	275
Laugh and Grow Strong	279
The End Game	281
Recreation—as in Re-creation	285
Don't Count Out Miracles	289
Create Your Own Descanso	293
Recovery and Renewal	277
APPENDIX	
GLOSSARY OF HELPFUL RESOURCES	301

#### Introduction

I don't believe in accidents.

— Oprah Winfrey

On August 23, 2003, the day I turned fifty years old, I found a lump in my breast that turned out to be breast cancer. There was a feeling like—my God, how ironic is this? As a woman, you can't approach the half-century milestone without being a little wistful. But I was turning fifty with a vengeance. I was in the throes of closing the public speaking business I'd owned for a decade, moving to a rural community in Hawaii and writing my first novel.

Something much more important was also at stake. My husband and I were in the final stages of adopting a little girl from Guatemala.

Any cancer diagnosis is dramatic, but the timing made mine more dramatic than most. Suddenly, there was a hellish hole gaping in front of me. Could I hold fast to my dreams in spite of the diagnosis? Would I have the energy to drag myself out of bed, much less manage being a mother and doing some artistic work as well? Remember that John Lennon quote: How can I go forward when I don't know which way I'm facing?

Close my eyes, six years roll away. I hear the voices of those who thought they knew which way I was facing. My breast surgeon told me to pull the plug on the adoption process. Another advisor insisted something called the "chemo brain" would keep

me from completing, much less selling, a first novel. A good friend worried that I might expire of loneliness if I gave up my career and moved to a rural community. My accountant told me I couldn't afford it.

There is no getting around it—a cancer diagnosis causes a thousand hopes to die. Women are told they shouldn't give birth to a child, at least not for a half-decade. They are told they won't have the energy to keep working a full schedule and absolutely should not change careers while undergoing treatment. They are told they can't or shouldn't adopt, that they should stay with a job they hate—because they might lose their health insurance. They are even told they should stay in a terrible marriage—because otherwise who will take care of them?

And to all of that, I say—pshaw.

Women can and do take these risks right after a cancer diagnosis. They hold fast to their dreams against the winds of pain, and use the fragile strength of hope to sustain themselves. They do it because they must. Because, make no mistake—if we listen to the prohibitions of the naysayers and ignore what our heart is telling us, we are putting our very lives at risk.

I don't want to scare you, but our world, including most of our healthcare professionals, doesn't "get" cancer. Prevalent in our times is the shallow and naïve idea that a breast cancer diagnosis is such a calamity the patient must be urged to hang up the phone on her hopes and dreams. Every day, using the weight and authority of the profession, doctors urge recently diagnosed women to put their life on hold, without any idea of what that might set in motion. Unknowingly, these doctors sometimes send these women along the road to self-destruction. Women who face a cancer diagnosis are in for the fight of their lives, and they need a future to fight *for*, not another reason for despair.

Otherwise? They just might give up.

As each decade passes, we have more tools to combat breast cancer. But is it me, or do we also seem to have less courage? Since my diagnosis, I have come to believe that the killing of dreams and hopes is the real tragedy of breast cancer in our time. Survival rates from breast cancer have continued to improve. Most women diagnosed with the disease in the next decade will find their

health snaps back to normal surprisingly quickly. Yes, there will be difficult times during treatment and dark days—plenty of them. But in the end, most will ride over the entire crisis like a beach ball on water.

But what about those women who are convinced to alter a cherished plan because of a perceived calamity? In that case, their life will be turned upside-down. Their aspirations, hopes and dreams will fall out of their pockets and smash. That is why I believe those in the "helping professions" who tell patients there can't be anything mysterious and uniquely transforming in being extremely ill need to make a noose out of their negativity and hang themselves with it.

Have I shocked you? I don't mean to, but what cancer taught me is shocking—and it can't be sugar-coated. There are many excellent breast cancer survivor guides available these days, but *Busting Loose* comes from a different place. While there are many useful books that help women "survive" cancer, *Busting Loose* is designed to help you use an initially frightening diagnosis to liberate yourself. My premise is that breast cancer is not the end of the road, it's the gift of another beginning. A beginning based on going after what you really want out of life, and damn the consequences.

