


Notes from the Waiting Room



Managing a Loved One's End-of-Life Hospitalization

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Notes
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THOUGHTS FOR THOSE IN ACUTE NEED OR CRISIS

MAYBE YOU'RE FREAKED OUT. Your loved one is hospitalized. Maybe it's a surprise, a shock. Maybe s/he's in critical condition in an intensive care unit (ICU). Maybe terminal. Maybe there's a decision you have to make -- perhaps a life-and-death decision. How prepared are you to make it?

You and your family assemble at the hospital -- a foreboding environment. A teeming, technical, yet bland place where time moves strangely and what lies ahead is not explained. You're left alone with your languishing loved one, your uncertainties, doubts, and fears.

To ensure that your family's best interests are served, you must proactively unearth all kinds of information by asking endless questions, up front, of virtually every person who interacts with you in a professional capacity. To ensure that your loved one doesn't languish, you must have that information before each next choice point -- some moment that practically begs for a decision. How do you get it? How do you know what to ask for? How do you anticipate when the next choice point may occur?

If this loved one is your last living parent, and if s/he dies, you may have the double task of closing the

parental home and beginning to settle the family estate. A task that, depending upon circumstances, may not be able to wait another day if you're half a continent from your own life and home. The need to begin this work may arise even as your loved one lies dying.

THIS BOOK OFFERS A COMPILATION OF GUIDANCE YOU WON'T FIND ELSEWHERE. My experience during and after two terminal hospitalizations taught me that healthcare establishments neither talk about nor offer the information you most need to know -- especially what you need to know to help you in your hours and days of need, whether your loved one is terminal or hospitalized for less severe conditions. To the limited extent that institutions talk about matters vital to you, their communication is not offered in advance; it usually coincides with some disconcerting or agonizing choice point.

If you are your loved one's designated personal representative (known also as proxy, agent, surrogate, or Medical Power of Attorney) and your family's values are like mine, communing with your loved one, receiving direction from your loved one, and avoiding detrimental emotional shocks are among your family's most vital interests.

You may need help in making a life-and-death decision. But if you're not sure what death's onset looks like, you won't know that a life-and-death decision may be looming.

Unless you happen across an "angel"¹ in the hospital halls or during telephone calls, you may be at the mercy of people who, for various reasons, do not offer ample guidance, or any guidance, or don't even do their job well. Perhaps they do their job well but their job definition or professional orientation is limited in scope and doesn't reach as far as providing the kind of care families expect for their loved ones -- the kind of care we provide for one another.

During two hospitalizations fifteen months apart and totaling almost six weeks, my family received virtually zero advance notice of things to come, let alone any guidance. Without notification of what was likely or possible to happen, we experienced repeated, deep, destabilizing -- and unnecessary -- shocks. Our equilibrium suffered, and important opportunities were foreclosed, vanishing opportunities to commune with and receive treatment direction from our loved ones. Without guidance, our best interests were not served by providers or by institutional staff and representatives. Rather, we had to discover for ourselves how to have our best interests served, moment

by moment, time and again -- during the most urgent, stressful, and vulnerable of times of our lives.

Thus, this book. WITHIN A FEW HOURS' READING, YOU'LL LEARN WHAT IT TOOK US MONTHS TO LEARN AND PIECE TOGETHER from disparate sources (years, actually, if we include my subsequent research and contemplation). Through these pages, you and I will converse in the peace and quiet of your own reading environment. Unlike my family, YOU WON'T HAVE TO LEARN SOLELY ON THE SPUR OF THE MOMENT, when unexpected choices are conveyed with no prior notice. As if they would not rock your world. As if the choices before you weren't emotional bombs. As if the casual notification of the need to choose didn't add additional shock to the cataclysmic, intrinsic shock of a loved one down, possibly on their deathbed.

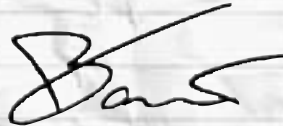
IF YOU ARE IN CRISIS, if right now is your spur-of-the-moment, I wish I could sit with you and help you personally. This book will have to be my stand-in. Although writing a book is primarily a mental exercise, I have tried to imbue this one with heart and soul; I hope that at times you can sense their presence and feel bolstered.

