

Preface

This book is about the unusual intersection of personal forces—physical, emotional, social, and spiritual—that predispose dying people to see afresh their old taken-for-granted worlds. Dying people encounter these unique combinations of personal experience and crossroad moments, often for the very first time in their lives. Above all, this book is about how it *feels* to die. But when I say *feels* I do not mean to isolate and describe emotions as if they have no intimate reference to the social, physical, and spiritual forces that create them. In this way I have chosen to write more about the key personal experiences that characterize dying, to describe the inner life of dying as an inseparable mixture of feeling, physical impulses, social interaction, meaning making, and soliloquy.

When I refer to the dying person in this work I am referring to a person who is consciously aware and expectant that death will come soon—often in the next few hours, days, months but almost as commonly within several years. However, irrespective of the calendar of events involved, this saturating awareness, expectation, and acceptance of impending death—sometimes in the foreground, sometimes in the background of the dying person's mind—informs the descriptions, analyses, and reflections in this book. I am not concerned with the increasing number of people who have advanced disease, commonly a spreading cancer, who will not acknowledge to themselves any notions of death or dying. These people are not dying in any sense other than perhaps a medically observed one. Such people often view themselves as people living with serious chronic illness. They are, or aspire to be, survivors to the end. I am also not referring to other people who wish to adopt a type of philosophical pose that suggests all living things are dying things *ipso facto*. Once we are born, we begin to die. Between these two extreme examples, of sequestering on the one hand and overinclusion on the other, are serious examples of people

who will truly die soon: through accident or by intent, through social and physical circumstances beyond their control, by their own hand, the hand of others (people on death row, for example), or from a killer disease. This knowledge changes the way they experience the world—emotionally, socially, spiritually, and, more often than not, totally. The prospect of dying shortly changes things, sometimes all things, for dying people. These changes occur right up to the last minutes and breaths of their organic life. And this book is devoted to the task of describing these personal changes.

Although dying is commonly portrayed as a dramatic affair, a problematic thing, a medical experience, it commonly plays out against type. More often than many like to think, dying is a surprisingly quiet affair, a mixture of both sad and happy traffic between loved ones and the dying person, and between the mind and the heart of the dying person as each aspect of one's self strives to attain some meaningful accord at the end of life.

Most books on dying often simply fail to provide a description of this handful of usual experiences common to our intimate encounter with death. Remember that medical observers write most books on dying, and they do so with an understandable but work-related eye for problems during the dying process. The emphasis, if not the accent, is on grief and loss, symptom management, and coping or lack thereof. If we put some distance between us and this kind of academic and clinical writing about death and dying—seeking to view all conscious experiences near death as a whole—our collection of normal and usual images of dying actually appears to be rather small. Instead, dominant images of dying tend to have a strong institutional look—fragments of hospice or hospital life, portrayals of depression and despair, an overattention to the violence of the body.

Absent from most of these snapshots of people facing their own death are the broader, more typical, less academically scrutinized normal personal experiences that might balance the human portrait of dying—courage, waiting, hope, reminiscence, love, being alone, or transformation, all of which might be added to what we know about suffering, fear, anger, or resistance. In the admirable but overwhelmingly professional focus on solving problems, we have neglected the more positive, adaptive, side of dying and in the process have given mortality a frightening face that is far beyond what we need. It is high time we had an introduction to what it typically means to *live* at the end of life.

To obtain a more balanced portrait of the inner life of dying people, I have included accounts of many other kinds of dying—from death camps, death row, suicides, war and disaster, accidents and trauma, aging and dementia, and many other examples. The recurring elements of personal experience in dying in widely different circumstances alerts us to what we commonly ignore or overlook in the forms of dying that are more familiar—in our hospitals, hospices, or nursing homes. This comparative method invites us to look again at all our recorded experiences of dying. I have attempted to identify the elements common to these different circumstances. To these sources I have added the academic analysis common in such accounts and blended these with insights about dying and death from some of the world's best writers and poets. Sometimes the expression of difficult experiences can use some help from wordsmiths whose trade is frequently in the ineffable.

