#### REVISED EDITION



#### SPIRITUAL CARE FOR THE DYING



A pastoral guide for hospice care workers and all who live with the terminally ill

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# The Work of Dying

WHEN A PATIENT IS ADMITTED to hospice in the early labor stage, the first priority is to control symptoms. Then you have some space for building a relationship. Now, this is a paradox. The work of the dying is to detach from the people and things of this world, and here you are trying to attach. But you are acting as a guide for the journey, and the patient can sense that.

One hospice midwife spent two hours listening as a family described their father's abusive behavior toward his nurses. When they felt she was adequately prepared they cautiously led her in to meet the patient, who had not been told she was coming. He took her hand, grinned, and exclaimed, "I've been waiting for you!"

A hospice midwife can be a breath of fresh air for the patient and family. And hospice care at its best dispels the stale energy of chronic sadness. Humor has served me well in this early stage! Many times I have walked into a patient's room and said, "It's your lucky day, because I'm your nurse. Rub my belly and I'll give you three wishes." There's nothing that brings people together faster than laughter, and it's often been in short supply for too long.

Touch is a universal language that can help develop a relationship. It's also healing, so don't be afraid. If patients seem to be especially reserved, test the waters with a pat on the arm or a squeeze of the hand. The worst thing that can happen is they'll jerk away or ask you to stop.

#### The Urgency to Love

With terminally ill patients, there is an urgency to love quickly if you're going to love at all. Be generous and openly affectionate. Patients often feel ugly because of the toll illness has taken on the body. Hugs and kisses send a message that they are still lovable.

When I first meet a patient, I always ask, "Have you been sick a long time?" There is a need to tell the history of the terminal illness in the same way that any traumatic event must be told time and time again. And if you are going to accompany this person on a journey, it's important that you understand the terrible twist of events that have brought you into the situation.

When the symptoms are controlled and some really good days are experienced, patients may declare that they're recovering, and the family may share this delusion. Whenever patients tell me that they are better, or that a healing has taken place, I rejoice with them. I say, "It's wonderful that you're feeling so well. This is a gift, whether it lasts a day or a lifetime. Enjoy it!" Denial is a powerful defense mechanism, and it isn't bad. It's just a defense. We all defend ourselves the best way we can, and if the patient is denying the approaching death, leave it alone. Never lie, but don't tell people more than they want to hear. There is no need to crush a hurting person with the full weight of the truth.

#### Life Review

Slowly, as you share experiences and earn trust by "wasting time" together, the patient will begin to open up to you. An important work of the dying is life review, sorting out the events of life and finding meaning. This usually comes in fits and spells, so always be eager to listen to stories. They're new to you, so you can often generate more interest and enthusiasm than the family, who may have heard them many times.

When the pathology works very quickly, or when the diagnosis is not made until the very end, patients and families are rushed to complete their emotional and spiritual business. They especially need a guide because they may not know where their attention should be focused. The midwife's ability to guide is directly related to her willingness to be a channel of grace. One midwife told me the story of a distraught family who clung to the bedside of their unresponsive mother one Christmas day. This midwife felt inspired to ask them if they wanted to move their mother, bed and all, into the living room by the Christmas tree. They agreed, and soon they had placed their mother's bed directly in front of the tree. Then an amazing thing happened. The woman woke up. The midwife asked if there was anything she wanted. She said, "Yes. A cigarette and a glass of wine would be nice." They rolled the head of her bed up and she took one puff from the cigarette and a couple sips of wine. Then she shared some things about her life that her family had never heard before. When she finished, she looked at her son and said, "It's time now." And she died. The midwife's willingness to act on an inspiration allowed that woman to share with her children a final act of love.

Life review, however, usually takes weeks or even months. Suggest bringing out photo albums to stimulate the process. If the family asks about calling out-of-town relatives, tell them to do it at once. Encourage the family members to come and spend time while the patient is still able to visit, and to say the things that need to be said.

## Reconciliation

Look for chances to spend time alone with patients, who may need to say things to you that they can't comfortably share with the family. Often there is lack of forgiveness in some area, and this must be resolved for a peaceful death to take place. If the death is approaching quickly, you may have to be a little pushy in encouraging the patient and family to forgive while there's time. If it's not possible for them to do this in person, encourage letter writing.

I suggest listening with compassion to stories of past hurts, and then gently asking, "But does it really matter now?" If they're Christians, call attention to the Lord's Prayer: "Forgive us our trespasses, as we forgive those who trespass against us." Remind people that forgiveness isn't a feeling but an act of the will.

#### Am I Going to Die?

Patients may choose to talk with you about things the family won't let them say, especially about their approaching death. I believe that every patient will talk about death eventually. If you are the person they share with, you are blessed. But it won't happen unless you listen with your heart. I've noticed that patients often make oblique references to dying just to test the waters. Don't ever let an opportunity to listen pass. Even if they change the subject, you've established an unspoken agreement that it's okay to talk about this when they're ready.