TO SAVE TIME, you may want to skip our italicized stories that begin each chapter. If you need infor-

mation you can act on right now and are inclined to consider my suggestions without substantiation, read each chapter's "notes," summarizations that look like this following each chapter's opening story. Then read sections that address your most pressing concerns.

Afterward, when you have the time, I suggest you read our stories. The snapshots describe events that occurred to my family and which could occur to yours. Our stories are vital to a complete understanding of the narrative; they will help you identify, understand, and overcome needlessly stressful situations associated with serious hospitalizations -- especially those that turn terminal.

Godspeed --

A handwritten signature in black ink, appearing to read "Paul". The signature is fluid and cursive, with a large initial "P" and a long, sweeping underline.

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THE NIGHT MY FATHER DIED, her connecting flight was delayed. She was aboard a conveyance that takes untold millions of living human beings as close to the heavens as all but a very few will go during our earthly existence.

My wife returned to earth, we surmise, at the very moment that Dad's newly-freed spirit may have been making a voyage in exactly the opposite direction (assuming, that is, that newly-freed spirits exist and have, or even need, a sense of direction).

Deborah's plane was scheduled to land in south Florida at 11:30 p.m. Due to a passenger emergency, it made an unscheduled stop en route. Our original plan had me picking her up at the airport and driving to Dad's nearby hospice room for their last communion. I had stayed at his bedside later than usual, but after learning of the delay, I piloted Dad's van through the seventeen-mile drive to his assisted living apartment, where I'd been living for the previous two weeks. There, I did another round of endless tasks associated with closing a home half a continent from my own—jockeying the phone, notes to myself, financial files, online research, legal queries, property dispositions, a canned dinner. I fell asleep on the floor; my dad's hospital-style bed had been returned to Medicare.

Almost immediately, the phone rang. The hospice nurse breathlessly told me that my dad's own breathing had

unexpectedly changed to end stage. In her experience, his passing might occur at any moment, even though its imminence caught her by surprise. Well, that was my father, I reflected. He was a black-and-white type of guy who did not engage in subtleties, and his dying process mirrored that in this seemingly sudden turn toward the end.

I made the midnight drive back on empty boulevards, speeding a little but not as much as I would have liked. I didn't want to risk being pulled over and further delayed. The hospital parking lot, full to capacity during the daytime, was barren now as I slipped his van into the spot closest to the entrance.

Grimly, I hiked up several flights of stairs and strode through the labyrinthine hallways I'd come to learn as if they were my new neighborhood. In the soundless hospice wing, the solitary nurse approached and told me my father had died twenty minutes earlier.

She expected me to want her hug—or to want to hug her. Maybe she needed that hug, or to give it, and I regretted that I didn't have it in me. I didn't share that thought with her, although I wondered in that moment if she thought me deficient as she stiffened from my unavailability. In retrospect, I surmise that at her lonely post, a midnight guardian of those who die, she needed a respite from unavailability and stiffness, hallmarks of the remains of the newly departed.

I was not present at my mom's passing fifteen months prior, and by the time I'd flown in, her remains were ashes. I'd never seen or encountered human death. I'd never experienced the evidence death leaves behind. I'd only experienced the absences of living far away from family visited once or twice a year and old friends seen once or twice a decade.

Had circumstances been different, my wife and I would have been present when Dad died, to be with him as his spirit took its leave. Instead, nineteen days after taking himself into the hospital, twenty minutes after his passing, I entered my father's room alone.

New Terms for a Clear Conversation**New Terms To Define Hospital Experiences**

NOTES FROM THE WAITING ROOM DISSECTS EVENTS you may encounter during a loved one's hospitalization and death. If things are to go poorly, chances are this will occur during the last weeks and days of your loved one's life. Since approximately fifty percent of Americans die in hospitals,² *Notes from the Waiting Room* focuses on what happens in that setting.

During this conversation I introduce a variety of new terms. Familiarity with these terms is key to understanding what can occur when loved ones' lives end in hospitals and the nature of hospitalization as we experience it.

