

**They Call Me
“Doctor Death”**

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*How Our Medical System
Robs the Terminally Ill
of Comfort, Time, and Dignity*

Dr. Ken Pettit


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They Call Me “Doctor Death”:
How Our Medical System Robs the Terminally Ill of Comfort,
Time, and Dignity

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Dedication

To my fiancé Megan, my parents, brothers and
sisters, children and grandchildren,
my grandson Parker, and my dear friend Steve.

To my wonderful team and many other staff
members I've worked with over the years.

We are all in this together.

And to the patients and families
I have cared for over the years.

How honored I am for being a part of your lives
at a very special time.

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INTRODUCTION ---

They Call Me “Doctor Death”

I was eating lunch in the doctors’ lounge one day when I walked a physician I’ll call Dr. X. He placed his hand on my shoulder and, with a half-smile on his face, turned to the other doctors in the room.

“How many of you want to see Dr. Pettit visiting *your* patient?” he called out. “You all know what he does here—he’s the *last* person you want to put on your case! Who in their right mind wants a visit from Doctor Death?”

Laughter rose around me, spilling through the room. I tried to join in, hiding my discomfort the way you do when Uncle Joe says something crazy at Thanksgiving dinner. The labels pinned on me varied—*Grim Reaper*, *Angel of Death*, *Prince of Darkness*—but the uneasiness I felt on hearing them never changed.

Dr. X is just being facetious, I told myself as the laughter petered out and the doctors went back to their hurried lunches. After all, he was one of my biggest advocates. He worked in the ICU and called me in all the time to handle the most difficult cases.

“Ken, this patient is not in a good place,” he would tell me. “I’ll do everything I can do to save him because that’s what

his family wants me to do, but we both know he's going to die pretty soon. I need you to establish some sort of plan. I can put in another tube, I can do another test, I can throw another drug at him, but we both know it's futile. Please, Ken—go talk to him as soon as you can.”

Dr. X does a good job handling his side of it, and I do a good job handling my side. Other doctors can talk about the next test or the next procedure, about a prognosis and possible progress. Other doctors can say, “I'm doing the full-court press. I'm doing everything I possibly can to help you pull through.” But I'm the “other doctor”—the one who bears the news that medicine can't fix the loved one's broken body, that reality has overtaken hope, that there's nothing more to be done.

I'm not a heart surgeon, an oncologist, or a neurologist. Rather, as a palliative and hospice care physician, I work with patients, both in and outside the hospital, who have advanced incurable diseases and are terminal (defined as having six months or less to live). I have my own hospice company with a staff of nurses, social workers, chaplains, certified nursing assistants, volunteers, and bereavement counselors who visit dying patients and their families. My goal is to prevent and relieve suffering for these patients, whether they choose to continue treatment or make the transition to hospice and “comfort measures,” where the focus is not on prolonging life but on helping them die a dignified death with as little physical and emotional suffering as possible.

Every day, I help patients face the choice of whether to continue treatment or to allow death to naturally unfold, so they can have the best possible quality of life up to the end.

It's never an easy conversation to have, and I've had it thousands of times. I don't want to take away their hope, but I don't want to rob patients of precious time by making false promises. Most seriously ill patients think they have to accept

every possible treatment and procedure. They get caught up in the momentum of a life-prolonging system that performs every procedure and treats every symptom. I’m there to help them understand that they don’t have to go down that road, that they can accept death and use the days they have left to prepare for it.

But far too many doctors don’t understand or embrace what I do. I’m called “Doctor Death” or “The Grim Reaper” because I’m the one with the bad news, who carts their patients off to hospice. I’m the fly in the ointment, the shadow on the wall, the person they try to avoid. I make them uncomfortable because I go against the grain of a medical establishment that views death as an enemy to be fought and defeated rather than as an inevitable and natural part of life that should be respected, not feared. My work challenges a medical establishment that routinely promotes aggressive treatments to the very end of life, which in the majority of cases only prolongs suffering for both patients and their families, preventing the terminally ill from dying “a good death.”

