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AFTER SHOCK: FROM CANCER DIAGNOSIS TO HEALING

*A step-by-step guide to
navigate your way*

Second Revised Edition

Puja A. J. Thomson

ROOTS & WINGS PUBLISHING
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Dedication

It is with great love and respect that I dedicate this book in honor of four remarkable people and their courageous journeys.

Two, whose youthful physical lives were snuffed out prematurely by cancer, but who both live on through the inspiration and immense courage they manifested throughout their cancer experiences. It was a privilege to be touched by their irrepressible spirits:

JEREMY CAHILL

Jeremy, the jaunty angle of your baseball hat said it all.

KATIE SCHOLL

Katie, your smile is in the gold and brown sunflowers you loved so much.

And two beloved friends whose experience with cancer came later in life:

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JANE FERBER, M.D.

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The revised editions are dedicated to the many cancer patients who face daily challenges with courage and faith and who continue to inspire me.

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Lastly, many thanks to the patients, family members and others who took the time to encourage me, by calling or writing to share how *After Shock*:... had eased their journey since the first edition.

I have been fortunate indeed. Thank you, one and all.

Foreword



OH, HOW I WISH THAT I HAD THE BOOK YOU ARE ABOUT to read when I was initially diagnosed with breast cancer in April of 1992! I remember sitting in the doctor's office across the desk from him while he spoke to me about my treatment options, outcomes and statistics. I have this visceral image of myself, nodding in agreement, while the words floated over my head. It was as if a glass window had come down between us; I could see my doctor talking but couldn't hear the words. Thanks to cancer, I decided to become an oncology social worker so that I could accompany patients to their appointments to be a second pair of ears; someone who could ask questions, take notes and offer support. When the meeting was over, I could process the session with the patient, clarify the information that had been given and offer to assist if further research was required.

Fast forward eleven years to December 2003—I had been accompanying patients to their medical appointments for ten years and knew personally and professionally a great deal about the stress and anxiety they undergo. As I was sitting with Puja Thomson waiting for her appointment with her surgeon, we began to review her questions and concerns.

She then wrote down some notes in her loose-leaf binder. I asked to look at her book and she showed me how she had begun to organize all of the aspects of her cancer experience.

Now, I've always advised patients to keep a book where they could write down their questions, reflections, information, resources, thoughts and feelings. Yet what Puja had organized was far beyond anything I had seen even though I had had the opportunity to review a great deal of published material collected by our Oncology Support Program. It was amazingly comprehensive. I immediately asked her if she would be willing to develop what she had structured for herself into a book, which I knew would be of great benefit to newly diagnosed cancer patients.

Here it is...all in one volume, beautifully written and organized, guiding you on your inner and outer journeys as you make choices of doctor and treatments, mainstream and complementary medicine, and deal with the many practical matters, questions and feelings that can easily overwhelm you. Puja's personal experience with breast cancer and her professional training and experience as an interfaith minister, creator of rituals, massage therapist, and Scottish organizer is a perfect combination to make the material that you are about to use the best possible method for organizing your cancer experience. We've gotten a lot of wonderful advice in the development of this project and I've been happy to encourage its unfolding. I believe that *After Shock: From Cancer Diagnosis to Healing*, thanks to Puja Thomson's talent and skill, continues to be unparalleled material for the successful navigation of anyone who wants to reduce the stress of their cancer journey. It will undoubtedly guide you step-by-step as you find your own way to recovery.

Barbara Sarah, LCSW

*Founder of the Oncology Support Program
at HealthAlliance of the Hudson Valley, Kingston, New York.*

*Recipient of the 2005 New York State Governor's Award for
Innovation and Research in Breast Cancer.*

*Co-founder of the Circle of Friends for the Dying.
www.cfdhv.org.*

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Introduction



WHEN THE NEWS THAT I HAD CANCER EVENTUALLY PENetrated my being in the doctor's office, I felt very shaky. Caught off guard, I was surprised at how vulnerable I had suddenly become. Nothing—not my competence as a health practitioner, nor knowledge of cancer, nor experiencing the personal pain of an intimate friend's struggle to beat "it" during the previous two years—nothing—prepared me to face the verdict of cancer in my own body.