As far as I know only two of these terms are, at the time of this writing, in general use in the medical world: discontinuity of care and time-based trial.

While a list of definitions might seem like an unusual way to begin a book, this list actually summarizes much of what *Notes from the Waiting Room* has to offer. The group of terms as a whole provides a framework for an in-depth discussion of hospitalization in general, and end-of-life experience in particular, whether in the hospital or elsewhere.

In addition to clarifying things, the right terminology serves two other important purposes. First, naming an experience helps us make meaning of it. Once we begin making meaning of experiences, we can better assess what we've been through. We can begin to figure out how systems function. Second, naming an experience offers several important personal benefits. Our experience is validated; we're not crazy or wrong. We realize that we're not isolated; we're not alone, either in our experience or our understanding of it. Naming an experience serves to formalize and normalize it (i.e., to see something as common rather than as an exception). Once we understand that our experiences are normal, we can examine institutional and societal behavior from a place of confidence, rather than sheepishly feeling that something is wrong with us for having "gotten ourselves" into some problem situation.

Opting to use new terminology makes us proactive proponents, and components, of change within the system. For example, when providers and institutions start hearing us refer to ourselves as "patient-families" again and again, they can't help but begin to modify their viewpoint of their customer base. When we inject the term "forecasting" into our conversations in doctors' offices and at the bedside, a new level of consciousness and attentiveness is bound to arise over time. Ask and ye shall receive.

With this in mind, here's my list of new terms and concepts to use when discussing the continuum of experiences during hospitalization and end-of-life.

Redefining Hospitals

The dictionary defines hospitals as places providing medical or surgical care. The trouble is that hospitals and lay people define care differently. This mismatch results in turmoil and anxiety when people experience what hospitals and providers consider to be care. Thus, it's useful to explicitly define what hospitals offer. Aside from Emergency Department services and walk-in clinics, in the context of serious and/or extended hospitalizations, *hospitals provide bodily repair services under the direction of independent physician-scientists.*

EVERYBODY WANTS TO GO TO HEAVEN; nobody wants to die to get there. In other words, being dead might not be so bad, but dying may be needlessly distressing, for both the patient and the family.

The Experiences Behind This Book

THIS BOOK IS NOT ABSTRACT. I have been involved with two deaths—those of my eighty-year-old mother, Ruth, in January 2004 and my eighty-four-year-old father, Mort, in May 2005. Both occurred during multi-week hospitalizations. Both were needlessly distressing.

I write from my involvement as a son who watched both parents die; as a personal representative (the designated power of attorney) for both health and financial matters, making critical decisions (including a life-and-death decision) on my father's behalf fifteen months after my mother's death; and as a trustee responsible for settling the family estate.

In both my parents' cases, their dying process was rife with unnecessary grief. I don't mean the natural grief that accompanies loss. I mean the needless grief we experience during health crises due to unforeseen patient-family languishing, unnecessary pain for our loved one, and requirements to make decisions we may not feel qualified to make—but which we must make nevertheless. The needless grief was not intrinsic

to the situation (unexpected terminal illness) but was due to shocking extrinsic (external) causes.

I write as a layperson for lay people. I expose what causes much of the needless shock (and resulting grief) that can accompany any hospitalization and end-of-life experience.

I am not suggesting that grief be eliminated or is unnecessary. Grieving is part of loss, and healthy grieving is part of healing. In *Notes from the Waiting Room*, the focus is not on this natural grief but, rather, on how to prevent needless grief caused by shocking situations that need not occur.

Nor am I suggesting that every hospitalization past and future was and will be bad. It is possible to encounter truly caring providers. It is possible for communication to occur smoothly and for all to be right with your loved one's treatment. Such was not my family's experience, twice in a row, for the only parents I had.

Had my experience been limited to a single parent dying, I would not have proceeded with this book. I would have been just another family member among millions, griping about inexplicable and troubling experiences during a loved one's hospitalization or demise.

My second parent's demise included more of the same problems for the family, although different in their causes and details. The family was similarly impacted, even though we thought we had learned about hospitalization pitfalls, having lived through our mother's terminal hospitalization.

