



Voluntarily Stopping Eating and Drinking

*A Compassionate, Widely Available
Option for Hastening Death*

EDITED BY

**Timothy E. Quill, Paul T. Menzel,
Thaddeus M. Pope, and Judith K. Schwarz**

OXFORD

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To the patients, families, caregivers, and clinicians whose stories we shared in this book, and to countless other patients, friends, and family members who have needed and wanted both excellent palliative care and a wider range of end-of-life choices.

—Timothy E. Quill

To Bonnie, for her constant love and stimulating support, and in memory of my nephew, Paul Frederick Helm.

—Paul T. Menzel

For Linda and Phineas. And Reina, Larry, Nedra, Lessandra, Nathaniel, Matthias, Cameron, Clayton, and Tucker. I hope none of us ever need this book. But some probably will.

—Thaddeus M. Pope

To my friend Joan, the first person who asked me to help facilitate a peaceful death, over 20 years ago. I knew very little then, and she began my education in understanding how hard it can be to die well, and about some of the clinical challenges of VSED. To my patiently supportive and loving family members, particularly Jessi and Jason who, along with several very good friends, have indulged my passion for choice at the end of life and participated in endless discussions of the complexities involved.

—Judith K. Schwarz

How quiet
It is in this sick room
Where on the bed
A silent woman lies between two lovers –
Life and Death

—Langston Hughes, “Sick Room” (1926)

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Foreword

Why should I agree to write a foreword for a book about two of my least favorite things: dying, and abjuring eating and drinking? No one escapes death; I understand this incontrovertible fact. Whatever our wishes, in the face of our most determined, even desperate, efforts, the outcome is not at our discretion.

Dying is another matter. Many of us can have a say in the manner and, perhaps, the timing of our dying. How should we feel about this? In *The Myth of Sisyphus*, Albert Camus begins by naming suicide as “the one truly serious philosophical problem.” Later in that essay he offers this counsel: “It is essential to die unreconciled and not of one’s own free will” (p. 55). Camus, we should remember, was only 46 when his publisher’s car flew off an icy road in rural France in January, 1960, killing him immediately. The idea that the technologies and institutions of medicine might one day exercise undue control over the circumstances of dying was likely foreign to him.

There are some readers, I am sure, who prefer to “die unreconciled and not of one’s own free will.” But there are also many people, equally thoughtful and sincere, who embrace life as fiercely as Camus, acknowledge the inevitability of death as he also did, yet desire fervently to escape avoidable suffering and the affronts to dignity that so often accompany dying.

But giving up food and drink? My mother’s parents came to America from the Abruzzo, a region of Italy known for its natural beauty, its mountains—and, in the early twentieth century, its poverty. Whatever hardships they’d endured, by the time my father—from an impoverished Irish American family—appeared, they welcomed him warmly and did what good families do: they fed him. My father, who’d had to compete with his siblings for the often-meager offerings at the table, told us many years later that until he met my mother, he didn’t realize that food had taste. For my Italian grandparents, food was a tangible, daily expression of solidarity and love. Which makes the prospect of forgoing all eating and drinking resonantly poignant. If indeed food equals love, more or less, then surely denying someone food reveals love’s absence; so, at least, it may feel to us at first glance.

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Voluntarily Stopping Eating and Drinking: A Compassionate, Widely Available Option for Hastening Death invites the reader to think more calmly and deeply. Its attentiveness to clinical realities, law, ethics, and institutional constraints illuminate the decisions made by the multiple actors involved in each of the cases that form the connective tissue of the book. I often found myself wanting to argue with the authors (of the chapters on ethics, mostly). But at the same time, I admired their clarity and courage. Even readers who may disagree with some of their analyses will come away enlightened, their perspectives broadened.

This is an important book destined to shape practice, policy, and discourse on dying. It will be an important resource for clinicians, ethicists, lawyers, administrators, and policymakers, along with individuals and families weighing their options as life's end looms into view. *Voluntarily Stopping Eating and Drinking* is likely to shape public and private conversations about our options as death draws near.

Thomas H. Murray, PhD
President Emeritus, The Hastings Center

Preface

In the 21st century, people in the developed world are living longer. They hope that they will have a healthy longer life and then die relatively quickly and peacefully. But frequently that does not happen. While people on average are living healthy a *little* longer, they tend to live sick for a *lot* longer. And at the end of being sick before dying, they and their families are frequently faced with daunting decisions about whether to keep going with life-prolonging medical treatments or whether to try finding more meaningful and forthright ways to die more easily and quickly. To make matters even more complex, about half these patients no longer have the capacity to make decisions for themselves. So, families or clinicians must decide and act on their behalf, if the suffering associated with such situations is going to be avoided or minimized.

