



Demystifying Death
to Live More Fully

Nothing to Fear

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to Live More Fully

Julie McFadden, RN
with Margot Starbuck

A TarcherPerigee Book



tarcherperigee

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To my patients and their families

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About the Author

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Introduction

Maybe you found me on social media or saw one of my videos about death and dying on the internet. Perhaps you have no idea who I am. Here's what's important as we open this book. My name is Julie, I am a hospice and palliative care nurse, and I want to change the way we look at death and dying.

I've worked as a nurse for over fifteen years now, the first nine years of which were spent working in the intensive care unit (ICU). Later, after I intentionally sought out a career change, I moved to working as a hospice and palliative care nurse. This basically means that every day I work closely with people who are dying or close to death and their families. My hope is to help anticipate and alleviate suffering while optimizing quality of life in these final stages of life. Seeing people die slowly or sometimes unexpectedly in a hospital bed in the ICU made me curious about why we health-care workers weren't having conversations about the end of life with our patients and their families sooner. Seeing both patients and their families experience this kind of shock at the end of life drew me to hospice work.

I knew there had to be a better way to die.

A few years ago, I realized that my unique work as a hospice nurse gave me a level of firsthand experience about death and dying that most people don't know anything about. I'd also seen the contrast between an ICU death and a hospice death, and I recognized that if more people knew what I knew, they would make different end-of-life decisions. In talking with my patients and their families over the years, I realized that I wanted to normalize death by educating people about it in whatever ways I could.

Then, on a trip home to visit my family, I saw my tween nieces making dance videos on TikTok, and I got the idea to start my own TikTok channel about death and dying—a simple place where I could share specialized insights, debunk myths, and tell stories about this topic that seems so taboo in our culture. I started posting a few videos, and before I knew it, I'd gained over a million followers.

Clearly, this content had struck a chord.

I believe it's deeply important that we educate ourselves about death and dying because we're all going to experience it, one way or another. Most of the time, people either express a fear of death or simply don't want to talk about it at all. Many people don't ever discuss the topic with their loved ones, so death is often a surprise, a shock, resulting in unnecessary suffering. But it doesn't have to be that way.

After personally witnessing hundreds of deaths, I have arrived at a place where I no longer fear the process of dying. Through my work as a hospice nurse, I've witnessed so many amazing, beautiful, and even miraculous things. I've been with dying people whose eyes fill up with wonder as they tell me they're seeing angels or hearing the most beautiful music they've ever heard. I've seen people's faces light up, smiling big in the moment right before they die. The most miraculous things that I see are the families—the love shared between patients and their families in the moments leading up to death. People who send me messages frequently assume being a hospice nurse is depressing and that witnessing death is sad and terrible, but in so many ways, I find that it's actually the opposite! I get to witness so much love and serve another human being during such a vulnerable time at the end of their life. It's an incredible and sacred gift.

When people are willing to discuss the end of their lives and accept that they're going to die, their whole being changes. They seem to carry with them a special kind of freedom, an attitude that truly helps them live their last days. Their fear decreases, they feel freer, and, ironically, they actually seem more full of life, even though they're dying.

I think this change in perspective can apply to *all* people because, technically, we're all dying. If we can face that fact and allow in a bit of that

freedom, I believe we all can live better lives here and now. In this book, I'll share my experiences as a hospice nurse to help readers understand that death isn't something to be feared. Now, it's perfectly normal and natural to feel some fear around death, but even just talking openly about that fear will help loosen the grip it may have on you. I'm going to share some stories and educational resources that I hope will show you that death can be beautiful. If death is normalized and discussed often, we each can walk toward our final days with a lot less fear.

This book isn't necessarily meant to be read from beginning to end. If you want to, you can use the table of contents as your guide. Only you know what you're going through. Perhaps you're caring for someone who is dying, care about someone who is dying, or perhaps you're dying yourself. Pick the topics that are best suited to your situation today. Take what works for you, and leave what doesn't.

