



# Encountering THE EDGE

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WHAT PEOPLE TOLD ME  
BEFORE THEY DIED

HOSPICE CHAPLAIN  
KAREN B. KAPLAN

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Encountering the Edge  
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# Table of Contents

Introduction: “Hey Doll!” .....	page i
Barney’s Unconventional Greeting	
Chapter 1: “You’re Too Nice Looking to Work for Hospice” .....	page 1
Being Made Welcome to My New Career	
Chapter 2: “What Do You Do with a Drunken Sailor?” .....	page 18
From the Singing Chaplain’s Repertoire	
Chapter 3: “Rabbi, You Have a Flat Tire!” .....	page 32
When the Chaplain Is Not in Charge	
Chapter 4: “She Thought She Was a High School Student” .....	page 47
Dwelling Full-Time Within a Memory	
Chapter 5: “What’s Next?” .....	page 59
Mutual Musings on the Afterlife	
Chapter 6: “I Call My Own Number Just to Hear My Husband’s Voice Again” .....	page 71
Mourners’ Trips to the Past	
Chapter 7: “So How Did the Two of You Meet?” .....	page 89
Reflecting on Life’s Key Moments	
Chapter 8: “Say, Are You a Belly Dancer?” .....	page 95
Hospice Humor	
Chapter 9: “Your Tears Are Jewels” .....	page 110
Having a Go at Telling My Own Story	

# *Introduction*

“HEY DOLL!”

*Barney’s Unconventional Greeting*

As I walked into Barney’s room a few doors down from the nursing home lobby, the last thing he wanted from me was pious talk. Knowing that I was a rabbi added an extra kick for the way he greeted me. You see, every time I visited him, he tested me with a forbidden-fruit glance and called out, “Hey doll!” Given the circumstances of Barney being in Act 3 Scene 3 of his life, I was charmed rather than offended. When we had first become acquainted, he was so surprised a woman could be a rabbi.

“I guess I wasn’t in the know about these kinds of things,” he said, looking embarrassed. “It’s been a long time since I’ve had anything to do with Jewish stuff.”

When I asked him why that was, he hinted at a life permeated with shady dealings. Skirting the edge of legal and illegal activities, he had drifted from place to place. Now homeless, he had no place left to go but this nursing home in a Newark neighborhood so iffy, the only safe time for me to drop by was in the morning.

The hospice social worker educated me that criminal types like to sleep in and get their day started in the afternoon. As it was, I saw a dense line of police cars just blocks away from the nursing home, primed for another tumultuous day.

Some weeks later, during one of my last visits with Barney, I hazarded a reference to some Jewish songs and prayers. He was stunned that a prayer beginning with “Hear O Israel” (the most well-known Jewish prayer and referred to in Hebrew as “the Shema”) sounded familiar. Hearing me talk about prayers he had not heard for decades, he was taken aback that they comforted him. “Funny how things come in a circle,” he reflected. “I heard Hebrew when I was a little kid, and now,” he made a face signifying that he did not have long to live, “I’m hearing about it again.” He had come home to his Jewish heritage.

At our last visit several weeks later, Barney was almost unconscious. The nurses on the morning shift said he was not responding anymore. But when I came in and said, “Hey doll!” he lifted his left brow and smiled ever so slightly before resuming his voyage onward in the untroubled waters. I sat with him awhile, thinking about my own penchant for flirting with the playful aspects of religion, and for having sought out a vocation that would be full of surprises at every turn.



Throughout my seven-year career of encountering people at death’s door, friends and family have puzzled over my offbeat

## *Encountering the Edge*

choice of career. “Isn’t it depressing? Doesn’t it get you down?” easily take first place for the most frequently asked questions. Other top contenders I get include:

“What do people near the end want to talk about?”

“What do you say to them?”

“What wisdom do they share?”

“Come crunch time, what do they really believe will happen to them?”

“How do they cope with knowing their time is near?”

And one of my own favorites, which even the patients themselves ask:

“Why do you want to do this kind of work?” (Read: “Why on earth would you want to? You must be a little strange.”)

Some people persist with even more intrusive inquiries such as, “Doesn’t this work make you think about your own mortality a lot? Have you ever seen anyone die right in front of you?” And most aggressive and most revealing of all about the questioner’s fear of death: “Are you sure you should be writing a book like this?” Some people have been so upset about my writing this career memoir, you would think I had self-sabotaged hopes of finding an audience for this book by calling it *Disturbing Confessions of a Hospice Chaplain: Terrifying Tales*.