Yes, we’ve learned to cure a wide range of illnesses, allowing countless people to live longer lives. But our medical powers are neither infinite nor infallible. Each year, thousands of people older than eighty-five die in intensive care units while undergoing futile treatments.

A 2017 Kaiser Family Foundation poll found that seven in ten Americans say they would prefer to die at home, yet according to a study by the *Journal of Palliative Medicine*, about 71% of Americans have little to no understanding of palliative and hospice care. And close to 60% of patients who would benefit from palliative care never receive it (*New England Journal of Medicine*). Those who do are in hospice for too short a time to receive its full benefits. According to the National Hospice and Palliative Care Organization (NHPCO),

in 2017, about 40% of hospice patients were in hospice for less than two weeks.

No one wants to die, but some ways of dying are far better than others. You can meet your end hooked up to a machine. You can deny the reality of your mortality, or you can find peace with death in the comfort of hospice care, where the process of death is natural.

I've been pretty good at helping people die a good death during my career, and it doesn't have anything to do with my knowledge of medicine. I like to think that I'm a knowledgeable physician, but what I do best is connect and communicate with dying patients and their families. I'm able to openly talk about a subject few of us want to discuss.

My work is difficult, not because I have difficult conversations about death, but because I'm prevented from having those conversations until it's too late. You can do chemotherapy and radiation and all the treatments you want because everyone wants to live another day. But while you're chasing after that goal, you lose the opportunity to be at peace with whatever life you have left.

The Covid-19 pandemic brought these end-of-life issues into stark and heartbreaking focus. Families couldn't be with their dying loved ones to ease their passing. Doctors did their best to counsel family members via Zoom. And as cases mounted amid a national shortage of personal protective equipment, with doctors and nurses constantly exposed to a highly infectious disease, some health professionals began to question the value and morality of using every last procedure on severely ill and terminal patients.

That's why I wanted to write this book—to help people understand that we have the option to prepare for our deaths in

an early and proactive way, rather than accept treatments and procedures that only prolong suffering.

In the following pages, I look closely at my personal and professional experience with death. I examine problems in our current medical system and offer suggestions on how that system can be changed for the better. This is not a theoretical book or one focused solely on medical policy; rather, it’s based on my experiences with hundreds of patients and families. Throughout this book, I refer again and again to specific people I’ve worked with over the years (all names have been changed for reasons of privacy).

Among the major themes I address are the following:

- How watching friends and family die influenced my views on how the dying should be treated.
- How dysfunction, denial, and deception permeate our treatment of the terminally ill.
- How suffering is routinely prolonged because we fear talking realistically about death.
- How hope is oversold, leading dying patients into believing that they’re getting better.
- How medical technology often prevents terminal patients from “dying a good death.”
- How financial accountability is either misused or absent from our medical system in treating the seriously ill or hospice patients.
- How physicians and caregivers can improve the ways they communicate and interact with patients around end-of-life issues.
- How the average person can be empowered to ask questions and challenge assumptions about their care when nearing the end of life.

- The crucial importance of advance planning—how everyone should have in place advance directives and a designated medical power of attorney (MPOA).

We're all terrified of death, but we're dying from the moment we're conceived. If someone says to me, "Aunt Sue is not dying," my response is gentle but direct.

"Well, every one of us is dying, so let's take that off the table."

If a patient has been in the hospital nine times, the reality is that she probably would have died at least two or three times had we not intervened. We don't give the patient and family the opportunity to get off that crazy train. So, yes, the patient is dying. They're dying of their disease and we keep getting in the way.

The hospital is a terrible place to meet your end. We don't do death well. We start too late to prepare for it and we focus on the wrong things. We want to control something we can't control, and we experience unnecessary and destructive guilt as a result. If someone sends their loved one to hospice, that person can come to believe that they've sentenced their loved one to death. But death is as natural as birth, and a large part of my job is helping families accept that fact. Hospice is not a death sentence but a service that helps people die as comfortably as possible.