A quick disclaimer: I do not officially represent either hospice as an organization or any specific hospice provider. I'm sharing my experience and knowledge with you as I've learned it working with hundreds of hospice patients over the years. Always ask your doctor for the most accurate and up-to-date information. Use the Resources section at the end of this book to get in touch with the right people. Like everything else having to do with your care, ask all the questions and remember that you are the boss.

I hope that, in these pages, you'll discover what I've discovered in my work: that living a life of acceptance helps us live better and die better. Let's take this journey together.

—Hospice Nurse Julie

Chapter 1

The Gift of a Peaceful Death

Before I became a hospice nurse, I worked in the intensive care unit (ICU). In the ICU, doctors and nurses are doing everything possible to keep people alive, and their incredible work saves thousands of lives every year. But we rarely discuss the end of life until it's too late.

People often ask me why I decided to become a hospice nurse. This story is why. I had an ICU patient named Scott who had just had major surgery that was meant to help his advanced-stage pancreatic cancer. I had seen many people get surgeries like Scott's to help extend their lives, and it often worked. In the best cases, successful surgery can add years to a patient's prognosis.

In Scott's case, things went well at first, but after five days, he developed a bilateral pulmonary embolism, which is a blood clot that goes into the lungs and stops blood flow. The only reason he didn't die from this immediately was that he was already in the hospital. Because of this incident, he came back to the ICU.

Scott was intubated, which means he was hooked up to a machine to help him breathe. As time went on, he would seem to be getting better and even could walk around on his own, but inevitably something bad would happen again. He would be doing really well and then get a blood infection or pneumonia. We just could *not* get him better.

For months, Scott was basically in and out of consciousness. He was on medication to keep his blood pressure normal, and because of the high doses of these meds, his toes turned black. This is called "necrosis," and it means

the tissue is literally dying. So even if Scott recovered enough to leave the ICU, he would need to have his toes amputated.

Here's the thing: in the ICU, it's all risk versus benefit. We were trying to keep his vitals up no matter what, and sometimes that meant sacrificing comfort and, yes, toes. In the ICU, you have a job to do, and that job is to keep a patient alive at all costs.

As nurses, we were just doing our job. We stayed focused on the numbers that showed how well his kidneys were functioning, how well his liver was functioning, how well his lungs were functioning. We watched these numbers to see which were trending up and which were trending down.

We focused on these minuscule things and reported them to Scott's family, but they had no idea what we were talking about. We would smile and tell them the "creatinine numbers" looked good, but we knew that meant only his kidneys were getting better. However, this information would lead Scott's family to think that eventually everything was going to be better and maybe he would go home one day. But he was still going to die from the cancer, and that wasn't going to change, regardless of how healthy his kidneys became.

This is what we were taught to do in the ICU, and I had become used to situations like this. Our medical team would focus on treating the person, but we were missing the forest for the trees. For a long time, I didn't give this much thought—but watching Scott, I started to think that maybe we had blinders on.

Scott was in the ICU for months. I had developed a good rapport with Scott's family. His wife was always by his side, and she was often anxious and worried. I cared deeply about him and his family. I wanted to speak up, but I was afraid. It was unheard of to have end-of-life discussions with ICU patients and their families. After all, we were supposed to be trying to get them better. But after seeing how much families were suffering, I became convinced we were doing them a disservice. We weren't being honest with them about their loved ones.

One day I finally thought, "Enough is enough." I had seen this pattern in too many patients. I decided to say something during rounds—the daily

meetings during which a patient's medical team discusses the patient's care. The head doctor, fellows, residents, medical students, nurses, and patient's family would all be there. I wanted to keep my statements pretty general because I didn't think anyone had told Scott's wife yet that he was dying. We knew he wasn't going to get any better, but no one at the hospital would say it.

At rounds, I finally said, "I think we need to have a family meeting to address the bigger picture."

Right away, I knew I had said what everyone had been thinking but couldn't find the words for.

"Yes," everyone agreed, "that's what we need to do."