In this context, many people are searching for more and better options to hasten death. There are two main groups. First, there are those who are currently suffering unacceptably. Second, there are those who want to preempt the last phase of the dying process and thereby avoid potential suffering or unacceptable deterioration in their future.

Voluntarily Stopping Eating and Drinking (VSED) is a lesser known, available option for persons who are looking for an escape from these situations by hastening their death at a time of their own choosing. For some, the possibility of directing the stopping of their eating and drinking in the future may allow them to continue living without fear that they might eventually become trapped in an unacceptable condition without the potential for escape. Others who are looking for an escape *right now* might be able to initiate VSED without needing permission or assistance from others, and without having to worry about breaking the law.

In that sense, VSED is different from other “last resort” options such as Medical Aid in Dying (MAID) which is currently legal in only eleven states and the District of Columbia in the United States, and in fourteen jurisdictions elsewhere in the world. VSED is theoretically a possibility for almost anyone with decision-making capacity who has decided that continued living is no longer acceptable. Stopping eating and drinking may also

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be potentially accessible to those who have lost decision-making capacity but earlier made their preferences for this option extremely clear through a detailed advance directive.

VSED is not only more widely available but also a much more compassionate way to hasten death than is widely appreciated. Despite its wide accessibility legally, VSED is frequently portrayed as a “dismal choice” and dismissed as “starvation.”¹ This is distinctly misleading. Dying by starvation and dehydration in normal circumstances is indeed a terrible process. But for persons near the end of life who are determined to end life on their own terms, the process of dying by VSED can be relatively comfortable and peaceful, particularly if they have good palliative support. Properly pursued and supported, VSED needs to be recognized as a much more viable option than it currently is.

This book begins with an overview of VSED. The Introduction defines the process and puts it in the context of caring for seriously ill patients, including potential options for hastening death. Part I of the book (comprising the first six chapters) then focuses on VSED by people with decision-making capacity. In Chapter 1 we present four real clinical cases of patients with decision-making capacity who seriously considered and then initiated VSED, concluding each case with a brief list of its notable characteristics and issues raised.

Chapter 2 explores the clinical aspects of VSED in much more detail, including how the process played out in each of the initial four cases. A main advantage of VSED is that it gives power and control directly to the initiating person. But the process is also associated with predictable difficulties including dry mouth, thirst, eventual weakness, and sometimes confusion toward the very end. Fortunately, these challenges can be anticipated and usually managed with careful advance planning and skilled assistance from clinicians and caregivers. VSED typically lasts 10 to 14 days from initiation to death provided one is disciplined about not drinking. The initiating person is usually alert and capable of meaningful interaction with family and friends for most of the time but will usually become very weak and much less responsive toward the end. Chapter 2 gives state-of-the-art clinical instructions and

¹ For example, a *New York Times* editorial supporting the legalization of MAID refers to VSED as one of only two “dismal choices” available to those living in jurisdictions where MAID is not available. Some “manage to get a lethal dose of drugs . . . under the table Others are advised to starve themselves to death” (New York Times 2016).

practical ideas about how to implement VSED if appropriate and desired, including strategies for managing some of its predictable challenges.

Chapters 3, 4, and 5 in Part I explore the associated ethical, legal, and institutional aspects of VSED for patients with decision-making capacity, returning regularly to the practical issues raised in the initial four case presentations and in the clinical chapter. Part I closes (in Chapter 6) with a summary of “best practices, enduring challenges, and opportunities” raised by VSED when it is initiated by patients with decision-making capacity.

Part II of the book (comprising Chapters 7 to 12) has the same general structure as Part I, but it explores the more controversial option of stopping eating and drinking for persons who have lost decision-making capacity before initiating the process. In this situation, decisions about implementation must be based on the person’s previously articulated Advance Directive for Stopping Eating and Drinking (AD for SED).

Many patients who still have decision-making capacity would not want to continue living in a future of unacceptable suffering or deterioration, and for some that would include situations in which they will have lost decision-making capacity from a condition like progressive dementia. But they would also prefer not to act preemptively while they still have capacity to do so, because they are still finding their life meaningful and are not suffering in ways that are unacceptable. Can they postpone the decision to hasten death by stopping eating and drinking until their capacity is lost, but still be assured they can access this escape by empowering others to act later on their behalf?