The issues I face every day and that I address in this book are nuanced and complicated. Doctors are trained to save lives, to use every means and technology they have to preserve life. The families of the seriously ill and dying often want to see everything possible done to save their loved ones. It's not easy to make decisions when you're in a hospital bed. In the abstract, we can say that we don't want to pursue further

treatment, but we may change our minds when death is near. Until you’re wearing those shoes, you don’t know what you’re going to do.

But if we all die someday, we have the power to choose the best way for that to happen. I hope this book helps everyone—patients, families, and medical professionals—break our collective silence about death, so we can develop better ways of talking about, treating, and encountering what we will all someday face.

Dr. Ken Pettit
Jan. 1, 2021

CHAPTER ONE ---

You Don't Have to Do This

Steve was my best friend. I was nineteen when I met him through our mutual love of motorcycles. About six years older than me, he quickly became the older brother I never had. We rode thousands of miles throughout the West on our Harleys, sometimes 300 miles a day, the wind whipping our hair and the sun burning our faces in those wide-open spaces.

I was in college at the time, taking pre-med classes while working as a hospital orderly, hoping to go to medical school someday. Steve was a police officer, and his work had the same quality that attracted me to medicine—helping people in crisis. I became more and more drawn to law enforcement and eventually became a reserve officer in the same department where Steve worked. When offered a full-time job on the force, I grabbed it.

I loved my new career, whether it was helping victims of a car accident, intervening in domestic violence, or preventing a robbery. There was a thrill to the work, an adrenaline rush I couldn't deny. My best friend and I were working together and motorcycling on weekends, living life to the fullest.

But after two years on the force, my urge to go to medical school kept nagging at me, and Steve knew it.

“This job isn’t the real you,” he told me one day. “If you stay in police work much longer, you’ll never leave. It’s a hard job to walk away from—the pay is good, you’ll have a family someday, you’ll be able to retire in twenty years, and you’ll be hooked. Those twenty years will flash right by, and you’ll wonder where they went. If you truly want to be a doctor, Ken, you need to get out now before the job consumes you.”

An “ah-ha” moment, big time. I left the police department, became a paramedic who drove ambulances and flew in helicopters, and then a registered nurse working in the emergency room. I finished college and was accepted into med school. Throughout this big shift in my life, Steve and I stayed good friends.

Since he was six years older than me, he was getting close to retirement age while I was still studying to be a doctor. Nearing the end of his law enforcement career, he decided that he wanted to become a physician’s assistant (P.A.). He was accepted to my medical school just as I finished my academics and was doing rotations. We were living next door to each other, having good times when we weren’t busy with our training.

During Steve’s second year in the P.A. program, he began to change a bit. One time, he asked me to help him with a very simple thing, getting a garage door unstuck. It caught me off guard. Steve was a very handy guy—he took motorcycles apart and put them back together—but I figured he was just stressed out.

Not long after that, on his way back from a rotation, his truck got a flat tire and he couldn’t remember how to change it.

Throughout our more than ten years of friendship, he

never forgot my birthday—a card, a letter, a phone call, a meal. But, for the first time, my birthday came and went without a word from him.

One night, I got a frantic call from his wife. Steve had had a seizure at home and was taken to the hospital. The diagnosis: a huge brain tumor. He was only forty, a very young man.

I was in my fourth year of medical school, he was in the second year of his P.A. program, and we had been scheduled to graduate at the same time. Our plan was to open a little medical practice together and do the work that we loved best for the rest of our careers. Now, in a very short time, those best-laid plans slipped upside down.

Steven underwent brain surgery and radiation. There wasn't a lot of chemotherapy available at the time for the type of cancer he had. The doctors were chasing after a cure that didn't exist.

When I graduated from medical school, he was pretty debilitated, able to walk only with a cane (he was too proud to use the walker he really needed), yet he had his wife drive him to my graduation ceremony, the one we were supposed to attend together.