For the first time in a long time, I felt like I had done something good. I had spoken up and advocated for a patient and their family. It immediately felt right.

That same day, the medical team and the family met with a social worker. The family was given all the facts. Scott had terminal pancreatic cancer. Necrosis had spread to his extremities. Scott was dying. That was the medical reality. But there was another reality, too—the reality that the family had the power to decide how Scott died. They knew him best. They knew how he had lived, and they could give him the gift of a peaceful death if they wished to. With these facts in hand, the family met in private. They decided to remove Scott from the machines that were prolonging his life, and he died later that evening.

Scott's death affected me deeply. It felt strange to advocate for someone's death, even though I knew it was the right thing to do. I felt deeply saddened but empowered at the same time. That was the hardest part. As an ICU nurse, I was committed to treating patients, but something else inside me knew that sometimes it was better to look at the bigger picture. I knew it wasn't right that we kept people in the dark about what was really happening to them. They needed more information, but no one in the ICU was providing it.

People have an incredible capacity for love and compassion. But they need the correct information in order to know when compassion is a better

choice than treatment. When we finally did share that information with Scott's family, they finally felt empowered to help Scott die peacefully.

This experience convinced me that, to paraphrase author and podcaster Glennon Doyle, I could do hard things. Speaking up that first time opened up a new world to me, one where I had a voice and could advocate for patients and their families. It convinced me that I could make a difference, even if the end result was the patient dying. I knew in my gut it was the right thing to do, and it gave the family the power to do what they thought was best for their loved one.

I love these patients deeply. I'll never forget them or their families. Speaking up for Scott allowed him to die peacefully, and it profoundly changed the trajectory of my career and my life.

The Difference between the ICU and Hospice

Death in the ICU gets drawn out because, as I mentioned, doctors and nurses are doing everything possible to keep people alive. They're using medications. They're putting people on multiple machines—machines to keep them breathing, machines to filter their blood, machines to work on their kidneys. They're doing surgeries to keep vital organs functioning. That's their focus: preventing death.

To be clear, this is often amazing, life-saving work. But if you really want to know what the inside of an ICU looks like, take a look at the Netflix series *From Scratch*, in which a character named Lino is dying from a rare soft-tissue cancer. A scene in one episode when he's in the ICU felt so much like my experience as an ICU nurse. All the doctors are streaming in and out of his room—the kidney doctor, the liver doctor, the infectious disease doctor—but none of them are talking to each other. The whole time, no one is addressing the fact that Lino has terminal cancer—because that is the oncologist's job.

That is exactly what really happens, and it's exactly why I left the ICU. Unfortunately, in the medical system we work within, it's difficult for providers to communicate with one another. We're taught to work within our

own little bubble. Because I've been there, I know what the staff are thinking. They're thinking, "Well, maybe I'm not right. Maybe the oncologist knows something I don't know. Maybe they know something that hasn't been relayed to me." So no one says anything.

And when no one says anything, it can get really ugly. I've seen patients lose limbs because we were using meds that squeezed their arteries and veins to keep their blood pressure up, cutting off blood supply in their extremities in the process. When your goal is to keep someone alive, keeping the blood pumping through their veins is more important than losing a limb.

But the truth is, some of the people in the ICU are going to die no matter what treatments they receive, yet we still work to keep everyone alive at all costs. Period. This all-or-nothing kind of thinking is everywhere, and it's not the fault of one person; *it's the culture*. What I am advocating for is injecting more information into the process so that families are prepared and empowered to make the right decisions for their loved ones—rather than defaulting to measures like amputation because they don't know there are any other options.

We are fortunate enough to live in a country that already has a solution to address this cultural blind spot. It's called hospice, and it's a program that helps terminally ill people live better. After my experience with Scott in the ICU, I made a change. I became a hospice nurse and started down a new path.