Like Part I, Part II begins (in Chapter 7) with four cases. Each focuses on a person at a different stage of losing decision-making capacity who made it clear the future conditions in which they did not want to continue living if capacity were fully lost. Each case presentation includes “notable characteristics” and “issues raised” to be addressed in subsequent chapters.

Chapter 8 explores the clinical aspects of Stopping Eating and Drinking by Advance Directive (SED by AD). It recommends that all patients who value a hastened death by an intervention like SED by AD if they lose decision-making capacity should initiate extensive advance care planning. They should include a detailed instructional advance directive, naming and fully informing a health care proxy, and ideally even providing a videotaped advance directive statement about their preferences with regard to eating and drinking in the context of future loss of decision-making capacity. The clearer and more specific a person can be, in advance of losing decision-making

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capacity, about one's genuine wishes in this domain, the more likely it is that those preferences can be actualized in the future.

Part II explores three main options with regard to empowering surrogate decision-makers to limit future provision or withholding of food and fluids if a person loses decision-making capacity:

1. **Withhold all feeding (both self-feeding and assisted feeding).** Otherwise provide maximum comfort measures (moistening mouth, pain relief, sedation for any agitation).
2. **Withhold all assisted feeding, and facilitate only comfort oriented self-feeding.** Provide easy access to foods that the patient appears to enjoy in amounts as much or as little as the person willingly eats by his or her own hand.
3. **Provide comfort-oriented assisted feeding if needed, but only in amounts that clearly contribute to the patient's immediate comfort.**

Chapters 9, 10, and 11 explore the ethical, legal, and institutional aspects of SED by AD, as well as the less controversial option of “comfort feeding only” when it does and does not include direct caregiver assistance. Part II closes (in Chapter 12) with a summary of “best practices, enduring challenges, and opportunities” posed by SED by AD, or receiving comfort-oriented feeding only in one of its two forms presented above, once decision-making capacity is lost.

Appendices available in the final part of this book are divided into six general categories, most of which will include citations or easily accessible links to materials of interest:

- Appendix A: Recommended Elements of an Advance Directive for Stopping Eating and Drinking (AD for SED)
- Appendix B: Sample Advance Directives for Stopping Eating and Drinking
- Appendix C: Cause of Death on Death Certificates with VSED or SED by AD
- Appendix D: Position Statements and Clinical Guidance
- Appendix E: Personal Narratives
- Appendix F: Glossary

We anticipate this book will be useful to a wide range of readers, including but not limited to:

- Patients and family members looking to explore the full range of end-of-life options for themselves or for someone they love. This might be for possible use in their current situation, or in the future with particular emphasis on VSED if they have decision-making capacity and on SED by AD if decision-making capacity is currently or may soon be lost.
- Clinicians of all kinds (doctors, nurses, nurse practitioners, physician assistants, social workers, nutritionists, chaplains) who care for seriously ill patients and want to be aware of all possible options for responding to unacceptable suffering or deterioration.
- Ethicists, lawyers, theologians, scholars, clinicians, patients, and family members interested in exploring the possibility of stopping eating and drinking at the end of life in a multidimensional way.
- Anyone, mortal as we all are, who wants to think through a wide range of approaches to the end of one's own life, or the end of their loved ones' lives.

We hope you enjoy the book and are stimulated and challenged by it. VSED and SED by AD are not simple options. But they sometimes provide the most viable approach available to remedy what is or might become an untenable situation for a given individual. They are sometimes critically important pieces of the challenging puzzle of finding meaningful, achievable options for hastening death in response to unacceptable current or future conditions.

Reference

New York Times. 2016. "Aid in Dying Movement Advances" (editorial). *New York Times*, October 10, 2016, A20.



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Many people and organizations have been instrumental in inspiring and supporting us in writing and editing this book. We especially thank all the contributing chapter and case authors and co-authors. They have provided material and perspective that the four of us could not, and they carefully attended to developing their contributions specifically for this book.

We are indebted to those who hosted and sponsored the conference, “Hastening Death by Voluntarily Stopping Eating and Drinking: Clinical, Legal, Ethical, Religious, and Family Perspectives,” in October of 2016 at Seattle University School of Law. It was there that the four of us first all met. The conference itself would likely not have happened had concerted interest in VSED not been shown several years earlier by Robb Miller, then Executive Director of Compassion and Choices, Washington (now End of Life Washington); conversations with him and others, including Erin Mae Glass and Lisa Brodoff, eventually led to the planning of a conference hosted by Seattle University School of Law. We are indebted to Dean Annette Clarke and others there for their support.

