

INTRODUCTION

In the mid-1980s, when I was 32 years old, I experienced a slight hearing loss on my left side. I thought it was a minor thing and went to see an ear-nose-and-throat doctor about it. His diagnosis stunned me. He said I had an Acoustic Neuroma, a tumor that originated from one of the 12 cranial nerves adjacent to my brain. While benign, it could create serious problems for my brain structures if it grew too large, and I would have to have it surgically removed as soon as possible. Although I am a registered nurse, I had never heard of an Acoustic Neuroma (AN) – and neither had any of my health care colleagues. As I had no idea what it might mean for me, I was upset and scared, to say the least.

I decided to get the opinions of several neurosurgeons and eventually chose a doctor at a large, prestigious teaching hospital. He had one of the best reputations and had operated on a number of these cases, which aren't all that common, even today.

The day before my surgery I found myself in the X-Ray Department waiting room, alone with stacks of well-worn, dog-eared magazines (back then, patients were usually admitted to the hospital the day before scheduled surgery). As I sat there, fidgeting and anxious, my worst fears about my impending surgery started to hit me. At some point I got up from my seat and walked over to the main desk, where the patient charts were neatly lined up. On impulse, I took mine. No one stopped me.

I knew that patients have the right to see their medical records at any time, except for special cases, say in the case of a patient who may be mentally ill. Most people – including me, until then – never exercise that right.

Back at my seat, I tried to absorb the detailed notes and comments from my various doctors' visits. My top-flight neurosurgeon had already reviewed possible after-effects of my operation with me: How the removal of the tumor might injure my facial nerve, causing the left side of my face to droop; how my eye blinking, speech, swallowing, dental health and appearance might be affected, temporarily or permanently. I had even walked around looking at post-op patients on my floor, but the implications of my impending surgery had not sunk in. Now they did. I felt alone, helpless and scared.

I was also frustrated with myself. Why hadn't I pursued the effect my surgery would have earlier? Why hadn't I asked more questions then? As a nurse, I was usually pretty assertive and comfortable with doctors. What had changed? Perhaps, now that I was "just" a patient, I felt deferential. Perhaps I did not want to appear to challenge my surgeon, certainly not about a medical condition and procedure I'd never even heard of. Maybe I was numb with fear. Yes, I think that was it.

Later that evening, I was visited by an anesthesiologist in my room. He held my chart and the surgical permits and release forms, and calmly discussed the anesthesia procedure he would use with me, but I scarcely heard a word he said. My eyes kept darting to the forms where it said, "*Total Removal L Acoustic Neuroma.*" I was preoccupied with how the next day's surgery might affect my life. By now I had admitted to myself that I was afraid of it. But I also knew that this was more than last-minute jitters. So, I told my anesthesiologist I

wanted to hold off on signing permission for anything, until I spoke again with my surgeon. He nodded politely and left.

A few hours later, my neurosurgeon arrived, looking serious and concerned. He said something to the effect of, "I understand you are reluctant to sign for anything more than a sub-total removal. You want me to leave some of the tumor in there to protect the facial nerve, is that it?"

I felt myself trembling and with a small voice said, "Yes, I think so."

My doctor again explained that, while a sub-total removal surgical procedure would protect the facial nerve, there were no guarantees, and he didn't recommend it. The reason he generally didn't do partial removals was that more surgery was often required down the road and at that point scar tissue became an issue.

My confidence was shaky, especially since I had failed to ask any probing questions before, but I somehow found the courage to say, "Okay, but can we talk about it?"

Without hesitation, my doctor explored the pros and cons of both options with me – partial or total AN removal – taking time to answer all my questions. When we'd finished, I felt a sense of relief come over me. I told him I'd take my chances with a sub-total removal of my AN. He nodded and reassured me he would do what was safest for me. What he said next I will never forget: "I will take good care of you." On the surgical permission and release forms, he wrote his own caveat, something to the effect of "Sub-Total, if clinically appropriate." I signed the forms.

I was surprised and grateful at how safe, comfortable and almost unafraid, I now felt. "My doctor and I," I thought. "We're in this together!" While I felt secure that he was "in charge" of my care, I

was also certain that he considered me to be an important member of his team.