But then again, you may be curious about how my visits with people from all walks of life have shaped my beliefs about the meaning of life and the nature of the hereafter. You might wonder what you would witness if you could invisibly accompany me on my visits. You might wonder what it is like to constantly improvise



how to respond depending on the patient's personality, mood, presence of family or of medical professionals, ethnic and racial background, and even socioeconomic level.

If you are nevertheless ambivalent about reading about this subject any further, it may hearten you to know how I myself reacted when United Hospice of Rockland in New City, New York made me my first hospice employment offer in 2005. It does not take much to imagine how I hesitated over this sharp turn in my career from pulpit to bedside. What was I getting myself into? Talk about encounters with the edge! I took a deep enough breath that would have pleased any yoga instructor and told the interviewer, yes (slowly exhale), I'd take the position. She told me the job would start the very next day, so I did not even have any time to emotionally transition from leading a congregation to being a chaplain under a nursing supervisor in the rule-filled world of health care.

But the result of that yes has often been privileged access to persons and their families during some of the more intimate and meaningful moments of their lives. What you will see here are recollections of some of these slices of life: some humorous in their own right, some edgy, some peaceful, some sad, some odd, and some uplifting. You will also find an inside look at spiritual and emotional issues that arise in hospice care, such as interfaith conflict, remorse, doubt, and guilt. These are not so much stories about death as they are about people's lives in the moment I see them. They reminisce over their experiences, thoughts, and actions whether past or present. They care about family issues just

## *Encountering the Edge*

as we all do at any other stage of our lives. The aim of each anecdote in this book is to portray how the moments in question were adventurous, inspiring, meaningful, perplexing, or otherwise authentic to those present. As you peruse these tales, you may in turn have these reactions, or at least get a glimpse into a time of life that was a fertile ground for the patient's search for meaning and for the affirmation of what each valued most.

When I told friends and family that I was going to write about my encounters as a chaplain, one friend cheered me on saying I would be preserving intimate spiritual events that many people would otherwise not know about. Moreover, he said this collection of stories would be my legacy. Mentioning my legacy is fittingly ironic, as much of my job is to encourage others to ponder what their legacy is, and to construct their life's meaning by doing so. For me to be the one considering my own is a deserved challenge.

Unlike many other books I have seen about hospice chaplaincy, this one is not about inserting any agenda overt or hidden to influence your religious beliefs or non-beliefs one way or the other. Some people are unaware that professionally trained chaplains do not visit clients to preach or persuade them of the superiority of a specific religion. As you will see, I aim to be like an amplifier that boosts and affirms the spiritual and emotional self-awareness of those I serve, whatever their beliefs, be they religious, spiritual, or secular. With no conscious intent to persuade them of anything, I seek to open myself to whatever they want to convey to me. And so I expose myself not only to the great unknown of death but to its unknown impact on each person's beliefs and priorities that fall

under its shadow. In a word, this book will make you privy to the dramas played out in these disquieting yet revealing moments.

One last thing which I must note before proceeding any further is the issue of confidentiality. Like congregational work, and like healthcare work in general, hospice service requires absolute confidentiality. No one else but fellow members of the hospice team such as the nurse or social worker is privy to what I say or observe about a given client. Nor is that divulged even to them unless it enables better holistic care. Thus, all the names in this narrative are pseudonyms, with no other conceivable identifying factors such as dates of the visits.

Everything else about these visits, however, is genuine. I have not, as a strikingly large number of friends and family have suggested, “enhanced” any of these tales. I have not made them more dramatic, or combined elements from one encounter with those of another. There is no need, as especially in the world of hospice, truth is not only stranger than fiction but is at least equally compelling. The only difference between this narrative and my day-to-day work is that many of the days are routine, with no particularly outstanding encounter to remark upon. On such days there are no families who wish to see a chaplain, leaving me to stop in the nursing homes to make sure the patients there are not in pain. Often these patients are asleep or minimally responsive or indifferent to the visit. On those days, the sadness of lives ebbing away just adds up, with no apparent benefit from my presence except in the occasional instance where I do see signs of pain such as moaning or rigid body posture and I report such things to the nurse.

