

Introduction

We don't plan to get sick. We certainly don't plan to die. But everyone, healthy or sick, will face illness and the end of life, whether we want to discuss the subject or not.

We experience disease, death, and dying every day. It's often the lead story on the local news. It's the newspaper account of a horrific accident or the killing of a local serviceman overseas. It's the obituary of an entertainment legend. We whisper quietly about our neighbor, friend, or colleague with cancer. We're often consumed by the tragedies of others.

But many of us can't talk about, acknowledge, or plan for our own infirmity and mortality.

We can laugh and make light of the subjects, however. We jokingly say, "Just kill me" when facing a long meeting or an encounter with an obnoxious relative. We order "Death by Chocolate" at our favorite restaurants. We refer to an attractive woman as "drop-dead gorgeous." We read the Darwin Awards—an annual listing of the dumbest ways people have met their deaths. At the water cooler, we chat about who was "whacked" on *The Sopranos*. We pass along the latest joke after a tragedy. We refer to death as "buying the farm," "kicking the bucket," "pushing up daisies," "biting the dust," and "corking off," instead of calling it what it is. Death.

But our own death? Our own loss of health? These topics are often off limits. They're too frightening, too depressing, too real to think about. We simply don't want to go there.

Throughout ancient civilizations, much of life was spent anticipating and preparing for illness and death. Health and restoring health were important cultural activities. Tombs were built for Egyptian rulers decades before their final breaths. Beautiful Greek cities were built in an attempt to restore health and ward off death.

Today, modern civilization may be more advanced, more educated, and more efficient, yet we often lack the foresight of our forefathers. Although we might spend money on business succession planning and life insurance, we still fail to acknowledge that illness is likely and that death is inevitable. We fail to talk about disease. We fail to plan for the end. We fail to share our wants, wishes, and wills with our loved ones.

All of us *want* the best potential health care, *wish* for the best possible medical treatment, but *will* have the best outcomes only if our health care is planned. We *want* to care for our families when we die, we *wish* great things for their future, but we *will* only have these results if we plan. Unless you're in the medical profession, it's difficult to know how to make decisions about health and medical matters. And if you aren't in the legal profession, it's difficult to know what to do today in case you get sick or die tomorrow. As different as medicine and the law may seem, they join forces in times of sickness and health, as well as death.

Planning for illness and death is the last thing most of us want to think about. But plan we must, whether by necessity in the case of a terminal prognosis or upcoming surgery, or by diligent, old-fashioned organization and preparedness. For the super-courteous, questioning a medical decision may seem disrespectful. For the superstitious, writing a will invites death. We have our own theory—failing to plan for illness and death invites tragedy. We may visit our doctors and

dentists for annual physicals and examinations, but we rarely review our affairs. (Let's face it, we all know how people feel about spending time with lawyers!)

As a doctor specializing in the treatment of cancer and an attorney with an emphasis in estate planning and administration, we know disease and death are scary, sad, and overwhelming. We understand how your medical care and your legal affairs are intertwined. Every day we work with people who learn that their deaths, or that of a loved one, will be sooner rather than later. We know first-hand the fear and anxiety facing these individuals and families. For this book, we also surveyed and interviewed hundreds of healthy people to learn what's important to them. (We've quoted many, changing their names but not their ages.) Not surprisingly, the sick and the healthy share the same apprehensions. What will happen to my loved ones? How can I care for them? How can I stay in control of my health care and my finances? *Wants, Wishes, and Wills* answers these questions by providing critical medical and legal information, whether or not the end of life is near.

Understanding your health care, ordering your affairs, planning for a long illness, and preparing for your last days can be complicated, emotional, and confusing. Instead of focusing on what you *can't* control, we believe that focusing on what you *can* control will empower each of you to make the best decisions for you and your loved ones. The goal of *Wants, Wishes, and Wills* is to offer you critical personal information that will help you make wise choices and retain control of your situation. We also help you understand new terms and concepts that may be thrown at you by health care providers, attorneys, and financial planners. Although we can't remove your fear of illness and life's end, we hope to remove some of the angst surrounding the subject by arming you with the information needed to overcome the different challenges that lie ahead.

David Kuhl, M.D., writes the following in his book, *What Dying People Want*:

...dying, like living, presents opportunity for personal growth and development. Dying involves choice. And for some people, the moment of realizing that death is inevitable, that their time is limited, marks the beginning of a new way of being. People generally die as they have lived. They can choose to embrace a particular event, or exist passively as though the inevitable—in this case death—is avoidable.

We encourage you to embrace the unavoidable, to tackle disease and death head on, and to make the choices that will allow you to retain control of your life, your health, and your death.

Wants, Wishes, and Wills is divided into six sections, each of which addresses a different subject. Those of you facing a health care crisis will likely focus on the sections related to health care, whereas others planning ahead will want to focus on the estate planning and legacy sections. Regardless of your current situation, *Wants, Wishes, and Wills* is a valuable resource for you and your loved ones. Because, as we know, everything can change in a heartbeat.

In each of the six sections of this book, there is a chapter dedicated to your wants (what you don't have), wishes (what you desire), and wills (your choices). We recognize that you have needs that must be met. These are your wants. You also have wishes that you hope will come true. Lastly, there are actions you can take that allow you to express your will.

