

BREAST CANCER SURVIVORS



FOR

BREAST CANCER SURVIVORS

A Guide to Recovery, Healing, and Wellness

Naomi Aaronson, MA, OTR/L, CHT, CPI, CET Ann Marie Turo, OTR/L



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Printed in the United States of America by Bang Printing. 14 15 16 17 18 / 5 4 3 2 1 This book is dedicated to Beth Mast, an occupational therapist and Pilates practitioner who has used Pilates to recover from breast cancer and who is now using Pilates on her journey through living with metastatic cancer. Beth says that, "Pilates can be done by even the weakest." It was the only exercise that she could tolerate after going through chemotherapy and becoming increasingly anemic, unable to stand even to brush her teeth.

Learning to live with cancer is an art, not a science. Each person must find her own way, in her own style. What is important to realize is that a way can be found regardless of the circumstances and prospects.

—Jane E. Brody

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Preface

Ann Marie's Journey through Breast Cancer

I was always a person who exercised, took a whole arsenal of vitamins, read everything on health and fitness, and ate correctly. As an occupational therapist, I prided myself on being up on my health and wellbeing. So when I got the diagnosis of breast cancer, I was in shock. How could this be? But in January of 1991, my doctor found a tiny lump the size of a pea in my left breast. My breast cancer journey began.

My mind was telling me: They read the wrong pathology report: DENIAL. I took care of myself how could this be: ANGER. If I could just have my health back, I'll never stand in front of the microwave again and will only eat organic foods: BARGAINING. There were days I couldn't dress myself, or days that I would put the same clothing on that I had dumped on the chair the night before: DEPRESSION. These stages should sound familiar to every person who has been diagnosed with a life threatening illness or disease. Many people will go through at least one or all of the Kübler-Ross stages of grief.

I was lucky. I received a lumpectomy/partial mastectomy and clean margins were reached.

In 2001, eleven years after my first diagnosis, breast cancer came knocking at my door again in the left breast. At that moment, I felt a sense of acceptance as I knew what I needed to do, but immediately, I moved again into the denial stage. I told my doctor that "I was here today for my yearly mammogram and not for surgery." The cycle of anger, bargaining, and depression repeated itself.

When you are diagnosed with a disease such as cancer, your life changes from that moment on. You begin to think about your future, and whether you will be here one year from now. You also think about what is important to you and your family, and what life really means to you. You make decisions based on the information that is available to you. You think about what you are willing to endure. The what ifs and the if nots play around in your head. But each of us is different and will make different treatment decisions. I made mine based on what I felt would provide me the best chance of survival and quality of life.

In 2002, three months after another partial mastectomy, I decided to enroll in Pilates reformer training (a reformer is a piece of resistance exercise equipment designed by Joseph Pilates). I had been trained in mat Pilates in 2001, but felt this was a natural next step. I got the OK from my surgeon and moved forward. When I look back on it today, it wasn't the best decision. I was not completely healed, had poor endurance, left shoulder tightness, and my scapula was nowhere to be found! My proprioception (awareness of my own body in space) and kinesthetic awareness (my ability to sense movement) was so poor that I had no clue where my left arm was or what it was doing. The training was tough, but I kept on telling myself, "If I got through breast cancer, I could get through anything." I don't recommend that you start with reformer training, but Pilates is an excellent way to heal. Pilates was the best thing for me then. It helped me regain my strength and the confidence to navigate the world after undergoing life changing surgery and treatment. The deep breathing along with the specific Pilates exercises in this book helped me to focus and relax, as well as stretch my tight chest, side, and back muscles. Finally, Pilates offered me the opportunity to regain control over a body that had betrayed me as well as providing a safe and nurturing space to relax and focus on healing and recovery.

That saying, "It's the journey not the destination," is so true. Pilates has come full circle for me in the healing process, as now I am sharing this modality with my patients and other health professionals. In 2004, I opened Integrated Mind & Body, a health and wellness studio, and completed my yoga, Pilates, and Reiki training. It was important to me to offer a range of mind-body therapies in addition to traditional rehabilitation techniques in order to holistically and optimally meet patient and client goals.

Naomi and I met at the Cotting Connection Conference in Boston in October 2007. The medical community, patients, and vendors were brought together to learn about some of the new and innovative treatments in the area of breast cancer treatment and rehabilitation. Naomi had a vendor table set up with her breast cancer CDs, courses, and books on exercise for breast cancer recovery and had presented a session on exercise. We are both occupational therapists with an emphasis upon improving function and wellness as well as fitness professionals, so we had a lot in common. We discussed doing a course together one day, exchanged business cards, and went our separate ways.

