Preface

Every year, thousands of caregivers, hundreds of thousands of patients, and millions of family members are forced to deal with questions about what life-sustaining medical procedures should be started, withheld, or withdrawn near the end of life. These decisions tend to be made in haste and late in the dying process, without the benefit of having full information on choices and alternatives. Often, patients suffer a good deal more than necessary at the end of life as a result, and family members are left with a haunting sense of guilt about the decisions they finally made: Did we stop the use of technology too soon? Or did we let things drag on too long?

Patients, those who care for them, and members of the medical care team should and frequently do collaborate on end-of-life treatment decisions. But too often, these decisions are shaped by a flawed understanding of what is appropriate in such circumstances. As a result, doing everything possible until the very end becomes the default rule—a rule that, when challenged, sometimes turns bedside discussions into courtroom deliberations.

There is widespread agreement among bioethicists, medical clinicians, legal experts, and religious leaders about what decision-making principles should apply as death approaches. This consensus holds that:

1. Patients should be able to make any decisions they choose about what medical technology they will accept or refuse (whether they are terminally ill or not);
2. If the patient is unable to make decisions for him- or herself, surrogates—family members or close friends—should be fully empowered to step in and make decisions based on what they think the patient would want or what they believe would be in the patient’s best interests;
3. There should be no distinction between withholding and withdrawing treatment; it should be just as acceptable to stop treatment once started as it is not to start treatment in the first place;
4. Artificially provided nutrition and hydration—tube feeding—should be thought of as a medical procedure that patients or their surrogates can decide to accept or forgo like any other medical treatment.
More often than not, frontline clinicians and members of the lay public are utterly unaware of these consensus principles; consequently, they act the way they think they are supposed to act—but fighting death at every turn, until the bitter, inevitable end.

In this book, I attempt to shed new light on the issues surrounding the difficult decisions that must be made as death draws near. By presenting and clarifying the essential elements of the “consensus position,” this volume will, I hope, help those confronting such decisions make truly informed choices—choices that take into account a broader range of options and reflect more humanity than is evident in the dying process most Americans suffer through today. The truth is that sometimes, perhaps often, the process of dying can be eased and even enhanced by a decision to shift from the medical technology of curing to the hands-on approach of caring. However, this truth cannot have much impact if the decisionmakers are unaware of it. Americans need to become empowered about death; we must know more about death if we are to make good decisions in the twilight of life. Most of us would prefer to die well, and it is hoped that Managing Death will help make that desire a reality.

James M. Hoefler