## *Encountering the Edge*

As I was agonizing over what to call this book, and believe you me I did agonize, my husband Steve was skeptical about the first part of the title. “Encountering the edge how?” he asked. I replied, “Well, I was thinking of people like a mountain climber or an ultra-marathoner or those scientists who work real close to an active volcano.” Unlike those adventurers, I do not put myself in physical danger, but I do face emotional danger. I jump into interactions that can be laced with escalating anxiety or impotent anger displaced onto me or through me onto God. But on the plus side, just like the ultra-marathoner, I undergo moments of exhilaration such as when a patient experiences spiritual healing or suddenly gains an insight into the meaning of her life. So as a hospice chaplain, I am living on the edge with its perils but also its joys. Not only that, I think using this expression about my work reveals a deeper reason for choosing it. I have taken on a challenge which forces me to see what stuff my beliefs are made of when applied to people facing suffering and death. I have taken on a dare to tear myself away from the false comfort of stock responses and to instead stand next to my clients as they totter at the boundary between the known and the unknown.

I think my personal temperament as a quiet person has a lot to do with my compatibility with this career, too. Countless patients, families, and interviewers have described my soft, low-pitched voice as soothing. I have imparted a tranquilizing presence as far back as I can remember, like the time my parents took my brother and me to see a great aunt and some other relatives in Philadelphia. That night, my brother and I were asked to decide

who was going to sleep in which room with which relative—or rather, my brother, by right of seniority, did the deciding. He chose to be with the ones he deemed the more entertaining relatives, while I was relegated to my great aunt, in my young eyes a stuffy old lady. After both she and I slept well through the night, she said, “I haven’t been sleeping well. But last night I slept like a baby.” That was my initiation into learning I could “enter the quiet immensity of my own healing presence” (John O’Donohue).

Visiting a patient for the first time might be like how deep sea divers feel as they are about to take the plunge. I do not really know what I am going to encounter until I come face to face with the patient and the give and take between us springs into life. The information on the medical records does not tell me much. What little there is states the disease, age, ethnicity, the pain treatment plan, and includes other information such as whether there are young children in the home. As for the spiritual component, I am lucky if I get the name of their religion. Take my first visit to Lynn, for example. This patient summoned me to her home (as the family told me on her behalf) with a peculiar stipulation: that I only visit her one single time. Usually patients decide this sort of thing after, not before, meeting me, and not for very flattering reasons. The exception is when all they wish for is a prayer good for onetime use only. I figured Lynn had some unresolved question and that after she got the answer to it she was going to conserve her future remaining energy for other people. For many patients, even speaking a few words, even opening their eyes, exacts a high percentage of their available energy, much as walking for several miles would deplete mine.

## *Encountering the Edge*

Upon entering her bedroom, all curtains drawn and no lights on to compensate for the dusk-like atmosphere, a hospice volunteer named Pam was finishing up a Reiki session as Lynn reclined on a velvety brown couch. Hospice volunteers receive training over a two-month period and then a volunteer coordinator assigns each person to one or two patients. They often are drawn to this service as a way to “give back” for help they had received for loved ones on hospice some time ago. As I watched Pam’s hands hover over Lynn’s outstretched legs, she explained that minimizing the light in the room made Lynn feel more relaxed. I felt a calm yet alert atmosphere among the three of us.

Pam let me know that Lynn communicated just by moving one sole finger. “She used to move more of her hand, but now that is all that is left for us.” Along with taking in the sadness of the implied drawn-out history of one loss after another, it was going to take a lot of intuition to figure out why Lynn wanted me there. Even if I could come again, she might not be conscious anymore or even alive. As I looked at her inquiring face, I thought about the concerns that all humans have. I thought about what every single one of us wants to know such as what our life story has amounted to. I knew that if I could guess her question and answer it, she would invest the effort to make that finger move.

As I tell you this story about Lynn, I think of Alice. B. Toklas’ account that Gertrude Stein’s last words to her devotees surrounding her deathbed were, “What’s the answer?” When no one replied, she then queried, “In that case, what is the question?” Maybe this was Gertrude Stein’s idea of having the last laugh.

But when I was with Lynn, knowing that she was aware I was a chaplain and for that reason had asked for me, I decided to ask and answer the most fundamental spiritual question there is if you get down to it: what is the meaning of life? This in part has to do with our legacy. Sensing the supremely caring atmosphere we were in, I answered, "We are here to both receive and to give love." Her hand relaxed. Her finger from the knuckle up painstakingly moved up and down as if nodding, "yes yes yes."