Preparing for Death

Many people assume that dying is the worst possible outcome. But that's not always the case. Watching someone suffer or endure a poor quality of life for an extended period of time is far worse, in my opinion. Yet many of us look at death as the worst thing that can happen to us. We'll do anything to stop it, and because of that, we create unnecessary suffering for ourselves and for our loved ones.

I saw that up close during my years as an ICU nurse. I've seen what it looks like when our health-care system doesn't allow someone to die

peacefully. Hospital staff are just following procedures. They're not doing anything wrong, but they're doing everything to keep someone alive.

We have such a fear of death that we panic. Maybe we're the person who is dying, and we fear death. Maybe we're a loved one who's trying to help someone else go through it. Or we may even be that medical professional who was trained to keep people alive at all costs. But we can cause a lot of unnecessary suffering when we don't know how to stop, when we don't know how to let go—or maybe when we don't realize that we *can* let go.

So let's begin thinking about it differently: What if death isn't the worst possible outcome? How would that change the way we live our lives and treat the illnesses that we have? What if we value quality over quantity? Let's get curious.

What a Peaceful Death Looks Like

Rosa and Pedro were in their forties with two young children. Pedro was dying of cancer, and Rosa was taking care of him. I was their hospice nurse, visiting their home two or three times a week. They spoke only Spanish, and I had to use an interpreter to communicate with them, but Rosa and I became so close that I often forgot there was someone on the phone translating for us. I seemed to understand her through her eyes. We formed a deep connection.

Pedro's young age and the presence of the children made the situation especially difficult. His family was struggling, but the love in the house was palpable. The love overtook the sadness. I'll never forget this family because of the deep, deep sense of love I felt there. I got to see love in action.

In the last days of Pedro's life, the house was filled with family and friends. The day that Pedro died, I was there. Rosa's head was resting on his chest. She was gently speaking to him in Spanish. Both Pedro's and Rosa's parents were there also, circled around the bed, loving him, honoring him, and caring for him. Pedro's parents rubbed his head. Everyone surrounded him, saying wonderful, loving things and supporting this man as he took his last breath. You could *feel* the love.

This is what a prepared death looks like.

Since leaving the ICU and moving into hospice care, I now get to truly *serve* patients who are dying. Unlike the scramble to keep people alive in the ICU, when people who are dying have the choice to *prepare* for death, they can experience a *peaceful* death.

My friend Ashley Bryant, a death doula and the founder of Distant Shores Deathcare, uses this analogy: Imagine you're on a beach with the ocean in front of you. The ocean is death. Will you get pulled into the ocean via the undertow, against your will, kicking and screaming? Or do you cross this ocean in a boat you made, with your friends and family beside you, shoving the boat off and sailing of your own accord? That is the difference between a prepared death and an unprepared one.

Everyone has an end-of-life journey, but when you're on hospice, you get to embrace yours. It's not quite "borrowed" time, but you do have a kind of gift that people who die suddenly do not have. When you know you're dying, you get to make a plan. You get to grow into acceptance around it. You get to tell your family and friends you love them. You get to plan visits with them.

The more you let go and accept that you're dying, the better you'll live while you're still alive. The more peace you make with the idea of your death, the more peacefully you'll exit this world. And the better prepared you are for your death, the better prepared your family will be for your death. When you prepare—by facing your death squarely, by getting your financial things figured out, by making your funeral arrangements—you are caring for your family. When you ready yourself for death, you don't have to suffer in pain. You get to ask for help. You get to celebrate and *live* the days you have.

I mentioned that the death of Pedro, who was physically comfortable and surrounded by loved ones, was a beautiful and peaceful death. But I've also witnessed those who've died differently.

I cared for a woman named Martha in the ICU. She had a terminal cancer diagnosis but had come into the hospital for an extensive surgery that was meant to extend her life. Unfortunately, she, like Scott, kept having complications during her hospital stay that would land her back with me in the ICU for months. By her sixth month in the ICU, her toes and fingers were necrotic, and she was fully dependent on machines to keep her alive. The

ICU team began having family meetings to discuss the reality of the situation: we were keeping her alive, and the likelihood of her “getting better” was extremely low. But her family refused, time and time again, to turn off the machines and allow her to die peacefully.