When I was ready to walk across the stage, I glanced up at the stands but couldn't find him. I knew he was there, watching me graduate, knowing all the while that his name wouldn't be called.

As I started my internship and residency, which were pretty grueling, Steve's disease continued to progress. He could no longer walk and became bed-ridden. He was confused much of the time and couldn't remember basic things.

During my evenings off, I spent the night at his house to give his wife some relief, an hour to go grocery shopping or to

decompress. I'd help her turn him or get him into the shower— Steve was a big guy, 6' 4" and 220 pounds. I helped him clean himself, dried and dressed him, and got him back into bed.

You can get very restless when you're dying. Steve would ask me to help him sit up, and a moment later, he wanted to lie flat. "Turn me," he'd ask. A moment later: "Don't turn me." I could never get him comfortable. We'd circle around and around his conflicting wishes, trapped in a tormenting, never-ending loop.

By now, I was officially a doctor but had received zero training in how to deal with death. I was learning how to diagnose people and how to fix and cure them, but I didn't have a clue about how to prepare my best friend and his wife for what was coming next.

There was so much I wished I had known as Steve was dying. I didn't know what to say to them. I didn't know how to act around them. I didn't know how to help a dying person face his end. I was plagued with survivor's guilt. Steve and I had the best-laid plans. We'd open our medical practice and be the dynamic duo we'd always been. I still had my whole life ahead of me, and Steve had a few weeks at best.

All the shopworn clichés about death passed through my head:

"You need to push on with your life."

"It's okay not to feel guilty."

"You'll learn to live with the loss, and someday you'll benefit from it."

Empty clichés that meant not a particle of sense. I was emotionally bereft. As a doctor, I had been trained to save the world, but I was helpless to save Steve.

He eventually declined to the point where he was unresponsive in a hospital bed.

Unbelievably, I didn't know what hospice was. I knew it was a place you were referred to when you were getting ready to die, but that was about it. Never had I taken a course about or been trained in end-of-life issues. I knew nothing about the philosophies of hospice, the premises on which it operated, or the services it provided.

The goal of hospice is to make sure that you have some sort of peace and acceptance in facing death, whether you're the patient or the family. Steve didn't receive that support. He wasn't visited by a social worker or chaplain. I didn't know either was available. A nurse came by to give him various medications, but preparing someone to die takes much more than that.

Studies show it takes several months. Steve had about two weeks. He was in terminal condition with brain cancer. He had earned a black belt in karate. We rode Harleys together for thousands of miles. In his prime, he was 220 pounds. Now he weighed maybe 100 pounds at best and could no longer speak. I had my whole life ahead of me while he had lost everything.

He wasn't eating. He wasn't drinking. His urine output wasn't there. His wife discussed putting in an IV.

“He'll die if he becomes dehydrated,” she told me. “We've got to give him something.”

She convinced me to take that step. He was unresponsive, couldn't eat, and had lost over a hundred pounds. It was my job to keep him alive. We made arrangements and Steve underwent a procedure to give him long-term IV access.

One night Steve's IV stopped and it freaked me out. The finality of his death was upon us.

I put a stethoscope to his chest and heard a horrible heart murmur. Yet, I was still medically intellectualizing my best friend's impending death, deceiving myself into thinking I was saving him when there was no chance of that. He wasn't dying from kidney failure due to dehydration; he was dying from brain cancer. And yet, I was injecting him full of saline, syringe by syringe, two teaspoons at a time through his failing IV, until he got a liter of fluid into his system. Because that's what I knew, what I had been trained to do—to try everything to the bitter end.

His wife was also in denial, completely focused on IV fluids to keep her husband from dying. No one talked to her about the range of complex feelings I now discuss with patients as a hospice physician. No one talked to her about allowing the natural process of dying to occur.

Instead of stopping treatment, dealing with his wife's emotions, and making Steve as comfortable as possible in his last days, I fell into a desperate tunnel vision. We couldn't have him die from kidney failure. I had to give his wife every last bit of hope. I had to make sure he got his IV fluids.

