While advance directives hold a great deal of promise for ensuring self-determination and quality of life near its end, the majority of Americans face life-threatening illness without having completed advance care planning. The growing availability of sophisticated life-support technology only increases the likelihood of anguished decision making, if not planned for in advance.

This volume brings together scholars and practitioners from a variety of disciplines to explore the barriers to advance care planning and share helpful strategies to facilitate meaningful conversations among patients, families, and health care providers to promote better outcomes at the end of life.

The text recounts the history of advance directives, chronicling the evolution of an approach that initially focused on completing forms, to one that now emphasizes more comprehensive strategies for planning for dying and death. It discusses how to overcome barriers to effective advance care planning and how to improve the efficacy of surrogate decision making; and details public health, legal, and comprehensive community planning approaches to change how our current society deals with dying, death, and end-of-life care.

Authors include palliative care physicians, nurses, social workers, grief counselors, educators, lawyers, psychologists, sociologists, and medical ethicists. A wide range of contacts and additional resources are provided.

Key Features:
- Introduces a multidisciplinary, communications approach to advance care planning
- Addresses strategies to reform advance care planning
- Presents case studies illustrating the importance, benefits, and challenges of advance care planning
- Features successful initiatives in advance care planning and new directions that shift community practice related to dying, death, and end-of-life care
- Includes the contributions of physicians, grief counselors, medical ethicists, social workers, psychologists, lawyers, nurses, educators, and others
Advance Care Planning
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Advance Care Planning

Communicating About Matters of Life and Death

Leah Rogne, PhD
Susana Lauraine McCune, MA, CT

Editors
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Preface

This book is intended to help facilitate meaningful communication and effective decision making about medical care at end of life (EOL). With an aging population and rapidly expanding life-saving technologies that transform how we deal with life-threatening illness at any age or stage of life, concerns about how we want to live at the end of our days become more and more crucial for a growing number of people in our communities. However, research on EOL decision making shows that people have difficulty both asking and answering important questions about EOL care for themselves and for their loved ones. Many people are overwhelmed by the complexity of the health care system and do not know that they have the right to decide what kind of care they would like to have when they are critically ill or how to indicate their desires to their health care providers.

Advance directives (ADs) (living wills and health care proxies) have received great attention in recent decades as tools for providing for self-determination and quality of life near the EOL. Yet, despite years of enthusiastic advocacy by major health care organizations, they have not been as widely used as hoped. Due to complexities involved in making and documenting EOL care choices, lack of understanding of how they should document their choices, and discomfort about talking about dying, a majority of Americans face life-threatening illness without having a plan in place. Also, due to communication problems among patients, families, and health care providers and lack of awareness of how advance care planning (ACP) can best be done, people who have planned ahead and have ADs in place often do not get the care they had hoped for during the dying process. Furthermore, it has become more and more apparent that the focus on
autonomy and self-determination at the expense of any other ethical principles or human motivations may not take into consideration the variety of ways that people approach, with their loved ones, the profound and complicated challenges presented as we face our mortality.

Featuring the voices of scholars and practitioners from a variety of disciplines, this volume provides a history of ADs and describes barriers to effective ACP. Contributors share effective communication strategies that address some of the shortcomings of a forms-completion approach to EOL planning and show how a focus on facilitating meaningful conversations between patients and their families and among patients, families, and their health care providers can provide for better outcomes at the EOL. Authors describe innovative regional or statewide initiatives for promoting effective ACP and present some “big ideas” for how we as communities and as a society could be charting a new course for how we deal with life-threatening illness, dying, loss, and death. Those who are seeking guidance for their own ACP or who want to be a part of initiatives to help communities address these important issues will find a wide range of contacts and resources.

At the heart, this project is intended to provide individuals with the awareness of the need to plan ahead for their EOL and the tools to be effective in doing so, and to provide professionals with key strategies to be successful in facilitating communication with patients and families. Too often, after experiencing the death of a loved one, people will say “if I had only known…” or “if we had only talked…” Meaningful conversations with one another about what we value and what is important to us in life are the basis for an effective ACP process. We hope that readers—professionals, educators, and members of the general public—will find the perspectives, strategies, and tools (as well as the vision) the authors present in this volume to be helpful in providing a path to a dying process without regret.