Since these events occurred in different institutions, neighboring cities, and fifteen months apart, a pattern seemed to emerge. As I considered our experiences, I set out to learn if they represented the norm.

Because I don't have medical initials after my name, I want to authenticate myself to you, brief you on my research, and introduce you to the array of professional helpers who ultimately confirmed my early theses (they were uninvolved with my later theses, specifically those informing *The Option to Die in PEACE*, although some have reviewed it).

Beginning Research

After my father's death and before starting this book, I engaged in two levels of research into these matters. The first level was the kind of

Introduction**An Antidote to Profoundly Serious Problems**

I OFFER THIS BOOK AS A GUIDE AND AS A SOLUTION for profoundly serious problems you may face during your loved one's hospitalization—especially if that hospitalization becomes an end-of-life event. Potential problems include, but are not limited to:

- Institutional practices that are questionable at best and detrimental at worst
- Stress and heartbreak associated with not getting information with which to make critical decisions in a timely manner
- Unquestioned ideas and expectations about what our medical system provides that shape our experience and add angst to it
- Last intimate opportunities with your loved one infringed upon or lost
- Bureaucratic runaround
- Unnecessary and harmful shock due to the above
- Enduring a terminal hospitalization because you don't know about or understand the alternatives.

This book will guide you to become qualified in advance, learning how to best represent your loved one by proactively and effectively

dealing with “the system,” and by offering an alternative to hospitalized dying and death.

Understanding “The System”

THE SYSTEM MAY BE PERSONAL OR IMPERSONAL. The system shows up as institutional and personal assumptions, hierarchies, values, ethics, procedures, rules, obstacles, omissions, and intersections of diverse interests.

Contributing factors include:

- The patient’s—your loved one’s—mindset, values, and ethics
- Your own mindset, values, and ethics
- Your family dynamics, values, and ethics
- Our cultural milieu (societal and medical conventions)
- End-of-life medical entities and concerns—the curative, or allopathic, medical system comprised of doctors, nurses, hospitals, insurers; and hospice (a system providing end-of-life comfort, or palliative, care)
- Legal entities—the law itself, legal counsel, and governmental agencies
- Funeral and burial choices and entities
- Financial entities—banks, retirement fund companies, insurers, the government, and more mundane, day-to-day grantors of credit or service providers such as power, telephone, and internet providers (discussed in the companion book, *How to Efficiently Settle the Family Estate*).

During and after your loved one’s death, you will likely deal with the system in its entirety (especially if the deceased is your second parent to die or your spouse). If you are the legally responsible person, you will encounter most or all the entities listed above as you grapple with each phase of your loved one’s journey and the aftermath of their death.

Remember that *you and your family are part of the system*. This is true no matter what your viewpoint. To some extent, other entities in the system respond to your expectations and initiatives, your language and demeanor. To be sure, many of their activities occur due simply to how they function.

In any case, dealing with the entities during hospitalization and

SECTION 1 | EFFECTIVELY REPRESENT YOUR LOVED ONE 

NO MATTER WHAT YOUR LOVED ONE IS HOSPITALIZED FOR, s/he is at significant additional risk without your effective personal representation.

Effective means that you know how to function in the role of personal representative, and that you do so in ways that make a positive difference in your patient-family's experience and outcome.

Effectiveness in this role also requires that a protective legal framework be established around your patient-family by executing a series of legal forms. Without the suite of five legal documents I call "Power Documents," you run a real chance of the system freezing you out of decision-making. Will it? Who knows—but why place yourself at such a risk?

Thus, we begin with two chapters discussing "front-end" matters.

Chapter 1, "Be An Effective Personal Representative," examines how to function as a personal representative in a uniquely challenging environment, offering numerous steps you can take to ensure that you do.

Chapter 2, "Making Effective Declarations: The Essential Power Documents," presents the legal requirements you must meet in order to be recognized as your loved one's legal and authoritative voice, without which you and your loved one could be rendered powerless.