I would like to add that in my efforts to make this work as accessible as possible to a broad readership, I have dispensed with the defensive academic style of argument: detailed review of every morsel of relevant literature and extensive notes or explanations about my method. I have worked among dying people, and reviewed the literature on this population, for about thirty years now. I have taken the liberty of focusing on a broad range of examples from different settings, ages, social classes, and ethnic and religious background. I have been guided by trends in the current clinical work in this area but also allowed anthropological, historical, and cultural voices found in other literature to influence me.

The existing first-person accounts in the public literature overrepresent those from middle-class backgrounds and those who are highly literate, and my work reflects this dominance. We are at the beginning of our serious exploration of the human encounter with death, and I make no apologies that this book unavoidably reflects the limitations of the present time and state of the art. But whatever those limitations, my hope is that most of my descriptions of that fine balance of dark and positive experiences that characterize the core elements of the journey of dying will be clear to most thoughtful readers, and that, in any case, all readers will value the importance of the attempt for its own sake.

For as we approach a period when the tide of dying is rising, yet another mark of the baby-boom generation, it is more imperative than ever for us to gather up what normal images of dying we can find and attempt to join

them up with the other, more problem-based understandings. From here we might see what story or general meaning they have when we combine them, however imperfectly. Let us break away from an increasingly fragmented view of dying as a medical or psychological set of problems and reach for a new, more holistic, portrait of the inner life of the dying person. My aim in this book has been to build a deliberately interdisciplinary work focused on describing and understanding the common and recurring elements of personal experience while facing death.

In self-consciously attempting to create a more holistic portrait of the private experiences of the dying person, by deliberately reviewing and connecting our current rudimentary and unconnected observations, I hope to encourage my academic and clinical colleagues to improve upon what I have done. In any case, we need to make this an ongoing interdisciplinary project. And we need to start somewhere. Dying—the final and normal period of living—is underinvestigated. This is both ironic and dangerous because we now live in a time when new policies about palliative care, aging, intensive care, the determination of death, and euthanasia are being formulated with meager knowledge of the subject at the center of their different attentions.

At the same time, I also hope to offer general readers of this book a sketch of something less than they feared and something more complex, surprising, and wondrous than they might have first imagined. From the stories I have heard from the many who have lived in the shadow of death, and from a review of the literature that has sought to study the voices and the experiences of those who have gone before us, I now introduce the reader to what I believe are the most common personal elements of the journey ahead.

Martins River, Nova Scotia

Acknowledgments

I wrote this book while I was a guest professor in Canada, using the resources and facilities of the Department of Community Health and Epidemiology at Dalhousie University in Halifax, Nova Scotia. I thank my hosts—Adrian Levy, head of my department, and Tom Marrie, dean of medicine—for their hospitality and use of library and IT services. My friend and colleague Alik Karapliagou at the University of Bath in England was my graduate research assistant. Alik helped me with the initial groundwork of identifying, searching, and retrieving important lines of literature. She also helped identify fresh lines of writing and research we needed when we regularly reached the limits of the personal accounts of end of life care. My wife and academic colleague, Jan Fook, and I held scores of private conversations and debates about the ideas and perspectives offered in this book, which helped me hone and refine my reflections, as she has so often done in our many years together. My Canadian colleague Margie King and two anonymous reviewers read the manuscript, and each provided encouraging and useful feedback. My old friend and colleague Glennys Howarth read every line of this manuscript, as she has often done for me, providing critical feedback from her perspective as one of Britain's most senior death studies scholars. Keith Anderson, editor of the End-of-Life Care Series for Columbia University Press, was encouraging and enthusiastic about this project from the beginning. I was also lucky to work with Polly Kummel, my wonderful copy editor; meticulous and collegial, she provided deft guidance and mentoring for the final draft of my writing.

In 2003, during his own period of dying from a brain tumor, the British sociologist Ian Craib trenchantly criticized sociology's lack of engagement with the emotional and personal while academically theorizing about the human experience of dying. Those critical comments influenced my own