

INTRODUCTION

So why this book, and who is it for? The odds are over 40% that cancer will touch one's life. Our nation spends over \$150 billion dollars directly on cancer care per year. It is one of the largest single expenditures of the national health-care budget. There are over five hundred thousand deaths per year and over one million new cases. Including families, cancer touches almost four million people per year. There are few common medical realities that are surrounded by as much malefaction, mystique, and misunderstanding as cancer is. *When Tumor Is the Rumor and Cancer Is the Answer* helps one see past the understandably macabre mythology.

This work attempts to address the needs for knowledge when receiving the overwhelming news that you may or do have cancer. It attempts to cover not just the fear of the diagnosis or certain aspects of the journey of care but also the entire trek from when tumor is the rumor and cancer is the answer onward. It tries to envelop with knowledge the soul-sucking sense of loss of control, anxiety's favorite fodder and fuel.

Let us just walk around the table of contents. We open by addressing the hit-in-the-gut issues that come up immediately. First are some thoughts about the right recipe for the right mindset in handling the journey. Believe it or not, we are well wired to handle this stress. Thus, in "Read the Directions First," we look at how we might have a recipe for mental and emotional success as we gird up to weather the storm.

Then we specifically address the crucial issue of autonomy—the notion that you are an individual with explicit defined rights and that you can and will be in control.

We then address the problem of anxiety and its distinction from fear, the nature of cancer, and oncologists and the team they will lead in your journey, as well as how their world will become yours. This book teaches that anxiety and fear are not the same and that knowledge in all spheres—not just sterile clinical facts—is power and a therapeutic balm. Informed fear is a call to action, and the more informed you are, the better your clarity of resolve and the less your anxiety.

The section “The Enemy” explains how cancer is almost the perfect medical predator. It introduces the villain for what it is and prepares the stage for our fight against it. That fight starts and ends with defeating ignorance, using knowledge as our greatest weapon. The book addresses suspecting the diagnosis, the diagnosis, standard and alternative treatment, and symptom relief. This is followed by an in depth discussion on the problem of pain, clinical trials, future therapies, spirituality, and self-talk (how to talk with yourself when confronting cancer).

We then move into useful chapters on the ethics of cancer care, challenges of managed care, psychosocial issues with ethical and legal components, and the way end-of-life concerns play a common role in the care of oncology patients. Difficult concepts such as physician-assisted suicide, durable power of attorney, living wills, failure to diagnose, lost opportunities in life, euthanasia, and death by secondary intent (death occurring during a course of treating the patient and alleviating suffering) have led to cancer cases being second in frequency of lawsuits after cases of infant injury or disability.

One team member is largely shrouded in mystery despite his or her core responsibility often being shouldered rather alone. This is the oncologist, and just as orthopedists or pediatricians do, they tend to share similar traits. Understanding those traits can, in general, be both fascinating and fruitful. After all, to some degree these physicians are somewhat boxing with God and against a most mysterious of infirmities that affects all organ systems; all the while, they are engaging deep psychological and spiritual issues. The field is more on the cutting edge of applied genetics and immunology than others, and practitioners must master multiple modalities of care from chemotherapy to surgery, radiation therapy,

and transplants; and increasingly, biological, immunologic, and elegant genetically-based treatments.

Oncologists hold a very special position in the eyes of those they treat, in no small part owing to the nature of the enemy they fight. They are not magnificent demagogues (MDs) parsing out secret poisons to patients indifferent to the gravity of their daily toils. Nonetheless, they can find themselves often and appropriately playing the role of parish priest, psychologist, father confessor, coach, confidant, and counselor; it goes with the turf. In addition, as what little research there is suggests, they may not always be strong on emotional or psychological communication or expressing empathy.

Oncologists are human; we hurt with our patients and families. Ironically, though, there is not a lot of structured support out there for cancer doctors. The data is scarce, but what is there regarding burnout and psychological pain in oncologists is, not surprisingly, sad and sobering.

Although a cardinal rule is to always remember that the patient is the one with the disease, there is no doubt that the more informed we all are regarding the whole enterprise, from rumor to advanced tumor and the weight and impact and role each diagnosis has on all the players on the team, the better the outcome—in significant ways.

