



*Hospice is an often-misunderstood medical specialty. The reality of the work is complex, poignant, challenging, fulfilling, and even humorous. This collection of essays shines light on the struggles, gratifications, and life lessons taken from 30 years as a hospice social worker.*

## **Hospice: A Memoir of Life among the Dying**

By Deborah Lee

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DEBORAH LEE

# HOSPICE

A Memoir of Life among  
the Dying

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Print ISBN: 978-1-64718-973-0

Epub ISBN: 978-1-64718-974-7

Mobi ISBN: 978-1-64718-975-4

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Published by BookLocker.com, Inc., St. Petersburg, Florida.

Printed on acid-free paper.

BookLocker.com, Inc.

2020

First Edition

Library of Congress Cataloging in Publication Data

Lee, Deborah

Hospice: A Memoir of Life among the Dying by Deborah Lee

Library of Congress Control Number: 2020917582

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# 1

## **There's a Lot They Don't Teach You in Graduate School**

Graciela Hernandez was fifteen years old and dying of a brain tumor. I had only been a hospice social worker for about a year and a half when my team manager Larry asked me to go see her family right away. The issue, my manager told me, was that the parents were very dissatisfied with our nurse Peggy, and Larry had not been able to get a good understanding of what the problem was. I was filled with dread at the thought of making this visit. First of all, pediatric hospice is something that I personally have a really hard time with. A 90-year-old dying of end-stage dementia is not necessarily a tragedy. Even a 50-year-old dying of cancer, although the situation may be terribly sad, is somewhat understandable – he or she has at least had some time to live life. But a *child* dying is a sucker punch to the gut – tragic, wrong, unfair, unthinkable. I was not at all sure I could bear the raw grief of these parents, nor did I feel equipped to handle an angry teenager demanding to know why this terrible thing was happening to her.

This alone would have made my visit difficult enough, but there was more. We social workers are taught in our training that our chief tool is our *self* – who we are, and how we relate to our clients. In this case, my self was bringing some major issues to the table. For one thing, I didn't happen to think much of Nurse Peggy myself – she struck me as rather young for hospice work, and rather task-oriented, without much warmth. For another thing, I was concerned about bridging the cultural

gap – the Hernandezes were Mexican-American, and I am not. I knew a thing or two that might be relevant – such as the significance of a 15-year-old girl dying when she should be celebrating her *quinceañera* – but I wasn't sure that that would suffice to help me connect with this family. And finally, I was eight months pregnant. Here I was, coming to help these parents who were past the age of childbearing, losing their only daughter, and I was going to waddle into their home looking like a pre-Colombian fecundity goddess. Fat chance they were going to relate to me. So I did the only thing I could think of to prepare myself for this experience: I breathed a quick prayer asking for wisdom and strength, and rang their doorbell.

I needn't have worried about being met at the door by anybody's raw emotion. Mr. and Mrs. Hernandez were polite, but cool. They answered my initial questions, but the body language was closed. I knew I wasn't connecting, so I changed course and asked to meet Graciela. No display of raw emotion here either – Graciela lay, pretty but comatose, on her bed. I was ashamed of the relief I felt as I realized that Graciela would not be challenging me with unanswerable questions. It was time for Mrs. Hernandez to administer a feeding into the tube in Graciela's stomach, and I sensed the slightest warming from the mother as she saw that I stayed at her side, watching the procedure with interest instead of excusing myself while she completed this task. I found myself shifting inwardly from an intellectual approach to an intuitive one, and I let myself just soak in the atmosphere around me. I was still a relatively-new social worker, and trusting my intuitions was not something I was accustomed to doing, but it felt right at this moment.

With the feeding completed, we adjourned back to the kitchen table. I began asking some more of my usual questions, trying to make this feel more like a conversation rather than an interrogation. As we sat there talking, a song started running

through my head. It was “You Are My Sunshine”. At first I ignored it, because it seemed ridiculous in this context, but it wouldn’t go away. I began to feel very strongly that I was supposed to say something about it, even though I had no idea where this was leading, and I was certain that the parents would think I had completely lost my mind. Finally I blurted out, “This may sound really crazy to you, but this song, ‘You Are My Sunshine’, keeps going through my head here. I don’t know why that is, but I just felt like I needed to share that with you.” And I waited for one or the other of them to tell me that I was a lunatic, and that they would be calling my boss to have me fired. Instead, Mrs. Hernandez burst into tears, followed by Mr. Hernandez. Mrs. Hernandez looked at me like she was just now seeing me for the first time, and exclaimed, “That was her favorite song! On her first day of kindergarten, Graciela learned that song and she sang it around the house all the time!” That was when I started crying too.

After that, the pieces of the puzzle fell quickly into place. Peggy was a knowledgeable-enough nurse, but her examination of Graciela had been cursory, mechanical. Peggy did not have children of her own, and the Hernandezes felt that she did not truly understand what they were going through. They needed someone to see past their controlled, critical presentation to the agony within. When I “heard” their daughter’s song – despite the disease, despite the passage of many years – they knew I could hear *them*.

This was to be my only meeting with the Hernandezes; Graciela died not long afterwards. But I learned two very important things that day: I learned to trust my inner voice as an important component of my professional repertory. And I learned that I had found my calling.





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### You Two Need to Talk

Spouses – especially elderly ones – are often very protective of one another. So I was not surprised when I paid my initial visit to Mr. Klein, and Mrs. Klein immediately drew me into the kitchen to speak privately with me. She told me that her husband was in their bedroom, lying down, but she wanted to tell me something important before I could meet with him. “He has cancer,” she began. “He knows that, but he doesn’t know that he’s dying. Promise me you won’t tell him.”

I replied to this as I always did to such requests – assuring her that I would not bring it up, but that I *would* answer his questions honestly if he asked. In my experience, I explained to her, people don’t ask if they don’t want to know; conversely, if someone does ask, it is unconscionable to lie to them, even though the news may be hard to hear. Most people have things that they would want to do or say if they knew that their time was very limited. Once the initial shock has worn off and the tears dry, they want to update their Will, tell close family members how much they love them, and/or show their spouse where the important papers are. So hospice professionals feel strongly that patients have the right to get a truthful answer if they are asking questions about their disease or prognosis.

Mrs. Klein accepted my response, introduced me to her husband, and left the room. As soon as she was out of earshot, Mr. Klein hissed to me, “Close the door. I need to tell you something important.” He proceeded to tell me, “I have cancer. My wife knows that, but she doesn’t know that I’m going to die. I don’t want you to tell her.”

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I smiled as I affirmed that he was obviously a loving husband who cared deeply about his wife's wellbeing. But I had to tell him that she had just spoken precisely the same words to me about him. He seemed quite surprised.

He and I conversed for a few minutes, and then I said I was going to get his wife. I ushered Mrs. Klein into the bedroom, then told them, "I'll come back later this week to follow up with you, but right now, you two need to talk."



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