I agree with Oprah Winfrey. I don't think there are any accidents. In my case, breast cancer was a clear thread running through everything I'd ever done and been. Because I did not listen to my doctors and advisors, because I allowed myself to believe the disease had a purpose—to teach me, finally, to follow my heart—the year I received my cancer diagnosis was the greatest year of my life.

Don't get me wrong—it was a ferocious jolt. So ferocious there are times when the fear of cancer recurring boomerangs me into an emotional black hole. The struggle is ongoing for all of us. Some women get off easier than others, but in one way or another, no cancer patient entirely escapes the rough waters that lie ahead.

I'm not advocating being reckless—much the opposite. The disease requires each of us to take full responsibility for every moment of our lives, however things turn out. What I'm advocating is the recognition that nobody rescues us from the disease; in-

stead, we must rescue ourselves. The problem with being passive in the face of peril is that it cuts us off from our ability to act positively.

Many women are still being programmed to be what Virginia Wolf called the "Angel in the House." From childhood, societal strictures teach females to be "good girls"—to speak in soft, sanitized words and display emotionally restrained, decorous behavior. Before cancer, these women didn't actually know how to fight; hence, they are hamstrung in the most important battle they will ever face.

What I joyously discovered through my own cancer experience was a different model for how women can go through a terrible disease. The women whose stories I tell in *Busting Loose* found that the experience of cancer helped them rediscover and reclaim the fiery wild woman inside. I'm talking about that fiercely alive and ageless "bad girl" who exists in each of us in some unknowable combination of thought, feeling, physicality, and spirit. Even the most culturally repressed woman has a powerful alter ego inside that the disease gives shape to—like a genie released from a bottle.

Somewhere in the midst of surgery or treatment or chemotherapy, your own genie is going to claw her way out of your core. And there's no putting her back in the bottle once she's free. But that's a good thing, even a great thing, because she's going to help you sing your song and live your life for the rest of your days. The person you were before cancer? She suffered from an overload of personal anxiety and cultural repression. Frankly, she wasn't having as much fun as she could have had.

But she's about to do something huge—survive a devastating disease. Dealing with cancer is going to take her to a new level, where she's much more frank and able to face things most women are too fearful or embarrassed to talk about.

So, brace yourself. Breast cancer is a roller-coaster ride the likes of which you've never experienced in your life. A trip full of tears, aches, pains, but also love and heartfelt laughs. I'm going to describe what's ahead, and I promise to tell it like it is. Sometimes I'll make you laugh and sometimes I'll scare the bejesus out of

you, because I think it's in your best interest to know the whole realm of strange things that might happen.

Bottom line: How do women find within themselves the necessary stamina to conquer their fear? How do they bust loose from the physical, spiritual and emotional grip of breast cancer? Here's the answer, and I hope it doesn't stop your heart. We do it by throwing away the repressed "good girl" and all of her hang-ups. We do it by releasing our inner selves for battle. All of our inner selves—the bitch and the angel, the funny and the sad, the dark and the light.

It's time to steel your nerves and summon your cool and anger and faith. Because the wild woman inside is about to bust loose, and the moment she does, you will find yourself strong enough for any fight. From that moment on, we have not just survived, we have triumphed.

Here we go. Hang on tight. It's time to *bust loose*.

# PART I

DIAGNOSIS: BRACE YOURSELF

#### 1. Kill Fear before it Kills You

How does one kill fear, I wonder? How do you shoot a specter through the heart, slash off its spectral head, take it by the spectral throat?

Joseph Conrad

She had the most intense gray eyes I'd ever seen. Her demeanor matched her eyes. A quality of total attention. A stillness. The consulting room was deathly quiet.

She looked at my husband, then at me. A small woman, long-fingered surgeon's hands, a head too big for her body. She was the chief of Breast Surgery at the most respected teaching hospital in northern California. I could imagine her lecturing to medical students, admonishing arrogant residents to pay attention. Little did I know that I was going to come to both love and hate this small woman more than anyone I'd ever met in my life.