Pressured to make a quick decision about treatment, I felt as if I was being sucked into a big machine and onto a conveyor belt. My doctor seemed to know exactly what I should do before I even had a chance to get my bearings. Weighed down by these demands and decisions, I took time to walk, to meditate, and then share my news with a very few close friends.

I realized I faced three challenges: I needed to ask for support from others, to find a way to bring clarity and order into this fearful, confusing experience and to tap into my own intuitive understanding. Along the way, as I acted in accordance with these awarenesses, I discovered precious gifts in addition to those offered by my health practitioners. In asking for what I wanted from others, my heart opened to the gen-

erosity of friends; I found that good organization lessened my scattered energy; and in listening to myself, I began to allow a new balance to come into my life.

After Shock: From Cancer Diagnosis to Healing evolved out of my attempts to create a container and structure that would support my journey. From my first fledgling notes grew this tool to assist you in organizing your cancer experience, especially during the first crucial year. If you are facing an unwelcome recurrence, I hope you too will find this book helpful and encouraging. Its purpose is not to give detailed medical information or advice. I call on my personal and professional experience and training to offer practical suggestions and guidelines to help you clarify your own process, perspectives and choices. Woven throughout are stories shared by friends and fellow travelers as well as my own.

REACH OUT

With the discovery of cancer, it's really helpful to ask for support from trusted friends and family. It's advisable to find out as much as you can about your type of cancer from sources such as your local library, cancer resource organizations and the Internet. Your life will shift, as mine did, to include an all-absorbing round of medical visits. As you search for the best possible professional care, you'll probably meet with your primary physician, surgeon and oncologist. Next come tests and treatment, waiting for and receiving results. Perhaps you'll get a second or third opinion, or seek out a complementary practitioner. You will make decision after decision about your treatment and deal with all sorts of medical records, financial statements, bills and insurance plans. At times such tasks may seem endless.

GET ORGANIZED

Disorganization is definitely hazardous to your health! I quickly discovered that good record keeping was essential if I were to avoid ending up under a mountain of paperwork. I was amazed at how quickly papers accumulated—personal jottings of conversations or dreams, medical prescriptions, exam results, bills and so on. In the early days I just lumped everything together and I dissipated precious energy by

scrambling around to find a crucial piece of information from a pile of haphazard notes. Sorting things out is in fact a way of controlling this “runaway train.” It will save lots of time and contribute to your sanity.

REACH IN

In the midst of all this hard work, I felt pulled in another direction. While first and foremost I wanted to heal my physical body, I knew that more than my body was out of balance. I'd been neglecting some of my own advice for a healthy life. I had to reach inwards to find a centered place where I could create my own prescription for healing. Friends were vital, but I felt challenged to come to terms with my inner fears and questions such as “Why me?” “Who will take care of me?” and a host of “What if this, or what if that, happens?” It wasn't easy. Yet doing so led me to choose activities that nourished my mind, emotions and spirit as well as my body and had a profoundly beneficial effect. I thought of myself as being on a pilgrimage—a sacred journey towards healing and wholeness.

OVER TO YOU

There was a time when cancer was generally understood to be a death sentence. That is no longer true. In the last few years, at an unprecedented speed, new avenues of research, such as the personalized medicine revolution, have led to a greater knowledge of the variety of cancers and to hopeful new treatments. However, your active participation remains key to healing. Use this practical handbook as a tool. Adapt its many suggestions to your needs and temperament, as you make decisions, follow through on treatments, organize it all in your own loose-leaf binder or notebooks and create your wellness program.

Take heart, we are now among over 17 million living Americans who are cancer survivors, most of whom have no current evidence of the disease.

*Reach Out—
Don't Go It Alone*



So You've Just Been Diagnosed—What Now?

FROM THE FIRST MOMENT OF SHOCK UPON HEARING YOUR diagnosis, the earth may seem to give way under your feet and a whole range of unexpected feelings may flood through you. It is natural to fear the consequences. You may want to deny this is happening to you. You may feel paralyzed when it comes to making decisions. It is not uncommon to feel as if you are at the mercy of outside forces, or pressured by the seeming certainty of professional opinions. I certainly did. Please don't judge yourself or be ashamed of having cancer. There's no accounting for the fact that some people who do all the "right" things get cancer, while others who are not at all health conscious get off scot-free.

