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## PROFILE

## Pat Walter

## A Guide to Navigating America's Cancer Care

By Sue Kovach



In the late 1990s, Patricia C. Walter was living what she calls “my life with cancer.” While disease-free herself, cancer claimed both her mother and beloved husband Charlie within the short span of two years. During that period, Pat occupied several important roles: tireless caregiver, strong advocate for her loved ones, and relentless researcher into the difficult, often frustrating world of cancer care and treatment.

Through her experience with a fractured health care system that pays scant attention to patient needs, this suburban Philadelphia resident took on another role. Walter learned to navigate the maze of medical options that cancer patients often face after their diagnosis, and has become an advocate for all patients by sharing what she learned in a book. *Managing Cancer. Managing to Stay Alive* is Pat's labor of love, and an invaluable guide to avoiding the pitfalls of cancer care in

America.

“It's the book I wish I'd had when my husband was diagnosed,” says Pat, an editor and writer for a medical communications company. “At the time of diagnosis, people are scared to death. They want somebody to give them advice.

I've seen terrible things happen to people because they don't have information. This book has the information they need to go forward, manage the cancer, stay alive, and avoid mistakes.”

Available from amazon.com and at Pat's website ([www.managingcancer.net](http://www.managingcancer.net)), *Managing Cancer* contains the kind of sound, objective guidance that cancer patients and their families desperately need at a time when it is hard to think clearly or stay focused. Among the book's most important features are exhaustive resource lists (including cancer care centers and support groups), 400 questions to ask doctors, and advice from cancer survivors.



### CANCER CARE GONE WRONG

Pat distilled the wealth of information contained in her book from hard lessons learned firsthand during her husband's ordeal with cancer. A retired firefighter, Charlie was only 48 when diagnosed with the disease and given six months to live. The couple received the devastating news just five weeks after Pat's mother died.

From the start, the couple's experience was a difficult one. According to Pat, information was withheld, requests were ignored, and useless treatments were recommended. As a result, Pat believes, Charlie's life was shortened.

Tests revealed a large mass on Charlie's spine. The doctors suspected kidney cancer, but were unable to find a tumor on his kidney or anywhere else in his body. Without offering other tests such as an MRI, the doctors suggested surgery, saying the tumor was likely “encapsulated.” Pat and Charlie never questioned the doctors, which in hindsight, Pat says, “was the biggest mistake we made.”

Far from encapsulated, the tumor was wrapped around the vena cava, aorta, and spine. On seeing this, the surgeon simply closed Charlie back up. An MRI or angiogram probably would have detected the tumor's exact location, but the hospital did not perform MRIs and would not refer Charlie to another facility that offered this service.

“It was ‘easier’ for them to just do surgery,” says Pat. “This isn't uncommon. If I had known then what I know now, I would have made different decisions.”

The doctors offered chemotherapy and radiation, but Charlie refused both and went home with pain medication and hospice information. Meanwhile, Pat and her friends who work in medical publishing began researching kidney cancer and learned that Charlie had the worst kind: stage IV renal cell cancer with a bad metastasis location and poorly differentiated cell type. She also discovered something else.

“I read one of the best textbooks on cancer and learned that chemotherapy and radiation aren’t effective for Charlie’s type of cancer,” she says. “But they had offered it anyway.”

While Charlie resigned himself to the fact that he was dying, Pat refused to give up hope. More research led them to Dr. Stanislaw Burzynski in Houston, TX. His antineoplaston treatment for cancer, a non-toxic alternative to chemotherapy, was controversial. With no other options, the couple headed for Houston a month after Charlie’s release from the hospital. He enrolled in a trial at the Burzynski Clinic.

A CT scan performed after six weeks of antineoplaston treatment showed Charlie’s tumor had shrunk almost 20%. Strangely, the doctor at the Walters’ hometown hospital who had also read the scans never mentioned this fact. Even Pat could see the tumor was smaller. However, doctors at the Burzynski Clinic also noticed something on Charlie’s right kidney. Unsure whether it was a tumor or blood from the surgery, the doctors advised the couple to contact the original surgeon. After returning home, they did just that, and were stunned by what he told them.

“He knew there was a tumor on the kidney,” Pat says. “I asked him why he didn’t remove it, and he said, ‘Because he’s better off with two kidneys than one.’ He had no right to make that critical decision for us.”

Charlie’s spine tumor continued to shrink, eventually enabling him to stop taking his pain medication and begin regaining weight. Unfortunately, his kidney tumor was growing. Pat located a surgeon who agreed to remove the kidney, more than a year after the procedure could have been performed. The surgery went well, and Charlie resumed antineoplaston therapy eight weeks later in Houston. But it was too late. The cancer had metastasized to the liver, and when more liver tumors appeared a month later, Charlie refused any other options. He died on May 24, 1999, 18 months beyond the time he was given to live when first diagnosed.

## SURVIVING TRAGEDY, SHARING KNOWLEDGE



While at the Burzynski Clinic, Pat and Charlie were asked to speak with prospective patients about what they should expect from the treatment. Pat jotted down notes to remind herself what to talk about, and these became the foundation of her book.

“I talked to people about what had happened to them, one tragic story after another,” she says. “I saw patterns in the things that had occurred. People felt betrayed. They said, ‘If I’d only done this’ or ‘If they’d only told me that.’ ”

Hearing those stories solidified Pat’s commitment to write *Managing Cancer*. She saw the need for a comprehensive resource that provides patients with the clarifications and explanations they were not getting from other sources. She also wanted to encourage patients to stand up for themselves.

“I absolutely share Life Extension’s philosophy that good patients understand the basics about their own bodies and should be advocates for their own health,” says Pat, a Life Extension member.

“At the heart of this book is the belief that patients should be knowledgeable and take their health care into their own hands.”

The most important things that people can do, she says, are to ask questions from the start and find the right doctors.

As Pat notes, “If you’re knowledgeable, why turn your health over to someone else without questions? Never assume anything. You have a right to ask questions, and a good doctor will answer them. You deserve truthful and respectful answers, and if you’re not getting them, find another doctor. And another and another, if necessary, until you find ones who give you those answers.”

Most cancer patients are diagnosed by non-oncologists. Pat advises going to a larger medical institution or major cancer center and finding two specialists: a doctor and a pathologist.

“You need a doctor who’s thinking about your type of cancer every day, and a pathologist who’s an expert in the particular cancer you have,” she says. “The first treatment is your best chance for a cure, and that’s based on the pathology.”

Pat’s book also discusses subjects often glossed over by the medical establishment. High on the list is nutrition. She points to Life Extension magazine as a good resource for patients and families.

“We’re now finding that micronutrients lower the toxicity of chemotherapy drugs without lowering efficacy, and offer some protection from radiation-induced toxicity,” she explains. “Yet the cancer care system doesn’t even address nutrition. Life Extension has so many articles about nutrients and supplements, and people are looking for that kind of information.”

While Pat does not claim to have a fix for today’s fragmented system of cancer care, her book is designed to help cancer patients and their families understand and navigate their way through the system. Her hope is that by doing so, their experiences and outcomes will be better than hers.

“It’s an illusion to think that the various parts of the system are working together,” she says. “I’m trying to show people that you really do have to be responsible for yourself.”

*For more information, visit Pat Walter’s website, [www.managingcancer.net](http://www.managingcancer.net).*



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