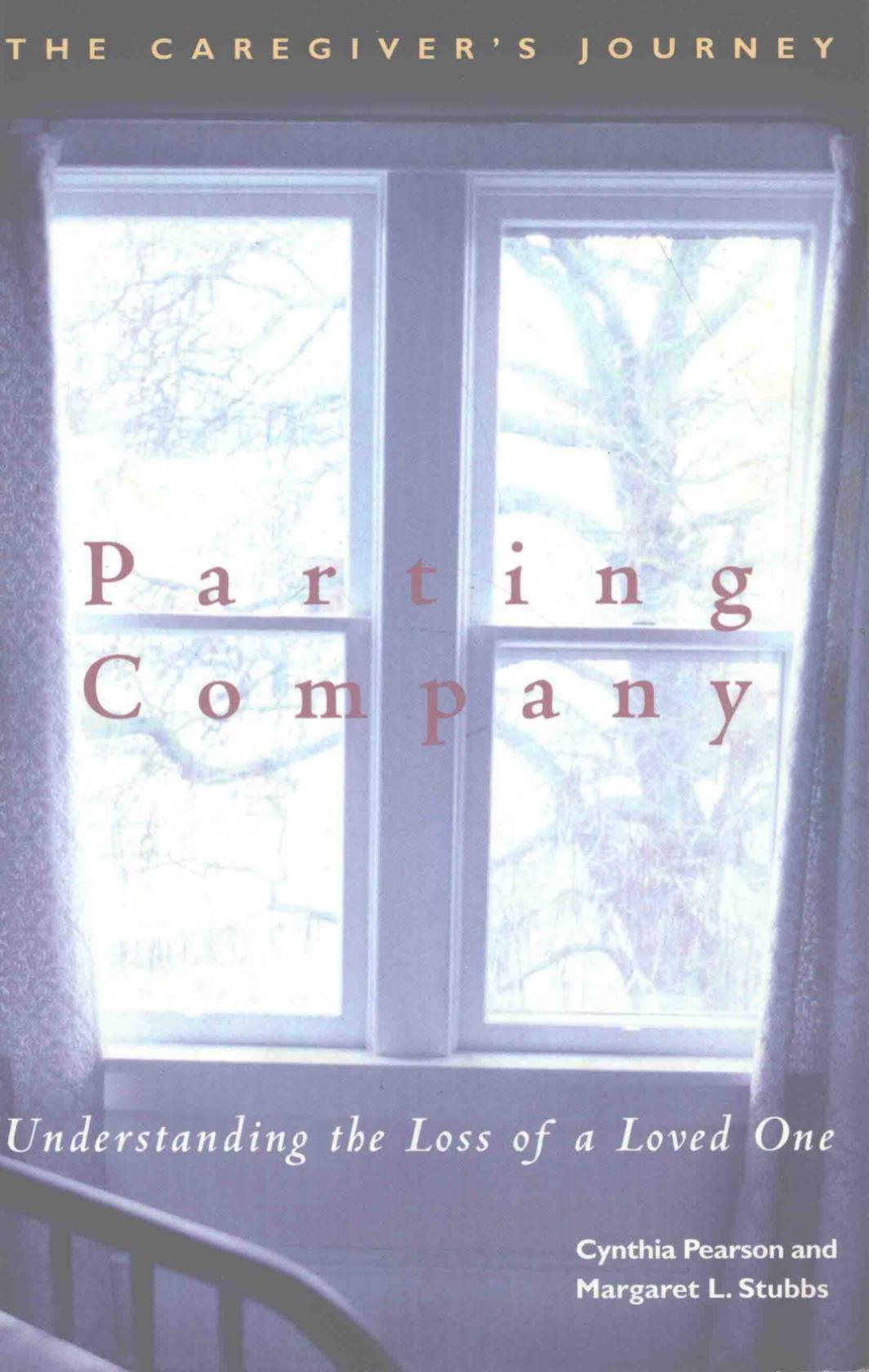


THE CAREGIVER'S JOURNEY



P a r t i n g
C o m p a n y

Understanding the Loss of a Loved One

Cynthia Pearson and
Margaret L. Stubbs

Parting Company

*Understanding the Loss
of a Loved One*

The Caregiver's Journey

Cynthia Pearson and Margaret L. Stubbs



Seal Press

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*We dedicate this book to all who find themselves
caring for others in their last days.*

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Parting Company

Introduction

The Wisdom of the Witness

The focus for this work developed one rainy night as we, friends since childhood, prepared for a funeral. Peggy's mother had died three days earlier, after Peggy had cared for her at home during her end-state cancer. Cynthia had managed the care for her paralyzed father for two years before his death and was currently assisting a beloved niece who was dying at home of a brain tumor. That night, we began comparing notes on our experiences of caring for the dying. Our conversation grew increasingly candid and emphatic. We had both been astonished to find that nothing we came across in the existing literature had prepared us for what we had been—and were still—enduring.