If you feel particularly eager to delve directly into the everyday situations encountered during hospitalization or the weightier aspects of whether even to go, Sections 2 and 3 await you. Chapters 3 through 9 discuss progressively more disquieting and significant situations. Should you skip to them, I strongly urge you to return here and read Section 1: understanding what effective personal representation entails and constructing a secure legal framework around your family's affairs are your patient-family's bedrock foundations, and the only aspects of hospitalization that are under your sole control.

SECTION 2 | EFFECTIVELY MANAGE HOSPITALIZATION 

THE HOSPITALIZATION SECTION examines a range of incidents that typically occur in hospitals. Some may be known to you; many are probably not. If you haven't experienced them for yourself, you won't know about them, because hospitals don't tell you.

I will point out, clearly and uncompromisingly, hospital faults as my family experienced them. I'll untangle what leads to grave conditions with grievous consequences, some of which I consider malpractice (as in "bad professional practices," distinct from bad medicine, although the lines do blur). I'll state my conclusions in direct terms.

By the end of this section, you'll know how to avoid experiences similar to ours as much as is possible. You'll also understand my family's felt responses to our experiences and why you should avoid our fate. Although I stated this in the preface, it bears repeating: *My goal is that you understand both intellectually and emotionally the conditions and events a family is likely to endure when dealing with end-of-life hospitalizations in the hope that you will act to preclude unnecessary pain.*

It would be easy to sidestep criticizing these institutions because they, and treatment providers who work in them, improve and save lives. Sidestepping would be wrong, because their way of serving induces angst among their patient-families. It would be doubly wrong, because for

those facing end of life, the conditions I'll describe infringe on precious, irreplaceable moments in the days prior to death.

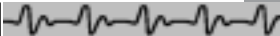
In critiquing hospitals, it's important to differentiate between the services they provide. These include emergency trauma care (the emergency room in the Emergency Department, or ED), walk-in specialty clinics, short-term stays for acute problems (like broken bones and non-catastrophic surgeries), and finally, the area this book focuses on: extended hospitalizations of a week or more, typically near or at the end of life.

Because of the many personal circumstances resulting in hospitalization, it may help readers to approach this section with some mental flexibility. Much of what I present here is applicable to almost any hospitalization. Because any hospitalization can shift from serious to *very* serious, one might say this presentation can apply to every hospitalization. And because this book emanates from my family's particularly egregious felt responses during two terminal hospitalizations, my recurring focus includes profound issues arising during end of life and the weeks leading to it.

This conversation focuses primarily on the ways hospitals function and how this impacts patient-families. In this respect, the health-care industry is like the stereotypical "geek," a technically skilled person who's uncomfortable with everyday social discourse. That's of little consequence at a dinner party, and of enormous consequence when your loved one is dying in a geek-like environment—especially when the institutions proclaim far and wide that they provide loving care (which is, plainly, false advertising).

Hospitals differ from one another in many ways. These include policies, staffing, hierarchy, culture, and more. Use the information in this section as a guide. Ask, ask, ask, to clarify how things work at any institution your loved one is bedded within.

Chapter 3, "Differing Sensibilities: Care and Communication in Hospitals," analyzes the schism we experience due to the related issues of what constitutes care and the communication disconnect between the medical establishment and laypersons. We will reorient our thinking about what hospitals are and provide (and to who), so as no longer to be

SECTION 3 | THE IMPERATIVE TO CHANGE END OF LIFE

WE HAVE TOGETHER EXAMINED the nature of hospitals and hospitalizations, with a particular focus on understanding and protecting ourselves against detrimental, unanticipated impacts on patient-families.

Hospitals, physicians, and the related cast of providers play a vital and respectable role in our lives. They are ever-present when we need them, and in many instances we are grateful for their accomplishments on our behalf.

This does not change their shortcomings, or our experiences due to them, nor our felt responses when enduring those experiences.

Since we are part of the system, it behooves us to ask ourselves what we want and expect of the rest of it. The medical world practically pulses with internal initiatives to change. Yet, hospitals are pounded from without by a public clamoring for reform, trying to resuscitate this nation's medical system because the system itself manifests ill health. We may want to ask ourselves how much change is possible, and whether or not incremental changes will fundamentally transform the system into something it currently is not.

