

3. MEET THE AUTHOR

"If I perform surgery on you and don't find anything wrong, I am going to be very angry with you!" said a surgeon as he leaned over me while I lay in agonizing pain on a stretcher in the emergency room. All I remember is being very confused and wondering why he would say that to me.

I had had this pain on and off for three years. Each time it was stronger and lasted longer. Tests were done; I was referred to specialists and was in an emergency room previously because of the same pain. Each time I received a strange look. I was even told, "It's all in your head!"

But this time, the doctor admitted me to the hospital. I lay in bed for nearly two days with no pain medication, no water, and no food. "In case they had to take me to surgery", was the explanation. On the third day, my abdomen rebounded and I was finally taken to surgery.

They found a cyst had caused one of my ovaries to twist, letting blood into the ovary but not letting it out. Over the three years, the cyst had grown to the size of my fist. This time the ovary remained twisted, became engorged with blood, and was about to rupture—causing the rebound response.

This missed diagnosis was the beginning of a long story. I experienced complications, nearly died, and have permanent damage due to the complications. I will tell the rest of the story later in the book, to illustrate important points.

What qualifies me to write this book and develop the guidelines and forms in it? If experience is the best teacher, I have had plenty to learn from, positive and negative, as a patient and as an advocate for others. Because of these experiences and interest in medical and health-related topics, I have read extensively and researched the topics included in the book.

Some say I should have a doctor or nurse's degree to write this book, as they are the experts. They are expert in the care of the body. This book is not about care or medicine, it is about process, managing those processes and storytelling. It's about the steps you take and the way you go about managing your health care. At those, I am an expert. I am a trained, professional process consultant with a medical background and have a master's degree in storytelling. I have lived with health issues all of my adult life, survived three medical errors and cancer, so I write this book from a patient's experiences, perspective, and many years of reading and research.

I have a degree in Medical Technology. Med Techs are trained to do medical laboratory work, including blood bank, microbiology, serology, urinalysis, chemistry, and hematology testing. I received my degree from the University of New Hampshire and did my internship at Mary Hitchcock Hospital in Hanover, New Hampshire. Our classes were with second year medical students at the Dartmouth Medical School; thus, we gained a doctor's perspective and deeper background knowledge than the typical med tech program offered. Having access to the medical library while there allowed me to research diabetes and other medical subjects of interest. I have two sisters who are Type I diabetics, one fourteen and the other four years of age when diagnosed. One of my nephews became diabetic at age six.

While in college I had two research jobs, one in virus / tissue culture research and the other a mycoplasma pneumonia project for one of the pediatricians at Mary Hitchcock Hospital. I was very interested in research and virus work, so upon graduation accepted a research job at Yale. I married, moved, and returned to hospital lab work until I became a stay-at-home mom when my first son was born.

My first son was one of five boys born in our neighborhood within a two-year period, all with similar digestive problems. I became suspicious of our water supply. We observed a blue color when water was collected in a light colored bowl. Shallow pounded wells were our water source and the water was very acidic, causing copper and other metals to leach from the plumbing into the water. I had consumed that water for three years prior to my pregnancy and the water was used in my son's formula. I accessed the Yale medical library to research possible connections between digestive problems and metals. I did not find studies that showed a direct correlation, but did learn that certain metals in the body have an exchange relationship, e.g. copper and zinc, calcium and magnesium. We had consumed a lot of copper from our water pipes and it made me wonder if our bodies were low in zinc, but I couldn't find information that showed this might be the case or that a low level of zinc would cause digestive problems. My instinct that these metals might be the cause was all I had to go on. We installed a water neutralization system and eventually, my son's digestive system began to function normally.

Years later, results of a study done in Colorado revealed that the lack of zinc in infant formulas caused digestive problems and confirmed to me that I was on the right track with my assumptions. All of this is to say—I have been a researcher, at heart, all my adult life. I continue to research health-related topics and seek ways to receive the best health care on a regular basis as my family and my own health issues arise. Researching your medical conditions is an important part of the using your *Savvy Patient* HEALTH RECORD to your advantage. This book provides guidance and reference resources to help you get started. My medical background, personal research, personal experiences, my education, and professional work have provided me with the foundation and knowledge for this book. In some ways, I feel I have almost been a professional patient. I received the bad genes from both sides of my family and have had to deal with health issues all of my life, including vague and hard to describe symptoms. I have struggled and learned to be aware of how my body functions and have tried to communicate my symptoms and body functioning to my health care providers in a way they could understand—sometimes they did, sometimes they didn't. Having nearly died three times because of medical errors that resulted in lifelong chronic conditions, I have learned a lot about what can go wrong and have gained valuable insights into how errors can be prevented. My hope is that by sharing these stories with you, you will be able to understand the importance of becoming an empowered and involved patient who takes more interest in and responsibility for your health care and avoid preventable medical errors.