When the time came for us to take charge at the deathbeds of our loved ones, we were filled with sadness, anxiety and a great sense of duty. We also felt ignorant. We had never had the responsibility of caring for someone who was dying, and we wanted to know more, much more, about what it would entail and how we could manage it. We both assumed that, just as we had done when we were pregnant, we would be able to find support, information and guidance by reading about the subject. But none of the reading spoke to the reality we were experiencing—the

intense emotional, physical, intellectual and spiritual significance of being in attendance during a loved one's death. Indeed, much of what we consulted brought frustration and self-doubt instead of enlightenment and solace.

Most of the books were by professionals who presented remote, generalized ideas about death and dying. But we were experiencing death as pragmatists, not philosophers. When we tried to understand our own circumstances in terms of these generalizations, we seldom found a fit. We wondered then whether there was something wrong with us or our family members. When we looked for more particular cases to address our immediate and practical concerns, we found personal memoirs. These accounts were too specialized and time-consuming for us, however, as we frantically sought to anticipate the actions we might be called upon to take.

We eventually concluded that the main problem was that most of the literature on death and dying was about how we die. Very little was about how we *live* while those in our care are dying. The spotlight was consistently on the person dying. While valuable to us in terms of what we might do to help or understand a loved one better, there was little that helped us to help ourselves. No material spoke directly to the transition we experienced as caretakers of the dying, to our feelings of disorganization or to our fears about how we would fare both during and after our loved one's death.

Fortunately, as we reflected on our respective crises after the fact, we developed an alternative perspective on the mismatch between what we read and what we learned from experience. We came to realize that being with a dying person and witnessing death had simply not been adequately detailed. Eventually, we resolved to write the book we wished we could have read while going through the deaths of our family members. In it, we sought to place what had been missing for us—information from the survivor's perspective about the true phenomenon of being in attendance during dying. We now identify this experience as “death-in-life”: the transformative experience of being present at another's death as a caregiver, witness and survivor.

Throughout the research and writing of this book, we maintained the perspective of untrained, unpaid and thoroughly committed

caregivers. What was it we had needed to understand, and how could we learn about it? We began by talking about what would have been helpful to us, speaking with hospice professionals and designing interview questions we hoped would evoke the insight and information we had needed when we were dealing with the deaths of our family members. Then we began talking to other survivors and caregivers and recording their answers to our questions.

Parting Company presents many perspectives on the experience of attending to the dying, including those of both lay and professional caregivers. The first-person accounts we have gathered and the observations we have made about them in the commentary at the end of this book place the caregiver at center stage. We wanted to record people's real experiences: what *actually* happens rather than what can or should happen. We hope that these accounts will inform and enlighten those family members and other loved ones who are confronting the death of someone close to them.

These interviews provided us with insights into how death happens within our ongoing lives; how we as caregiving family members come to reckon with a loved one's dying; how we come to accept death when it occurs, or sometimes refuse to accept it; and how we stretch, or cannot stretch, to accommodate death-in-life.

At the outset of our project, we understood our need for the details of dying as witnessed by caregivers. But we did not fully appreciate their wisdom or the importance of their perspective until we were well into our research. The interviews, with caregivers like ourselves, confirmed our experience that the struggle to understand and make meaning of death-in-life is largely absent from public discussions about caring for the dying. The main consequence of this omission is that the caregiver's experience remains hidden; isolation and lack of information remain the norm. An equally important consequence is that the caregiver's reality has been ignored in formulations of public policy intended to help us with the end of life. For too many of us, the result is that such policies do not meet their intended goal.



When computers were new to the average American, teachers of computer literacy began to use the term “FUD factor.” This referred to the fear, uncertainty and doubt that plagued their students as they encountered a completely new and sophisticated technology for the first time. As we collected interviews from a diverse group of people who have experienced the passage of others into death, the notion of a FUD factor became a valuable tool for us. Fear, uncertainty and doubt form the matrix in which we perceive death and dying.