Soon, his IV got totally plugged up and we couldn't use it anymore. Steve went into renal failure, and within a week, he passed away. My actions hadn't prolonged his life for more than a couple of days at best.

Today, instead of aggressively treating a terminal case up to the end, I would have made Steve and his wife as comfortable as possible. I would have helped them accept his passage. I would have given them time to process his death rather than deny it. This would have allowed them to go through what Herb Knoll, author of *The Widower's Journey*, calls "anticipatory grief" or "pre-grief," a period that gives loved ones the time to gradually adjust to the reality of a coming death.

But I did none of those things because I didn't know about

them. This was a hard lesson to learn, and it wasn't just Steve who taught it to me.

My father came from a family with a long history of lung disease. To make matters worse, he grew up in an era where everyone smoked—in cars, in airplanes, in front of children. And Dad was in the military, where one of the only things to do was smoke.

I was still in medical school when my father ended up on oxygen because of COPD (chronic obstructive pulmonary disease). He was only in his early or mid-fifties, and yet the outlook for his life expectancy wasn't good.

While he was undergoing treatment, there were a lot of advances in treating lung disease, including lung transplants. Because of his close relationship with my mom, he wanted to give her every hope and decided to take that very aggressive route.

Dad went through living hell to get on the transplant list. While battling his COPD, he ended up getting prostate cancer. You have to be free of cancer for five years or more before you can get a transplant. He also had a heart attack, so he had to be deemed recovered and healthy enough for such a major operation. If someone can't walk two feet to go to the bathroom, you can't put that person on a table, crack open his chest, and replace his lungs. You've got to have a lot left in the tank to recover. Dad was hospitalized for months, in and out of the ICU, until he finally met the criteria to get on the transplant list.

We lived in Phoenix, and he had to go to Tucson for the operation. He lived in an apartment near the hospital for three months so he could make his frequent medical appointments.

He seemed to do fairly well for a period of time and was

able to move back to Phoenix, but then he became extremely sick from the medication that prevented his body from rejecting the transplant. He was flown by helicopter back to the Tucson medical center and was in the ICU, on and off a ventilator numerous times. He returned to Phoenix, had another setback, and was again flown by helicopter down to Tucson's ICU unit.

After an especially rough day, the two of us began to talk about the end of his life. I said to him, "You know, Dad, you don't have to keep going through this."

I didn't say it because I was a hospice doctor. I said it because I couldn't stand to see him suffer anymore. He was such a good guy, such a personable man. Everyone loved my dad. How much more could he take? How much more did he want to take? It was a conversation I wish I had been able to have with Steve fifteen years before.

Dad looked at me and said, "I'm not going to let your mom down. I'm going to keep fighting." After a pause, he went on. "But when the time comes and I'm stuck on that machine, and there's no chance that I'm going to recover, I don't want you to leave me on it for more than a minute longer than I need to be. Because if you do, I'm going to come back and haunt you until the day you die. And when I see you again in the next world, I'm going to kick your ass. So remember what I said, Ken—do not leave me on the machine if you know I'm not going to make it."

At that time, someone with a lung transplant has a 50% chance of living for five years if they get past the first year. The day before Dad's big milestone, his first anniversary, he had an appointment at the Phoenix clinic.

I told my mom, "Great. Just keep me posted on how everything goes."

That night, at 3 a.m., I got a call from her. “Your dad just went into cardiac arrest. I did CPR on him, called 911, and he’s on the way to the hospital.”

I was dumbfounded.

“What the hell happened? Didn’t he have an appointment at the clinic just a few hours ago?”

“No, they canceled it.”

I blew a cork. “What do you mean they canceled it?”

“They called and said they were really busy and running behind, and they didn’t want him to wait in a chair for hours. Your dad had a fever and was feeling pretty bad, but he felt there were people worse off who needed to see a doctor more than he did.”