In December 2007, Naomi contacted me and asked if she could interview me for an article in Advance for Occupational Therapy Practitioners that was entitled "Movement Towards Healing." We then decided to integrate our passion for the healing properties of movement and the power of occupational therapy to rehabilitate cancer survivors. We formed a company named Integrated Rehab and Fitness with the goal of educating other rehabilitation and fitness professionals. In September 2008, we presented our first course

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"Breast Cancer Rehabilitation Using a Pilates Based Approach" in Natick, Massachusetts. Since then, we have spread the word to therapists and other rehabilitation professionals about the benefits of Pilates for breast cancer survivors. Our CD Return to Life: Breast Cancer Recovery Using a Pilates Based Approach is available for continuing education at home. We are excited to be able to bring our information to breast cancer survivors throughout the world through publication of this book!

Our goal with this book is to help you heal, regain control, strength, and confidence, and be able to perform daily living tasks more easily, whether or not you've ever done Pilates before. We've provided various programs and modifications so that no matter where you are in treatment, what side effects you may be experiencing, or your general fitness level, you will be able to find exercises you can do comfortably and safely and achieve benefit. However, to attain wellness, exercise alone is not enough; you must adopt habits and behaviors that promote an improved quality of life. Wellness is a lifelong journey: a process of growing. Unfortunately, cancer treatment has some long-lasting effects. In the final section of the book, we've included ways to deal with issues such as chemo brain, sleep deprivation, and peripheral neuropathy.

Throughout the book, we've also included the experiences of other survivors who have used Pilates as part of their journey to health. We hope you'll find their reflections and insights helpful:

Beth Mast, who is an occupational therapist as well as a Pilates instructor, underwent 16 months of treatment, including a double mastectomy, breast implants, chemotherapy, and radiation, and used Pilates daily. It helped her battle scar tissue, maintain strength and range of motion in her arms, address sensory issues such as sensitivity to touch, and move through menopause.

Nicole T. felt pain in her chest immediately after surgery, and was unable to sit up without assistance for two weeks after undergoing a mastectomy and breast reconstruction with saline implants. She had difficulty raising her arms, but this got easier over time. The more she did, the better she felt. The repetition was important to her. She warms other women beginning a Pilates routine that you will receive a lot of information at once and may not be able to absorb all of it. So you may have to re-visit the basics throughout your recovery. She found that it felt good to be in the company of people who understood her condition. When she finished her Pilates exercise sessions, Nicole left feeling loose and optimistic.

Grace T. had bilateral preventive mastectomies followed by silicone implant breast reconstruction. She had tenderness in both shoulders, tightness across her chest, and weakness in her arms. She felt beaten up, tired, sensitive, weak, and bloated. Gaining back strength and flexibility contributed to her confidence and reconnection with her body. This helped her to feel better emotionally. "Pilates is a great way to recover, as it seems meant for people recovering from illness as well as getting back to physical fitness."

Sharon B. had a lumpectomy with sentinel node biopsy, followed by a second surgery for clean margins, radiation, and chemotherapy. She experienced pain and muscle tightness at her scar sites and limited range of shoulder motion. Exercises such as Wall Angels, Swimming, and Scapula Protraction and Retraction have helped her recover.

Nancy M. had a lumpectomy and radiation. The Pilates exercises that stretched her side and strengthened her core helped her the most. She encourages others to start a program of Pilates immediately." Do not wait until the situation has progressed to a point where your body has become rigid from under movement. Pilates integrates well with breast cancer recovery, as the focus is on thoughtful movement or movement with intent."

Bonnie O. is a personal trainer who knows how important movement is. She experienced surgery and chemotherapy. Immediately after surgery her body felt like it had been hit by a truck, and in the weeks and months following she primarily felt tightness in the chest and shoulders, as if a belt was buckled tightly around her ribcage. She developed cording in her right arm, where she had 16 lymph nodes removed, and a frozen shoulder. Exercising regularly, focusing on regaining flexibility, and keeping her core strong aided her recovery.

We've made it our mission to educate others about the benefits of an integrated approach to rehabilitation and recovery. We hope this book will help you achieve maximum wellness, now and throughout your journey living life after cancer. This is your action plan for health!

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