In 1983, after a difficult divorce and nine years of being a stay-at-home mom, I found myself back in the work world. A biotech company opened in New Haven, Connecticut. They were looking for med techs for production because of the way we were taught to think and the fastidiousness of our laboratory training. I knew nothing about genetic engineering and molecular biology, a new science field, but was hired to set up the quality control department, one reason being my prior experience in writing procedures. I had rewritten all of the procedures in one of the departments at my hospital job. My boss needed someone to write test procedures for products they planned to make; both for in-house testing purposes and for inclusion in the catalog they would produce. Although not planned, our catalog became the lab manual for molecular biology courses in many college labs at the beginning of the biotech boom, until texts became available for that purpose.

I had a new career and became a self-taught molecular biologist by studying into the wee hours of the morning, after my sons were in bed.

And then one day...

"Margo, you are now a staff of one. I want you to teach the entire company, starting with me and the Vice Presidents, Total Quality Management (TQM)," said the company president as he walked into my office.

"We need to streamline the way we do things or we will not be in business long."

Shocked, I said. "How can I teach you when all I have had is a one-week course in the theory of TQM, 10 months ago, and no training in any of the tools that support the theory?" We had been purchased by a fortune 500 company that was implementing TQM company-wide.

"You can do it," he replied. "Why don't you start by working with two teams that are trying to make improvements?" He went on to explain what the projects were and who was leading each project. He encouraged me again saying, "You can do it" and then turned and left the room.

That was seven years into the job. By that time, I was at the director level and had used my insights and problem solving skills to innovate and improve a variety of processes within the company. Improving the way work gets done has always been a part of my being. As a student, I surfaced the need to improve the way the lab communicated and worked with other parts of the hospital and was put on a task force to work on solutions.

Beginning another career, I embraced the TQM challenge, located a seven-week intensive course in the tools and technology to support the theory, developed a set of courses, and trained the company, starting with top management and moving down the corporate ladder to the rest of the employees. One half of my time was spent training, the other half assisting teams in applying what they learned. I facilitated teams through either improving or re-engineering their processes and systems or developing new ones. I facilitated executives developing new visions for their aspect of the business and in creating and implementing new departments. We were very successful at streamlining our operation and significantly improved the company's bottom line. I continued as an internal Quality Management Consultant and later a Knowledge Management Consultant with our parent company until my retirement.

I will probably spend the rest of my life improving processes no matter what I do. As a consultant, I became known as *The Queen of One Pagers*, meaning I have the skill to capture the essence of a large body of knowledge by consolidating it into a one-page format. These *One Pagers* often took the form of a table or diagram. It is said, "A picture is worth a thousand words." To me, well-constructed tables and diagrams are pictures. They capture the essence of details in a quick and easy-to-read format and often help show how things connect and interrelate. The forms in the *Savvy Patient's TOOLKIT* are designed in this one-page format to do just that.

My work as a TQM and Knowledge Management Consultant has greatly enhanced my natural ability to develop new ways of doing things. The basic principles I used in business to assist others in creating and improving their processes and systems have been applied to the design and use of the *Savvy Patient* HEALTH RECORD. I will discuss processes and systems as they relate to you and the world of health care in the next chapter.

Not one to be still for long, after I retired, I entered the masters program in storytelling at East Tennessee State University and graduated in 2003. The program prepares people to become professional storytellers, which I had no intention of becoming. At the time, I thought I might continue consulting part-time and would fold storytelling into my work.

And, then...

My husband experienced kidney failure, the story opening this book. When I created the *Chronic Condition Form* in my head that night in the hospital, I had no idea that it would lead to this book. I knew we had to improve the way we thought about and managed our health care. My husband nearly died due to a medical error—my fourth personal experience with medical errors. During the next year and a half, he had two more emergency room experiences, a surgery, and a cancer diagnosis. It seemed we were living in one kind of medical facility or another all of the time. At the same time, our neighbor experienced several health crises and, without her children nearby, I became her advocate. As I advocated for them, the forms of the *Savvy Patient's TOOLKIT* were developed out of one need or another. When people asked what I was doing with my time, I described what I was experiencing, and the forms I had created to help us manage our health care. Their response was, "I sure could use something like that." I gave them forms to use and received very positive feedback. The rest, as they say, is history.

I have combined my education and work experiences with my experience as a patient and patient advocate, the insights gained from those roles, 40 plus years of reading, research, and my knowledge of storytelling to write this book and create the *Savvy Patient's TOOLKIT*.

What else motivated me to write this book? I think we, as patients, have been, and mostly still are, guilty of expecting our doctors to be clairvoyant; to be god's of some sort. We expect them to take vague descriptions of our problems and read our minds and, then, work miracles for us. Many people tell me that they go to the doctor and expect him to *take care of them*. They don't expect to do much for themselves. When a person does this, they are handing control of their health care over to the provider and putting themselves at great risk.

My desire is to see you empowered and involved in your health care the way my husband and I have become empowered by use of our *Savvy Patient HEALTH RECORDS*, and through it, enable you to become a *Savvy* patient who partners with your providers, *leads* your health care team and *proactively manages* your or a loved one's health care.

COMING NEXT

As a process consultant, I spent many hours helping people think through the way they did their work so they could improve the way it was done. I feel it is important to discuss basic process development and principles of systems before we go further, as they are foundational to understanding why we think and behave as we do.