In Section I, "The Wants, Wishes, and Wills of Your Health and Medical Situation," we address the issues of today's patients and their health and medical situations. Gone are the days, if they ever existed, of a family doctor who knew every detail of your personal and family medical history, as well as your concerns, fears, and anxieties. Instead, each patient today encounters a multitude of health care providers, from the clinician performing a diagnostic test to the nursing staff at the hospital to the countless medical specialists required to analyze

and diagnose each symptom and determine the best course of treatment. We help you organize your personal health care system, as well as select medical experts and facilities, pharmacies, and programs. Lastly, we outline the different health care conditions—because the more you know about your health, the more you can do to protect it.

Next, in Section II, “The Wants, Wishes, and Wills of Your Personal Situation,” we explain how to take charge of your personal situation. You can make a difference in your health care treatment—and we show you useful steps to do just that. Communicating with your providers is critical—we give you tips to improve how you talk with your caregivers. Health counseling and screening can improve your personal situation. So can the drugs, diets, and devices you use.

As the Terry Schiavo case made clear, the end of life isn’t always simple. Because Terry was in a vegetative state and left no written instructions as to her care, her family ended up in a protracted and costly legal battle over whether to remove her feeding tube—a question that the courts ultimately decided. Were Terry’s wishes carried out? We’ll never know. No one can make a decision for you without knowing what you want. With that said, how do you determine what you want? In Section III, “The Wants, Wishes, and Wills of Your Medical-Legal Affairs,” we talk about death, the different wishes of patients and families, and ethical dilemmas regarding the subject. There are also different levels of intervention. The importance of learning the distinction between pain intervention and a ventilator to help you breathe cannot be overstated. For those in serious medical situations, learning the different point-of-death definitions will assist you in determining your end-of-life wants and wishes, as well as providing guidance to the loved ones you’ve selected to carry out your intentions. We explain Living Wills, Health Care Proxies, and Powers of Attorney and how to select the individuals to carry out your wishes. We also discuss why you should communicate your wishes to your loved ones.

Our communities depend on the goodwill of strangers in the time of crisis. The medical community is no exception. Whether you're undergoing a routine procedure or a biopsy or you're the victim of a tragic accident, a donation of your organs or tissue can bring immeasurable benefits. In Section IV, "The Wants, Wishes, and Wills of Your Selfless Contributions," we explain how this works and how you can be a participant, or, alternatively, explain how you can be sure your desire not to be a donor is followed. We also talk about donating your time and energy to the many organizations needing your help. Lastly, we update you on informed consent, donation ownership, and record keeping.

Whether death is anticipated or unexpected, what happens next for many families is an unknown. Section V, "The Wants, Wishes, and Wills of Your Estate Planning," explains the process of estate administration to help remove the anxiety that many face. With that foundation, we explain estate planning and what you can do to simplify the administration process, reduce taxes, care for loved ones, and share your good fortune with charitable organizations. A comprehensive discussion of different estate planning vehicles (such as wills and trusts) is included.

Finally, we discuss the importance of leaving instructions for your loved ones and creating your legacy in Section VI, "The Wants, Wishes, and Wills of Your Legacy." We encourage each of you to take the time to share with your loved ones your hopes, goals, experiences, and personal history. Having the courage to confront death and share your thoughts and fears isn't easy, but for those facing life's final chapter, it's what they want and need. Leaving letters of guidance regarding children, as well as lessons of love and other valuable information, provides assurances and directions to those left behind. We want to encourage you to do everything possible to ensure that your wants, wishes, and wills are carried out in every situation. Lastly, we explain the legacy of your medical safety, rights, and records.

Wants, Wishes, and Wills is about just that: your wants, wishes, and wills. It is not about what you, your loved ones, your health care providers, or your attorneys think you *should* do. It's quite simply all about *you* and what *you* want. We often have patients and clients stating, "I don't know what I should do." Our response is always the same, "Do what you want, not what you think you should do." The end of life is not the time to be worrying about social conventions, hurt feelings, proper etiquette, or pleasing others. It's the time to decide what you want and to take the necessary actions to be sure that your desires are carried out. We think of *Wants, Wishes, and Wills* as a toolbox. We provide the necessary background information to help you evaluate your situation and then build a plan to accomplish your goals. You'll find checklists, resources, and Web sites, as well as additional suggested reference materials and a glossary at the end of the book.

Both of us help people deal with death and disease every day. We meet with patients and clients who know that death is not only inevitable, but close at hand. We know your questions, your fears, and your concerns. We know that understanding and planning can give you control, and from control comes peace of mind.

That's why we've written this book—to share with you our knowledge and to give you the tools you need to confront disease and dying. We use humor and honesty, tales and tributes, facts and figures, information and ideas. You may find our approach irreverent at times. But sometimes a little levity makes the subject easier. And that's our goal.

Wants, Wishes, and Wills is a valuable resource for personalizing your health and legal information. This book is not, however, a substitute for a health care plan and legal advice tailored to your particular situation and circumstances. It's important to have legal documents prepared by an attorney in the state where you reside. It's also critical to consult with appropriate medical specialists regarding your health care.

Like it or not, we're all going to die. We need to acknowledge it, talk about it, and plan for it. As one client of ours stated, "You cannot die smart unless you live smart." You live smart by planning. You die smart by having planned. Reading *Wants, Wishes, and Wills* is the first step to doing just that.