Hospitals will provide a hospital experience. How can they not? Expecting something different is like going to a roadside diner with gleaming stainless steel counters, very sharp knives, and a preoccupied staff,

with the expectation of eating a five-star meal. Even if the diner is redecorated with a warm motif and its staff trained in attentive customer service, in the end our overall experience of the meal will be a diner experience, not a gustatory masterwork.

Dying in an institution will yield an institutionalized death. How can it not?

We are part of the system, and we are the part that can most readily change our experience. Doing so requires that we understand fully what is at stake—because even more things happen during institutionalized dying than we’ve uncovered thus far.

We have to talk about death. Straight on. Is doing so distasteful? Scary? A depressing drag on happiness?

Perhaps it is at first. Just like anything we don’t want to discuss...like some personal problem between spouses, friends, or adversaries. For as long as we don’t discuss the problem, it sits there in the pit of our stomach or the set of our neck, shoulders, and jaw. Weighty tension intrudes on our life. Until finally we let it out and deal with whatever conflict may ensue (sometimes not any!). Then, we are relieved.

So, too, with discussing dying and death. By opening the conversation and engaging with where it leads, we can and will relax. We can, to mix metaphors, get the weight of the unspoken thing off our shoulders and instead try it on for size, considering which approach may feel right. We can loosen the set of our jaw with the fluid of our thinking and feeling. By speaking openly about death with one another, we can gain a fresh appreciation for the lives we are living.

Section 3 presents an uncompromising look at death from a physical, emotional, spiritual, and practical perspective. Here, we’ll consider our options going forward.

Chapter 8, “Death Looks Like This,” offers a discussion of death as I experienced it during my father’s hospitalization. Every aspect of effectively managing hospitalization evolves from the possibility of losing a loved one during it. Everything presented in Section 2 is thrown into sharper focus when reflected against the one-way mirror that death may be likened to. Try as we might, we cannot view what’s beyond that boundary.

SECTION 4 | TOWARD HEAVENLY DAYS

NO MATTER YOUR PROCLIVITIES, bringing a little of heaven's imagined peace into our end days is a valuable personal and societal goal. A peaceful demise makes sense spiritually, ethically, socially, and economically. I propose that we make it our business to make peaceful dying the norm, or at least a normal and supported option. Make viable a pathway to death that embraces dying as the end of human experience, rather than the beginning of a medical melee.

Notes from the Waiting Room postulates that because institutions will be institutions, we as individuals and families must take responsibility for the nature of our end days and how they play out...that a more natural way of dying aided by medical technology for pain relief and comfort will serve everyone involved better than relentless medical intervention in clinical settings.

Fortunately, the institutions may end up joining in this vision by adding to their service model in- and outpatient palliative care services (albeit primarily in response to economic and demographic realities, rather than an innate sense of mission). Until they do, in a manner and to an extent that the majority of hospital-goers receive care—whether curative or terminal—under a palliative umbrella, much needs to change regarding how hospitals and providers function.

Section 4 focuses primarily on steps hospitals and medical providers can take to reform their practice to better humanize their patient-familys' experience.

Chapter 10, "Epilogue and Proposals for Medical System Reform," first closes my father's apartment and my family's personal story, then sets forth numerous suggestions for medical reform.

In suggesting reform I want to acknowledge that physicians and nurses have voluntarily undertaken extensive training (for which they may have accrued substantial debt), and enter demanding professions, through which they attempt to help their fellow humans in direct and often profound ways. Their patient-families form a kaleidoscope of humanity, and they never know which type is going to cross their horizon next. They shoulder responsibilities unknown to many of us.

That said, we will utilize hospitals, even if increasing numbers of us choose not to die in them (a choice not everyone can or will make). We ought not abandon the effort to reform the medical establishment any more than its practitioners (distinct from the insurance industry) would abandon us—even though we would all be better off if the system abandoned dubious notions of what constitutes care, and own up to the realities of what it can and does provide.

In that regard, *Notes from the Waiting Room* concludes with thoughts addressed to medical providers.

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