The following day, my neurosurgeon performed a partial removal of my AN, leaving behind just the smallest amount of the benign tumor. As anticipated, I lost my hearing on the left side, but my facial nerve was spared, and I didn't experience any of the debilitating side effects that often come with this operation. I made a full recovery and soon was able to resume all my normal activities.

Looking back now, I realize, of course, that the advantage of having a strong health care background helped me to engage my doctor the way I did. Still, like most patients, I had started out tongue-tied and intimidated, and waited until the clock was about to strike twelve midnight before mustering the courage to speak up and take charge of my life!

What did I learn from this experience? First, there is value in asking questions and learning all one can before agreeing to *any* health care procedure. Second, it is important to factor quality of life considerations into all health care decisions. Third, most doctors, even world-class neurosurgeons, are approachable and willing to answer questions in terms patients and other lay people can understand. Finally, although I didn't realize it at the time, by more fully interacting with my doctor, I became a partner in my treatment. I became my own Not So Patient Advocate!

Indeed, the experience changed me and changed my life! When I returned to work, I developed a greater passion for the issues that affect patients and those who care for them. I became a tireless advocate for developing partnerships with health care providers in order to achieve satisfactory outcomes. I became the "go-to" person

for my family and friends who were facing a health care crisis. I offered tips, insider's know-how and questions to ask their doctors so they would not hang back or be tongue-tied, as I had been.

As a health care and human resources executive, I made it my goal to listen better to staff and patients and to explore options and possibilities with them. I swore I would never again let fear or passivity go hand-in-hand with inaction or ignorance. This was important especially when I was most uncomfortable challenging authority or the popular wisdom of the day. I'd remind myself of my 90-year-old mom's advice, "Why, that's the time to have a little moxie!"

Then, my health luck ran out. After 22 years – right in the middle of writing this book – some new and very painful symptoms began to emerge on the left side of my head. Consultations with medical specialists made clear that I'd need more neurosurgery. Ugh. They told me that scar tissue from my first surgery would present challenges, just as my original neurosurgeon had predicted; but they also reassured me that I would benefit from new advances in surgical and anesthesia techniques, as well as from follow-up radiation treatments that could eradicate the tumor for good, without any damage to other brain structures or cranial nerves. This time, I was part of the decision-making team from the start, right up to my surgery.

The actual procedure and post-surgical treatments, however, often left me so sick and weak that I was unable to think clearly and had to rely on family, friends and especially my husband, Arthur, to serve as not so patient advocates on my behalf. I am deeply grateful for their attentive care and help throughout my long recovery.

While this experience confirmed many of the things I had been writing about and allowed me to refine the message that is so close to my heart, it did change my mind about one major aspect.

I had started out insisting on the need to become one's own not so patient advocate, to "tough it out" alone without help from others. Wrong! I came to realize that that real strength comes from allowing oneself to be vulnerable (although many consider vulnerability a weakness). I've come to believe that when you understand what's causing you to feel vulnerable and you allow yourself to be cared for, you are better able to access the power inside of you. It's the biggest lesson I've learned: *When we are most vulnerable, we gain strength from those whose caring makes us feel safe.* I've lived it, and it's true. It's an active, not passive place. It requires proactive and constructive interaction. Throughout my second health crisis, I've been far less reluctant to draw on the support of friends and loved ones. As a result, I have come to realize the important role they, and in some cases, professional advocates play. Their care allows us to become better not so patient advocates for ourselves and to create productive partnerships with our health care providers.

That is where my story connects to you, and why I wrote this book. I want you to be able to experience for yourself, first hand, the incredible power of partnership. You'll discover that when it comes to health, patience is not a virtue. You will also discover the power that resides in each of us in our pursuit of health and wellness. We *can* choose good health habits and have proactive health discussions with our providers. We *can* seek and take responsibility for the health care we receive. It really is up to us.

The Not So Patient Advocate is not about ignoring the advice of doctors or other trained health care services professionals, however. That would be irresponsible and wouldn't serve you. Nor will this book provide medical (or nursing) advice or answers, other than touting the often untapped benefits of preventive care. It *will* show you how to develop confidence in your own power to effectively partner with your health care service providers in a variety of medical situations.