The news may come in many ways. Perhaps you were just always tired and didn't know why. Perhaps a routine mammogram or pap smear revealed something suspicious, and after follow-up tests your doctor called you in to confirm the dreaded diagnosis. Perhaps your mother's family is known to carry a cancer gene and you have watched other relatives succumb, hoping against hope that your turn would never come. Or perhaps you suddenly found a suspicious lump.

Whether your diagnosis is conveyed to you abruptly or as kindly as possible, the impact of cancer can still, without a doubt, be like a blow to the solar plexus.

Don't judge yourself or be ashamed of having cancer. There's no accounting for the fact that some people who do all the "right" things get cancer.

Other Considerations

SECOND OPINIONS

Although the phrase “second opinion” is in common usage, it is important to remind yourself that you are entitled to it. You also have the right to more than one second opinion, as many as you need, to become clear that you are on the right course. An additional expert opinion can be helpful in a number of ways. It may allay your fears and give you peace of mind. It may caution you that there is more to be taken into consideration than you have thus far been aware, or even that you might have to look for another doctor.

Never forego getting a second opinion because you think you might “hurt your doctor’s feelings.” That should not be an issue for you or your physician. On the other hand, don’t waste time shopping around.

- If you can, get a second opinion from a doctor who trained, practices at, or is affiliated with a different medical center. That way you are more likely to get a different perspective. Consider also getting an additional opinion from a complementary practitioner. Check with your insurance company to see what your policy covers.
- If you find a doctor with excellent references in the specialty you need but who is outside your health insurance plan (as happened in my case), it can be worth paying out-of-pocket expenses for a consultation, which may add to your understanding.
- Never forego getting a second opinion because you think you might “hurt your doctor’s feelings.” That should not be an issue for you or your physician.
- On the other hand, don’t waste time shopping around waiting until you find a doctor who tells you exactly what you want to hear. Eventually you may find someone who will do so, but that may not necessarily be the best course of action.

PROFESSIONAL COOPERATION

- Advise your cancer doctors of any other health conditions for which you are being treated even if the secondary condition seems unrelated to your cancer.
- If you plan to combine mainstream and holistic treatments, inform your physicians of the names of your complementary or alternative practitioners and be specific about their modality, and vice-versa.

There is an extensive range of complementary practitioners, and so it is important that your health care providers are all aware of the types of treatment you are receiving. If you wish to blend the best of all possible care, if possible, select a doctor who will support your intention. A physician, as a professional, should respect your decision to see another provider offering a different modality.

At some point you may benefit from meeting non-medical personnel: an aesthetician, cosmetician, hair/wig consultant, life coach, minister/rabbi/imam, personal trainer, prosthesis maker, psychotherapist, spiritual counselor, or yoga teacher. These people can be part of your team for reducing stress and maintaining balance in all aspects of your life. (Get references from your friends, other cancer survivors, health professionals, support groups, local health magazines, Internet sites and online chat groups.)

RESEARCH

A promising line of research is often made public before the research is complete and well ahead of its actual availability. The accuracy of a medical research study depends on many factors such as its design, the number of patients involved, the definitions of “success” used, and whether or not there is a control group. Scientists usually consider valid research to be randomized, controlled, double-blind, prospective studies. Such research is expensive and when applied to medicine often requires financial backing from the government, corporate businesses such as the pharmaceutical industry or philanthropic institutions. Most research money goes to mainstream medicine and fewer studies have been set up to examine alternative or complementary therapies. As a result, many doctors are either unwilling to recommend, or feel uneasy about recommending, complementary protocols which have not been validated through research.

On the other hand, while there may not be scientifically valid research proving the efficacy of the various complementary practices, there is certainly a great deal of consistent anecdotal “evidence” that such treatments can work. Many people have been helped by modalities that have been used for centuries, especially in other countries or cultures. There