Even with the machines, Martha began to decline and had to be resuscitated with chest compressions several times. Again, despite us explaining how much Martha was likely suffering, the family could not let her go. The hospital eventually had to bring in the ethics committee to explain why turning off the machines and allowing Martha to die peacefully was the ethical choice. Even after that, the family was resistant. It was just a sad, awful death for everyone involved.

As you think about the type of death you’d choose, imagine standing on that shore and choosing between those two ways to die. Martha’s experience was more like getting swept out to sea against your will, struggling all the while. The other option, the one Pedro chose, is the one where he got to cross that ocean in a boat that he lovingly made with his friends and family. After saying their goodbyes, they cast off the boat and Pedro sailed off of his own volition.



A peaceful death can look many different ways.

There are certain signs when someone is actively dying, which I’ll discuss in more detail in chapter 5—changes in breathing, skin color, temperature, and so on—and we can witness those even when someone is experiencing a peaceful death. Although some of these signals may feel foreign to us, they’re a normal part of the process of natural death. They’re not causing the person who is dying discomfort.

When people who are dying, and their families, accept the interventions that hospice offers, those more distressing symptoms are rarely seen in the final stage when a person is actively dying.

Here are some examples of what to look for:

PEACEFUL DEATH

- Pain and/or other symptoms, if present, are managed.
- End-of-life wishes have been discussed and written out.
- The person is clean, safe, and comfortable.
- The person has all the support they need.

UNPEACEFUL DEATH

- Pain and/or symptoms are not managed.
- The person is not clean, safe, and comfortable.
- The person does not have the support they need.
- The family is refusing to let the dying person go.

A person who is in the early stages of their journey toward death, who is still alert and oriented, can continue to make choices that allow for a peaceful death until the very end. They can be clean, safe, and comfortable. They can be free of pain. They can invite the people who mean the most to them to be present. They can create the environment they need to die peacefully.

When they're no longer alert and oriented, those around the dying person can take over. They can surround the person with loving care. They can create a positive mood in the room with lighting, music, and gentle touch. They can speak gentle words of love and affirmation. That's what Pedro's family did.

What's worse than death is a death that's resisted, painful, or chaotic. But a peaceful death? A good death? It's what each of us deserves.

Many Times

Maribel hadn't married and didn't have any children. Although she'd had many friends who loved her dearly, at the age of 102,

just about everyone she'd known throughout her life was dead. At the end, Maribel had a caregiver, and she had me.

During one of my last visits, her caregiver and I sat together looking through Maribel's photo albums and talking about how wonderful she was. As I reflected on her life that had lasted over a century, I wanted to make sure I'd understood correctly that she'd never been married, even for a short time. Although she'd been unresponsive all day, I suspected she could still hear me, so I asked, "Maribel, were you ever married?"

Matter-of-factly, she answered, "No."

"Maribel," I continued, "were you ever in love?"

Eyes closed, in a weak voice, and with some attitude, Maribel answered with certainty: "Many times."

The caregiver and I just laughed. *Hell yeah*. I knew that others might see a 102-year-old woman dying without being surrounded by family and friends as tragic. But with those two words—"many times"—I knew that despite the absence of children and grandchildren in that moment, there wasn't sadness in that house. Maribel had lived a rich, beautiful life with parents, siblings, friends, and lovers who just weren't in the room. And although I can't anticipate exactly what the afterlife will be like, I couldn't help but imagine Maribel drifting off to sleep and waking up surrounded by all these people she's missed for a long time.

Embracing the Sacredness of Death

I am asked all the time why in the world I would do something as difficult as working for hospice. People often ask, "Isn't it so depressing?" It's sad sometimes, yes. There's really no way around that. But I don't find my job to be depressing. In a way, it's actually a sacred gift to me. This is one of the reasons that sharing the stories of the prepared deaths I've experienced is so