Leah Rogne
Susana Lauraine McCune

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I would like to thank the many elders I served as a nursing home social worker for the wisdom they offered on how to live well until we die. I am forever grateful to my mentor Michelle Matchie for introducing me to the heart and soul of dying and for her many lessons about the meaning of life and death. I would like to dedicate my work on this book to my parents, Katherine and Leslie Rogne, who gave their children the gift of planning well for their end of life.

—Leah Rogne

I would like to thank Mary Wienek, PhD, and Philip Cushman, PhD, for giving me the wind I needed to fill my sails when they sagged so I could do what I believed needed to be done, even though at times on this journey land was far from sight. I thank the hospice patients and families and the grieving young people with whom I have been honored to work for their courage and honesty. They continue to inspire me. I would like to dedicate this book to my mother, Elizabeth Louise Hudson McCune, who gave me the gift of understanding the necessity of preparing for dying and showed me how to live and die courageously. My work on this book is dedicated to her. I would like to express my deepest gratitude to Dr. Leah Rogne for trusting me enough to embark on this project together and for mentoring me as a budding editor and author. Thank you, Steve, for traveling with me on this journey. Thank you, Dad, for believing in me.

—Susana Lauraine McCune
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Finally, in memory of those who have gone before, and for those who will come after, we encourage you to communicate with loved ones and professional caregivers about advance care planning. We encourage you to communicate about matters of life and death.
Introduction: A Matter of Life and Death

Leah Rogne
Susana Lauraine McCune

The principle of respect for autonomy, captured in ideas of negative liberty and noninterference, has a particular appeal in the United States, which is founded on the belief that all people have the right to live as they choose. Autonomy is a formative notion on which U.S. culture and our system of health care is largely based. Such a preoccupation with autonomy obscures the fact that we ultimately lack control over aging, illness, disability, suffering, and death. To admit this lack of autonomy is to admit that the human condition is beyond our control; to relinquish autonomy is to acknowledge our deep vulnerability....

Martha B. Holstein, Jennifer B. Parks, and Mark H. Waymack, 2011, pp. 11–12

At the end of the day, an advance directive is just a piece of paper. But an effective program for advance care planning is an opportunity to help people grow, create meaning, and make their lives (and deaths) better.

Benjamin H. Levi and Michael J. Green, 2010, pp. 8–9

To advocate human conversation as the means to restore hope to the future is as simple as I can get. But I have seen there is no more powerful way to initiate significant change than to convene conversation....

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Chapter 1  Introduction: A Matter of Life and Death

It is always like this. Real change begins with the simple act of people talking about what they care about.

Margaret Wheatley, 2009, p. 22

PLANNING FOR ENDINGS

One of the most difficult, terrifying, and confusing moments of life is when a life-threatening accident or illness strikes you or a loved one. Among the most challenging aspects of these events is that people are faced with decisions about accepting or foregoing, initiating or withdrawing aggressive medical care. These options require complex decisions.

In the midst of such confusion, patients and their loved ones are not only confronted with a life-threatening illness and complex decisions about care; they are also forced to deal with a medical system that they often experience as unfamiliar and impersonal. At these times, a myriad of perspectives and needs converge. Yet, if plans are not made in advance, patients, their loved ones, advocates, and clinicians are forced to make decisions about medical care quickly, under less-than-desirable circumstances.

The growing availability of sophisticated life-support technology only increases the likelihood of such tough decision making. These evermore regularly occurring situations call for Americans to face end-of-life (EOL) decisions before an emergency—to acknowledge their mortality and begin thinking about and planning for medical care through life and death in advance. The optimal time to make these decisions is not during a crisis, as these critical care choices can result in irrevocable consequences.

Our current conceptions in the United States about how health care is given, along with the consequences of our lack of communicating about considering medical care in advance, have implications not just for individuals, but also for society as a whole. Due to these conditions, both individuals and communities bear the costs—both emotional and physical, as well as financial—of not planning in advance for the medical care one would desire to receive at EOL.

THE PROMISE OF ADVANCE DIRECTIVES

Heralded as the Miranda warning for persons considering the EOL (Sloane, 1990), the Patient Self-Determination Act (PSDA) was passed by the U.S. Congress in 1990 with high expectations for what many thought would be a new day in which people would be able to exercise personal control of the dying process.

The PSDA required hospitals and nursing homes to ask people at the time of admission if they had advance directives (ADs) (a living will
specifying which procedures or treatments they wanted or did not want at EOL and a durable power of attorney for health care matters or proxy, in which they would name someone to make decisions on their behalf if the patient could no longer speak for himself/herself). The act requires admitting personnel to provide forms for patients to fill out and document that these procedures had been followed.