A primary step in our identifying and understanding death-in-life was discovering the concept of “liminality.” This term, derived from the Latin word for threshold, *limen*, was coined in 1909 in a seminal anthropological study, *The Rites of Passage*.¹ When human beings go through life transitions, there is often a ceremony involved, typically called a rite of passage. By studying these ceremonies and rituals, social scientists discovered that there are generally three phases: separation, transition and incorporation. The middle, transitional stage often involves the crossing of a threshold, either literally or symbolically. But in all cases, that middle phase is a state in which the individual is “betwixt and between,” neither here nor there. The concept of liminality has been taken up by contemporary scholars to describe many states of a transitional nature. For example, a 1990 study of the families of coma victims describes the family members’ positions as liminal, because their loved one is alive and yet, in most respects, dead to them and to the world.²

We recognized in these descriptions our position as caregivers at the deathbed. When we are living with dying, we too are in a state of liminality as our loved ones’ conditions and circumstances continuously change over time. Along with sadness, living with dying is full of fear, uncertainty and doubt, and leads one inexorably to ponder the most human and existential uncertainty of all: What happens when we die? The more we gathered the honest particulars of experience that characterize the turbulence and transcendence of death-in-life, the more we learned. We now think of this liminal experience of participating in the dying of another as a significant marker in the life course—one we hope will be more readily understood as caregivers’ perspectives become more prominent in our understanding of death and dying. Understanding the

liminality of caregiving for the dying became the underpinning for the three central principles we have derived from our research: Every death is unique, God is in the details, and the past is prologue.

How do we come to grips with a situation as profound as a loved one's dying? Many caregivers search for templates, in religion, for example, or in therapy, or by taking a course on death and dying. We too searched for templates, but eventually realized that with a subject as socially taboo and innately mysterious as death, we are unlikely to discover a how-to formula that will help us manage the ungainly monster that death is. We did not learn what we really needed to know until we began to speak personally and at length with others. Over time, as we reflected on our own experiences and talked to others about theirs, we came to understand that no amount of data can be amassed that will account for every death, nor is any one paradigm adequate to describe this human experience. Our first principle became clear: Death is unique in every case, and however any source might describe the experience, there is no right way to die or to attend the dying, no twelve-step program that can be applied in every situation.

We realized that we could learn more about this transition by embracing its ever-changing form than by trying to pin it down once and for all. Especially after we gathered several interviews, we found that we would benefit from adopting the stance in the well-known parable of the blind men feeling the elephant. In the parable, none of the blind men was able to completely describe the beast, because each had a unique and limited relationship to it. Yet each could describe a portion of the reality, and combined, their descriptions rendered more of the truth. Though we are similarly blind with respect to death, bits and pieces of what others have perceived will illuminate our own experiences. Daunting as death is, other landmark life events—for example, menstruation, making love and childbirth—have all been similarly mysterious, as is any experience before it becomes one's own. We think the best we can do in these situations is to ask others about their experiences and use the information they provide to give us a sense of what *does*—not necessarily what *should*—happen.

As soon as we began conducting interviews, we realized that such

firsthand accounts were what we had needed while coping with our loved ones' dying. In a new way, we understood the saying that God is in the details, our second principle. People's own stories conveyed the breadth and depth and mystery of dying that we had experienced during this transition. They shared common themes and concerns, yet each situation was unique. Most importantly, these stories provided what had been missing from "the experts" and other sources.

The third principle we came to understand is that how we cope with death-in-life—indeed, how we survive it—has to do not only with our current situation but also with our history: What is past is prologue for the caregiver. That is, how death has happened to loved ones in the past, how our families did or did not manage serious illness or sudden death, and how we learned what death was like have an enormous effect on what happens to us as we live with dying, and as we go on to survive the death of those close to us. For most of us, there is a store of death experience, usually unarticulated, which informs our current reactions. Our lives are full of unexamined instances of loss. We have found that when people explore these instances, they often recognize parallels between past and present experiences. This recognition often brings participants a wider array of possibilities for action in the current crisis.

Reflection on the past reveals unanswered questions, unaddressed feelings and unquestioned but characteristic patterns of family beliefs and rituals that have been carried out in response to death. These insights can help people to identify troubling areas, especially aspects of the current experience with which they are likely to need help. Just as often, people are able to identify strengths they or other family members brought to bear in times of death and mourning. Discovering that courage and ways of coping lie within their own past experience—and realizing that a store of strengths is already available to them—can be immensely comforting.

When fear, uncertainty and doubt derail us, we sometimes feel especially reactive, thoughtless, out of control. Our past experiences, including confusions as well as strengths, accompany us through our crises. Unless we pause to identify them—easier said than done at the height