This book thus looks at why some oncologists chose such a sobering field and offers to practitioners different insights into managing the whole patient and, in part, themselves during a difficult emotional journey for all.

Oncologists inhabit a world of words, wonders, hospital wards, and clinics that are foreign to the patient. This book looks into the front and back office staff as well as the rules of the road while an inpatient. The more each patient understands where he or she will spend so much time, the better the experience will be for all.

Most family and friends experience considerable discomfort when interacting with a seriously ill or perhaps dying friend or loved one. They wonder, *But what do I say?* Although the singular moment of death is experienced alone, the journey need not be. In the section “But what do I say?” I offer some help and observe that we are in this boat of life together.

When it is time to dock for some, we must hold fast to the loved one's hand and help him or her lovingly ashore.

We close by sharing some true stories of remarkable patients and their journeys.

This is not a medical text on the treatment of malignancy, per se, or prevention, screening, or cancer survivorship. This book describes what happens and what works best for the whole team when the possible diagnosis becomes the proven and potentially fatal diagnosis. A major aim of this book is the goal of reducing anxiety and helping those confronted with this disease to marshal their internal resources to conquer their natural fears and ultimately learn to become cancer survivors. I hope to address many of the often unspoken truths that, now found in one place, can act as a guide for what is for many the most frightening time of their lives. I hope to return that crucial sense of control.

Why do it this way? In large part, it is because little other published work does so. This book highlights the gift that improved patient–physician communication can be, especially when the patient and family are fully informed. There is never enough time in today's practices to fill all those gaps; this work will help. This is big-picture thinking with the picture being you and how it all can be decipherable—instead of it being a transaction of doing as advised, but doing so not as fully educated as you might have been.

Embracing that overarching concept is of incredible assistance when we see this as a journey with many well-known milestones and probable adventures along the way, with common waypoints for most. Think of it as understanding in more depth the nature of what largely happens to and for all. In explaining a professional sport, one needs to have context and overview in addition to the details of how the game inevitably proceeds and who does what when. That requires time and careful organization. Having such a continuum of understanding not only engages all those in the fight but also steels them to do their part as best they can and prepares them for what is next.

This book is needed because medicine is enveloped and cloaked in mystery. It is replete with magic decoder rings and secret handshakes. Irrespective of Hollywood's latest or greatest umpteenth version of a real

doctor show, society is largely ignorant of the mysterious and frightening world of cancer medicine. Cracking that code and empowering the patient with knowledge will undoubtedly lead to healthier lives and happier journeys for all.

This book is about teamwork. Patients are experts in teaching us physicians to be *complete* clinical oncologists. There is plenty of angst and agony to go around when pursuing diagnosis and committing to do battle against a malignancy. Wise physicians in many regards embrace patients on the journey as partners whose informed engagement is crucial to success. We ideally want them informed, forewarned, and feeling that although they are the one with the disease, and although their autonomy is first and foremost, this journey is a team effort. The more we all know about the terrain, the better.

Superb cancer care is only possible with teamwork. The enemy is the cancer and, many times, the anxiety the cancer and its treatment fosters. Everyone brings different skills, needs, agendas, perspectives, and languages to the fight.

Thus, the audience of this book is everyone on the team. It is an enormous responsibility and burden to care for cancer patients. It is no less an enormous burden and responsibility to be a patient with cancer or a family member of someone who has been diagnosed. There is the rub: the knife cuts both ways. Patients and families have a responsibility to learn as much as they can and participate in their disease as much as possible. Furthermore, using all manner of techniques, health-care providers have a responsibility to share their perspective on the burdens and responsibilities of their role on the cancer-care team and express appropriate empathy—a surefire way to increase trust.

Musician Roy Clark penned some great lines in his tune “Yesterday, When I Was Young”: “I ran so fast that time and youth at last ran out. I never stopped to think what life was all about ... And only I am left on stage to end the play.” I hope that this book will help you gather more tomorrows and realize you are not alone.

Now, read the directions first.