The hope was that completing living wills and appointing proxies would lead to a better dying in which individuals’ preferences would be granted in their final days. Guided by a strong commitment to the ethical principle of autonomy and the deeply held ideology of individualism so embedded in U.S. culture (see, e.g., Chapple, 2010; Holstein, Parks, & Waymack, 2011; Kaufman, 2005), ADs were seen as an extension of personal control on unto death, after the individual could no longer speak for himself/herself.

By the mid-1990s the rosy glow only half a decade old had begun to dim, and scholars and practitioners began to question whether this initiative had had the results it had intended. The comprehensive intervention project and research report, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), found that the PSDA had made little difference in whether patients’ preferences were upheld at the time of death (Teno et al., 1997). Surgeon Tonelli (1996) argued that it was “time to pull the plug” on living wills, as studies began to indicate that the documents had not fulfilled their promise and that dying patients did not experience a better death for having completed them. Fagerlin and Schneider (2004) asserted:

A crescendoing empirical literature and persistent clinical disappointments reveal that the rewards of the campaign to promote living wills do not justify its costs. Nor can any degree of tinkering ever make the living will an effective instrument of social policy. (p. 30)

At the same time, Fagerlin and Schneider did not call for the elimination of living wills. Living wills are appropriate, they said, for some patients; persons who have a high need for control should be informed about living wills and proxies. But the PSDA was bad policy, they argued, and we should “abjure programs intended to cajole everyone into signing living wills” (Fagerlin & Schneider, 2004, p. 39).

In an editorial in the prestigious Annals of Internal Medicine, Harvard professor and physician Joan Teno said it was “time to move on,” citing the empirical literature showing that having a living will had not reduced hospital costs at EOL. Nevertheless, Teno stated she didn’t “mean to imply that advance directives are unimportant” (Teno, 2004, p. 59).

Proxies, by which persons give someone else the legal authority to make health care decisions for them if they cannot speak for themselves,
have fared somewhat better. The body of research shows, however, that too often the surrogates chosen by the individual either do not know they have been given this responsibility, are poor predictors of what their family member or friend would want, or refuse to act when difficult decisions are required (Covinsky, Fuller, & Yaffe, 2000; Emanuel, 1995; Tonelli, 1996).

So, 20 years after the PDSA, where are we now and where are we going? In the wake of strong concerns on the part of practitioners and scholars about the effectiveness of ADs, conversations about EOL planning have shifted from product to process (Hammes, 2003; Wenger, Shugarman, & Wilkinson, 2008), from a focus on completion of documents to a focus on ADs as tools to stimulate communication between patients and families and their health care providers about EOL care. Advance care planning (ACP) has come to be seen part of a comprehensive and ongoing approach to educate ourselves and our communities about dying and death and to provide knowledge that can help us prepare ourselves, our families, and our society for a better way to die.

ORGANIZATION OF THIS BOOK

This volume brings together scholars and practitioners from various disciplines—social workers, sociologists, psychologists, physicians, ethicists, political scientists, nurses, and others—to assess the current state of efforts to plan in advance for dying and death and suggest paths toward a more effective approach to death education and EOL care.

The essays in the book are organized into five parts. Part I details the history and current status of ADs and their use in EOL planning and care, focusing on current challenges, including resistance to talking about death and dying, legal and ethical issues, the problem of overtreatment, and the cultural and spiritual considerations around EOL care. In Part II, authors discuss a variety of innovative ways or best practices to facilitate meaningful conversations about EOL, and Part III highlights successful initiatives in ACP. Part IV presents some big picture ideas about the kind of ethical view, leadership philosophy, and community development orientation it will take to undertake the kind of cultural transformation necessary to create a new way to deal with dying, death, loss, and care. Finally, Part V presents selected resources on death and dying, ACP, and palliative care.

Increasingly in the coming decades, the aging of the population in combination with rapidly advancing medical technologies will force an unparalleled number of people and their loved ones to make unprecedented decisions about life and death in an age of simultaneously abundant technology, economic disparity, and strained resources. No forms or legal documents, no matter how carefully crafted, can automatically guarantee us the death we want for ourselves or our loved ones. But we can prepare
ourselves by having the courage to convene conversations about dying, death, and loss within our families and communities and with our health care practitioners, as well as by raising the awareness of the entire community—of any age, any health status, in any venue—of the centrality of issues related to death and caring for the dying as a universal human experience.

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