What advice will you follow? Will you make sure to get a second opinion (or third!) and insist on the best care available for yourself and your loved ones, even if you have to travel outside your home city, state or comfort zone to get it?

If not, what's holding you back? If you don't have enough information about a condition, what will you do to learn what you need to know? Can you picture yourself being sure that you've done everything you can to get the best health care for yourself and those you love?

If you can't now, you will be able to by the time you finish this book. My guiding you through the process of becoming a Not So Patient Advocate for yourself is informed by my background and experiences as a patient, Registered Nurse, clinical nursing supervisor, hospital department director, and Human Resources professional. Although I have not maintained a license to practice clinical nursing for some years now, I have been an insider for more than 20 years as a corporate health care executive and chief human resources officer in a variety of health care settings. Those years have deepened my understanding and commitment to share with you how the health care system can work for the benefit of patients and those who serve

them. They have fueled my passion to complete this book so that you can be an insider, too!

Through the chapters that follow, I'll help you to discover how to take action for a variety of health challenges. I'll help you learn and practice what it takes to be your own Not So Patient Advocate. As a coach whispers into the helmet of his quarterback, I'll whisper to you, whether you're the patient or serving to advocate for family or friends. Even in the throes of a health care crisis that threatens to overwhelm you, you'll feel the fear or frustration you may have felt in the past melt away.

But first, you have to be willing to get into the game.

I presume that if you've read this far, you're ready to do that.

So here is what you can expect on our journey together. Each chapter deals with a specific aspect of the health care maze. To get things going, you'll read about real people and their stories. Some of them are cautionary tales, all are true. Only the names, locations, and some minor details have been changed.

Each story will be followed by three sections, **Powerup**, **Workup** and **Checkup**.

In **Powerup** a general discussion of the topic at hand provides background and context, and lays out the realities and challenges you and your health care providers face. I believe we can be far more effective communicators and advocates in the health care arena if we understand the terrain.

Please bear with me if your situation isn't covered exactly as it applies to you. Try to find commonalities. If I were to write about all of the places and situations where health care services are provided,

this book would be too heavy to stash in your glove compartment or purse, where it will most surely come in handy!

Next, the **Workup** section will offer how-to advice and action steps that will serve you.

In the health care arena, a "workup" refers to the process of collecting and analyzing data – such as nursing assessments, physical exams and lab tests – in order to make a diagnosis, and plan appropriate medical care. Think back to when you have had health issues. Your physicians and health care services providers wouldn't have considered taking any action before they had completed their workup on you. In the very same way, this book will help you to develop skills you'll need to do your own **Workup** as a Not So Patient Advocate (NSPA). To become a fully satisfied health care consumer and partner with your provider will require some investment of time and energy on your part. And here's the good news: I've done a lot of pre-work for you so you'll be ready to dive right in, no matter what the health care issue!

Finally, **Checkup** will offer a summary of key points to keep in mind when dealing with the particular health care challenge discussed in the chapter.

While this book is designed for you to become your own NSPA, it will be helpful to anyone acting in a supporting role during a health crisis as well. There are situations where the best option may be to seek the help of a trained professional patient advocate or a family support advocacy group, which specializes in providing assistance or communications for vulnerable populations, such as children, the elderly, or those with health conditions that make it impossible for

them to speak on their own behalf. But in most cases, *The Not So Patient Advocate* will serve as your guide for those times when you must navigate uncharted health care waters on your own.

Now, even during a major crisis, you will be more prepared to avoid emotional, physical, mental or financial trouble. You won't ever have to feel alone or be without resources again. This is your book. Make it your own. Carry it with you. Read it in waiting rooms. Write in it. Discuss it with your doctor, other health service providers, co-workers, friends, and loved ones. Let it be your trusted companion and reference guide whenever and wherever you find yourself in the health care arena.

I firmly believe that you can get the health care you want and need without fear or frustration. You *can* become your own NSPA. The power is yours to use. I believe in you.

So let us begin...