"You have breast cancer," she said.

My brain took it in, but I wasn't tracking properly. I didn't believe her.

She pointed to a series of films mounted on light-boards and plunged into a medical discussion. My husband got up and followed her around, looking carefully at everything and asking for more details. His scientific mind was working hard—trying to disprove what she'd asserted.

Within seconds, I realized I couldn't hear them, although they were only a few feet away. Reality was starting to penetrate—I

have cancer. I have cancer. I have can— A high-pitched scream rose inside, like the shriek of an hysterical child.

Maybe I did scream, because another doctor, a surgeon-intraining, reached out and patted my hand.

"When life hands you lemons, make lemonade," she said cozily.

I wanted to flip her out of that operatory like I was a heroine in a Jackie Chan movie. What would she say if her plane suddenly lurched, or if she was in a dark alley and a stranger lunged? Make lemonade? Both of these women were going to be involved in my treatment, and in some ways I owe my life to each of them. But I think at the moment I would have sold my soul to have never met either one.

I was about to freak out. Correction: I was freaking out. My thoughts reverted to a whitewater raft trip I'd taken in Idaho. The T-shirts the guides gave us read "This place sucks. And you're not getting out." I was being sucked down in a whirlpool, and nothing was going to save me.

I don't want to scare you, but that's how it happens. When we first learn we have breast cancer, fear is no longer an emotion. It is a demon that takes control of our body and confuses our mind.

And here's the really bad news. You can't stop the fear...not entirely.

There is one thing I wish I had known during that first appointment. One thing I wish every woman on earth could be told, because it would make the early days much easier.

That screaming voice warning of coming darkness? It's telling a lie.

You will survive your cancer. Maybe not forever, but then, no one lives forever. You will survive it long enough to enjoy many good times ahead. You will certainly survive it long enough to fully comprehend all your treatment options and get a second opinion, so don't let your doctors rush you. And more likely than not, you will also survive it long enough to accomplish all your hopes and dreams.

Here's something else to keep in mind, because it is tremendously helpful.

Nothing will ever terrify you as much as being told you have cancer. Nothing that happens afterwards will be as traumatic as the moment you hear that initial diagnosis.

Every women I've spoken with—including those who are facing their last days with the disease—have confirmed that the initial diagnosis is the most frightening and painful time in the whole experience. No surgery, no treatment, no physical pain—in fact, no other experience except the loss of a loved one—hurts as terribly as hearing those three words: "You have cancer."

But once we've survived that, we're well on the way to becoming an entirely different person. Stronger. Better. More ready for life with all its joys and sorrows.

Finding out you have breast cancer is like being thrown in an abyss. But there's a bottom down there somewhere, and once you reach it, you're already past the worst.

TITLE: Busting Loose: Cancer Survivors Tell You What Your Doctor

Won't

AUTHOR: Cheryl Swanson

PUBLISHER: Zumaya Publications LLC GENRE: Self-Help/Health/Breast Cancer

Trade Paperback, perfect-bound, \$17.99, 324 pp., Trim 6 X 9; ebook, \$6.99; Paperback: 978-1-934841-74-7; ebook: 978-1-934841-75-4

RELEASE DATE: 10/20/2009

#### **COVER COPY**

Cheryl Swanson was inspired to write *Busting Loose* when a confluence of events had her undergoing treatment for breast cancer, adopting a child from Guatemala and writing her first suspense novel—all at the same time. More than a quarter-million women will be diagnosed with breast cancer this year in the United States. Many of these women will succumb to the passive role of a medical victim, not realizing that alone might kill them.

Busting Loose shows women how they can use the light of their cancer experience to climb the mountains in their lives. It explains how to deal with fear in a positive way. Most of all, it encourages women to never let their diagnosis limit them and to get back quickly to what ignites their passions and brings them balance and peace.

Available from independent booksellers and online at Amazon and Barnes & Noble. Ebook: Fictionwise, eReader.com, and Kindle.