Occasionally, patients ask me, "Am I going to die?" That question always leaves a lump in my throat, and I try to remember to pray first before responding. You must be honest, but the wording of your response must be finely tuned to the patient's need. You may very well say the wrong thing, but if you roll with the punches and let the patient set you straight, you'll probably be forgiven.

When patients broach the subject, I ask, "Are you afraid?" or "What is the worst thing that could happen?" (Some men, especially young ones, will be offended if you ask about fear, but naming it is half the battle.) Try to zone in on the specifics. The number-one fear is for the well-being of their families after they die, and a close second is fear of the actual death. *Will it hurt? Will it be awful for my* 

*family to see? Will I die choking or gasping for air?* Some patients worry that they'll die suddenly, before they're ready.

Most people haven't seen anyone die, or their only experience of death is what they've heard or seen on TV. I reassure them that death is usually a very gentle, gradual process. Even though I know it can happen, I tell them I've never seen anyone choke to death, which is true. I tell them that we will do everything within our power to see that they don't hurt. And I describe the physical process if they want to know.

Then I ask, "What do you think will happen after you die?" Most patients have given this a lot of thought and candidly share their beliefs with me. But occasionally a patient will say, "I just don't know." My next question is, "Do you believe in God?" If they say no, I retreat and storm heaven with prayers. But when they say that they do believe in God, I share what I've seen with my own eyes.

I tell them about patients who saw angels and loved ones already on the other side. I tell them about patients who die with an expression of radiant joy, who obviously are seeing something beautiful at the moment of death. And then, with their permission, I pray with them.

### Spiritual Distress

I have read over and over that hospice staff should never try to obtain a last-minute conversion, that we should just accept the patients where they are. "People die the way they live," seems to be the motto. I agree that there is no place for proselytizing in this work, but each patient has a body and a soul, and the soul is more important by far.

A co-worker had a patient who was in deep spiritual distress, evidenced by extreme fear and restlessness unrelated to physical symptoms, and she asked me to go see him. "He's an atheist," she said, "so you can't pray with him." My answer was, "Of course I can, but he doesn't have to know about it."

I had called on my informal community of prayer warriors upon hearing of his distress, so he'd been steeped in prayer for almost twenty-four hours when I finally went to visit him. His distress was markedly improved when I arrived, and I prayed silently at his bedside as he slept.

I gently touched his wrist to take his pulse, and he stirred slightly. I whispered, "It's okay. I'm Kathy, from hospice." He opened his eyes and looked into my eyes so deeply, I felt he could see into my soul. It seemed to me that he knew why I was there. I never spoke to him about God, because I felt it would be insensitive to do so in front of his profoundly atheistic family. But there was no need; I ministered to him just the same.

On the other end of the spectrum, I'll share a story with you from a courageous, free-spirited midwife whose faith and hospice vocation were both quite new. She admitted a spiritually distressed patient to hospice at the point of death, and asked the family about the woman's faith. They replied that she had none, and neither did they.

Now, God would have had to send me a personalized telegram to persuade me to do this, but my friend asked if she could pray with the woman. The family quickly answered no, so she asked if she could pray silently at the bedside! They consulted a bit, and hesitantly agreed. The midwife related that her silent prayer was along these lines: "God, I don't know this person, but she seems like a nice enough lady. Surely you won't let her die without any faith in you!" She popped in and out of the room, silently praying each time.

At first, the family watched her suspiciously, but after two hours of this the midwife found the family gathered around the woman, confidently urging her to trust in God and go to him. She died soon after that—a peaceful death. Amazing grace!

It has been said that there are no atheists in foxholes. The dying process is the ultimate foxhole for those with little or no faith. The few patients I've had who claimed to be atheists changed their "no" to a "maybe" toward the end. They want to believe in a loving and forgiving God, and as a Christian midwife for souls it would be irresponsible not to gently share my faith with them when presented with the opportunity.

Once we had an extremely troubled young man at the in-patient hospice. From his family's account, he had squandered his life and left a trail of hurt in his wake. He never slept, but constantly thrashed in his bed and refused our attempts to comfort him. After medicating him aggressively for days, we came to the conclusion that he suffered from tremendous spiritual pain.

One evening we decided to use the "tag-team" prayer approach. We took turns sitting in his room in silent prayer. I had the second shift, and after about thirty minutes he looked at me and I saw something in his eyes that gave me the green light. I asked if he was afraid, and he snarled, "No!" and pretended to go to sleep.

I continued to pray, and a little later he said, "Of course I'm afraid! Who wouldn't be?" I asked, "What part scares you the most?" He said, "The whole damn thing," and pretended to sleep again.

Then he turned and looked at me and I asked if he believed in God. He said yes, so I said, "He's a forgiving God, and he loves you more than you love yourself. All you have to do is ask for his forgiveness."

He pretended to sleep again, and I continued to pray. Finally, in the voice of a small, frightened child he said, "I would ask for forgiveness, but I don't know how."

"Then you're in luck," I said, "because I do. I'll go first, and you can repeat the words." We prayed the most beautiful prayer, and I can assure you it didn't come from me. When we finished, he closed his eyes and slept for the first time in a week.

I wasn't there when he died, but they told me he saw angels.