I couldn’t believe it. “He’s a lung transplant patient with a fever and they didn’t insist he come in?!”

Later, when I talked with his doctor, he said it was a miscommunication. At any rate, had Dad had the cardiac arrest at the clinic, his prognosis wouldn’t have been better. He had a temperature of 103, so I knew he was septic at that point. He was in the ICU and back on a ventilator.

There’s a procedure called a “hypothermia protocol” that can be used to treat someone in Dad’s condition. You put the patient under a cooling blanket to drop their core temperature. When you warm them back up, you’ll sometimes see improved neurological function. Some people (not many) have recovered enough to go home. My mom wanted to try it, to give Dad every last chance. She needed the peace of mind that she had tried absolutely everything, and for her sake, I went along with it.

When they warmed him back up and did their neurological testing, Dad had minimal brain function. He was completely unresponsive and helpless. Although he could no longer speak to me, I had the feeling he was looking for a way out, and

I had to give it to him. I remembered what he had told me: “Do not leave me on the machine if you know I’m not going to make it.”

One of the intensive care doctors walked in and said to me, “Ken, you know where this is at and where it’s going. Do you really want to keep doing this?”

I called a meeting with my mom and one of my three siblings and communicated with Dad’s brothers. I told them what Dad had said to me. “And now we’re here. He’s not going to get better. He’s not who he was anymore, and we need to shut this down.”

My mom and my brother agreed. My other brother couldn’t be there. When he married his wife at eighteen, she was already on dialysis; she died at thirty-seven after being in the ICU more times than my brother could remember.

“Ken, I can’t go through this again,” he told me. “I can’t watch Dad die. I went through it so many times before.”

He hadn’t found peace because his wife had never been in hospice. She was in the ICU right up to her death. She went through heart surgery just weeks before she passed. Neither she nor my brother had the time to fully prepare for her passing.

My sister couldn’t be there either because she wanted to remember my father as he was. People find closure in their own unique ways.

After talking with my family, Mom and I and my brother went into Dad’s room and shut the machine off. I thought it was ironic that his lungs were functioning with textbook perfection, keeping his body alive, and now I had turned off the ventilator. His lungs—his lifelong nemesis—were doing great, and still we couldn’t save him.

Three or four minutes passed, and I heard the alarm go off at the nurse’s station. A couple of minutes later, the doctor

came in and pronounced him dead. I had my grief, but I also had my peace.

To this day, I feel my dad picked his time. Not consciously, not in a way we can understand, but he chose his day. He died two weeks before my parents were to celebrate their fiftieth anniversary. I believe he knew it was coming; he had purchased a gift for my mom and put it away for her, which we found after he passed.

My father had been through hell and back. He had suffered enough, and perhaps he felt we had suffered enough with him. I will always think he picked his moment.

As with Steve, much of my father’s suffering was needless and prolonged. He told me multiple times when we were alone: “I’m tired. I’m not sure how much more I can do this. But my wife is telling me I’ve got to keep fighting, that I can beat this.” And so his fight became a performance for her.

I carry the experiences of Steve and my dad with me as I help families deal with death. I understand what they’re going through because I’ve walked in their shoes. I never mention Steve or my dad when I speak to them. I don’t say that I had a friend who was pumped full of fluids during the last two weeks of his life, only prolonging his agony. Or that my dad went through living hell to get a lung transplant. I don’t bring up my personal history because the focus is on the family, and we all have to find our private ways to deal with mortality. But what happened to Steve and my father is always with me in my work.

Today, when I talk to a patient who is near the end of life, I close the door when no one is around and say, “Do you want to keep going?” I say it straight and they know exactly what I’m talking about.

And sometimes they'll tell me, "I can't do it. I can't keep going."

"You don't have to do it."

These are the words that set them free, and that freedom enables us to open a dialog together. I'm able to understand who they are, what they want, and what I need to do to advocate for them, to be their voice. I'm able to start working to bring everyone in the family together, so their loved one can die with dignity and the least possible pain.