The four of us have gained greatly from working with each other. The collaboration required for a volume as integrated as this one is extensive and demanding. Each of us is grateful for all that the others contributed and for making the whole experience enjoyable.

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Timothy E. Quill:

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best possible care for seriously ill patients and their families. My interdisciplinary palliative care teammates, including nursing aides, social workers, nurses, nurse practitioners, physicians, administrators, and researchers, bring this comprehensive practice to the bedside every day. Together we have become so much more effective than we could be as individuals. Finally, to my wife Penny and daughters Carrie, Megan, and Crissy for their ongoing support and love, and for their outstanding work as clinicians caring for seriously ill patients and as advocates for more comprehensive care for all those in need.

Paul T. Menzel:

My fascination with many of the questions that motivate this book originated in teaching biomedical ethics over many decades at Pacific Lutheran University—particularly some of the writings of Norman L. Cantor, John Robertson and Rebecca Dresser, and Nancy K. Rhoden. My first close acquaintance with actual VSED was its unflinching preemptive use by Jephtha Carrell, as conveyed to me in subsequent conversations with his wife Demaris. Colette Chandler-Cramer extended and sharpened my understanding with her clinical experience, providing invaluable material for my first publication on using advance directives to withhold food and fluid by mouth, co-authored with her. Bonnie Steinbock enabled me to see a critically important approach to handling the “then-self vs. now-self” problem created when previous directives and the current apparent wishes of a person in advancing dementia conflict. And Dena Davis, my co-author of Chapter 9, has greatly expanded my understanding of the complexity of using ADs to halt oral feeding in severe dementia.

Thaddeus M. Pope:

Judith Schwarz and Stanley Terman have opened ivory tower windows, pointed me toward the trenches, and directed my scholarly attention to practical issues that are materially relevant for seriously ill individuals. I am grateful for the 2009–2010 partnership with Lindsey Anderson (Imbrogno) to produce our first major VSED article. By inviting me to speak with their members, Compassion & Choices, Final Exit Network, and other organizations gave me hundreds of Socratic questioners who helped refine my thinking. But I most appreciate individuals like Phyllis Shacter who have shared how my VSED scholarship helped their family members. I hope that this book guides and supports many more.

ACKNOWLEDGMENTS xix

Judith K. Schwarz:

I am grateful to the many patients and their family members I have been privileged to support over the years, some of whose experiences are included in this volume. I continue to learn so much from them, and thank them for their willingness to share their stories with others who benefited from hearing about their experiences. I greatly value the relationships I have had with skilled hospice and palliative care clinicians over the years, the depths of their knowledge, and their willingness to share their expertise with me. My colleagues at End of Life Choices New York—Ayana Woods, David Leven, and Lillian Mehran—have provided much support and collaboration. They were instrumental in helping to develop our “dementia directive,” one of the first advance directives to stop eating and drinking in the country, downloaded from our website by hundreds of people. Each brings an important contribution to our efforts to expand choice, improve end-of-life care, and gain access to medical aid in dying in New York State.



Contributors

Editors

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terminal illnesses and their families about end-of-life options. She publishes regularly in nursing and palliative care journals. For years her work has focused on voluntarily stopping eating and drinking as an option to achieve a peaceful, patient-controlled death. More recently she began responding to requests for assistance from patients diagnosed with an early stage of dementia. With colleagues in other disciplines she developed the End of Life Choices New York “Dementia Directive” that has been completed by hundreds of individuals.

Other Chapter Authors

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Ty Markham is a long-time educator and licensed clinical psychologist. A passionate environmentalist, she founded and chaired a nonprofit environmental organization in Utah for many years. She continues as a board member and is also serving on the board of another nonprofit organization, “Scenic Utah.” Now semi-retired, Ty runs a seasonal wellness retreat/bed & breakfast business near one of Utah’s red rock national parks, where her favorite pastime is hiking with family and friends.

Stanley A. Terman, PhD, MD, a bioethicist and board-certified psychiatrist in Sausalito, CA, introduced general readers to VSED in 2007 with *The BEST WAY to Say Goodbye: A Legal Peaceful Choice at the End of Life*. He has continued to dedicate his career to help those who fear future prolonged dying in advanced dementia and loved ones searching for ways to help their relatives who have already reached advanced dementia. His two protocols, “Strategic Advance Care Planning” and “NOW Care Planning,” use My Way Cards®—a patient decision aid that illustrates and describes about 50 conditions—that asks, “Would this condition cause you enough suffering to want to die?” Dr. Terman is currently writing on how some flaws in current advance directives can be overcome by using the criterion “severe enough suffering.”

