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Navigating Communication with Seriously Ill Patients

Second Edition

When clinicians communicate effectively, patients retain more information, have higher trust, and a better quality of life. Such a patient-centered approach is the cornerstone of clinical care, and this book is an essential how-to guide on improving these skills.

Grounded in innovative and evidence-based methodology, perfected through over 20 years of teaching in the VitalTalk training program, content includes foundational communication skills, how to help patients plan for the future, what to do when you are really stuck, and strategies to work through conflicts with colleagues. In this updated edition, emphasis is placed on the roles privilege, race, and power play in the medical encounter, and new tools are provided to help clinicians navigate this landscape with greater self-awareness and sensitivity.

This practical guide is filled with skills and roadmaps, demonstrating how to be clearer when sharing information, more competent at understanding patient concerns, and more effective when making recommendations.

Robert M. Arnold, MD, FACP, FAAHPM, is Distinguished Service Professor of Medicine in the Division of General Internal Medicine and the Center for Bioethics and Health Law at the Icahn School of Medicine at Mount Sinai. He was the Past President of the American Society of Bioethics and Humanities (ASBH) as well as the American Academy of Hospice and Palliative Medicine (AAHPM). He has mentored both investigators and educators, and helped start VitalTalk, a nonprofit organization whose aim is to ensure that every seriously ill patient has clinicians who can talk about what matters most.

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Navigating Communication with Seriously Ill Patients

Balancing Honesty with Empathy
and Hope

Second Edition

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978-1-108-92585-3 — Navigating Communication with Seriously Ill Patients

Robert M. Arnold , Anthony L. Back , Elise C. Carey , James A. Tulsky , Gordon J. Wood , Holly B.

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equipment that they plan to use.

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For Zeke Tulsky (1997–2023), who lived for human connection and instinctively understood the power of empathy to heal and to comfort. Like Zeke, in our work with patients may we always find the goodness in each person and the value of hearing their story.

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“This book helps us to step away from our checklists and learn how to build genuine human connections with the people we are caring for.”

Diane E. Meier, MD. Center To Advance Palliative Care. Professor,
Department of Geriatrics and Palliative Medicine, Icahn School of
Medicine at Mount Sinai

“Written by world-renowned educators, this expansive new edition will help clinicians not only understand the structure of compassionate serious illness communication but also the rationale behind it.”

Vicki Jackson, MD, MPH. Blum Family Endowed Chair in Palliative Care.
Chief, Division of Palliative Care and Geriatrics, Massachusetts General
Hospital. Co-Director, Harvard Medical School Center for Palliative Care.
Professor of Medicine, Harvard Medical School

“Every clinician committed to fostering meaningful connections with their patients and their families needs this book on their desk.”

R. Sean Morrison, MD. Ellen and Howard C. Katz Professor and Chair.
Brookdale Department of Geriatrics and Palliative Medicine.

“The updated *Navigating Communication with Seriously Ill Patients* presents foundational communication strategies along the trajectory of serious illness, now with critical attention to inclusiveness. It is an essential text for all who care for seriously ill patients of any age and life stage and their families.”

Joanne Wolfe, MD MPH. Pediatric Palliative Care Physician. Chair,
Department of Pediatrics, Massachusetts General Hospital. Chair,
Department of Pediatrics, Brigham and Women’s Hospital.
Professor of Pediatrics, Harvard Medical School.

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Preface

In 2009, when Tony, Bob, and James wrote the first edition of this book, we drew on a decade of experience studying and teaching communication, primarily within oncology. In the 14 years since, as medicine and the world have changed enormously, so has our approach to communication skills training. We've moved beyond only cancer care (Oncotalk) and created tailored courses such as Geritalk, Nephrotalk, and Cardiotalk to accommodate the full spectrum of serious illness. We've recognized that good communication depends on an interdisciplinary team and have sought to develop a far less physician-centered approach. We've learned from a now-robust literature on serious illness communication and incorporated wisdom from around the world on how to communicate best with patients and families. We've been profoundly affected by the long-needed awakening to the central role race and culture play in our society, including the delivery of health care, and have thought deeply about issues such as power and privilege in serious illness communication. And, perhaps most importantly, we created VitalTalk (in 2012) as a nonprofit vehicle to broadly disseminate communication skills teaching at a much larger scale. In doing so, we have trained more than 1,000 faculties who have, in turn, touched tens of thousands of learners around the globe. With the creation of digital learning tools and new pedagogical models we hope to reach countless more. In the process, we've also been deeply gratified by the power of the VitalTalk community that has arisen to support this work. The project has grown well beyond the three founders, and this edition was written together with Elise, Gordon, and Holly, who have been partners in our work since the early days of VitalTalk.

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Preface

What Has Changed, and What Has Stayed the Same?

The last three years have brought a global pandemic, a huge shift toward care via telehealth, and, of course, a reckoning about health equity. The daily emails we receive from our health systems look radically different than just a few short years ago. The need for high-quality communication has become an even greater priority for many health systems as they see the kinds of skills we offer as part of the solution to their problems. During the height of the COVID-19 pandemic clinicians struggled to communicate empathically and effectively to patients making profound treatment choices, sometimes in the setting of true scarcity, and families unable to be with their desperately ill loved ones. And, as telehealth has boomed, so has the need to learn how to transmit empathy through a screen. Also, while race and culture have always played a role in health-care communication, many of us are now far more aware of the benefits and damage we can wield with our words.

VitalTalk has sought to respond to each of these challenges. Within weeks of the pandemic reaching our shores we produced the COVID Ready Communication Playbook to help clinicians with these difficult conversations. To our amazement, it was rapidly translated by our community into 25 languages. We adapted our face-to-face courses to be taught over a virtual platform and, in doing so, found ourselves teaching communication skills for virtual visits. We rewrote our cases and broadened our simulated patient actor pool to better represent the wide diversity of patients for whom we care. And we introduced anti-racist concepts into our mobile courses and new talking maps. Finally, we are excited to have just released a new mobile course entitled, “Building Connection: Practical Skills to Promote Racial Equity in Healthcare Communication.”

We have emphasized this work too little in the past and we hope that our current efforts can begin to fill some of the gaps that currently exist in communication skills training. We are also aware that paying close attention to difference has always been at the heart of what we do at VitalTalk. The communication tools we promote are meant to create an

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environment in which every patient's needs are addressed and where care is driven by what matters most to the individual patient. When one patient's needs are not met, we all lose out.

So, over the past 14 years much has changed ... and much has remained the same. Clinicians still care for patients confronting dreadful diagnoses that will change the course of their lives. They must still help them navigate these illnesses, cope with the outcomes, and, too frequently, make heart-wrenching decisions about treatment. And, too often, they still fall into familiar traps that lead to circular conversations, dissatisfied patients, and frustrated clinicians. The VitalTalk approach is about combining one's authentic self with evidence-based global communication skills and situation-specific talking maps to break these cycles and thereby to nurture meaningful conversations and healthy relationships. We also hope these tools will help with communication across differences, and when we see these opportunities, this book will point them out.

Who Is This Book For?

This book is for all clinicians who want to communicate better with seriously ill patients and their family members. We wrote the first edition with physicians in mind and yet some of our most positive feedback came from nurses, social workers, and others who found that these skills deeply resonated for them as well. Therefore, we enter this revision even more cognizant that patients receive the best care from an interdisciplinary team. Although some of the tools we discuss are most directly relevant to prescribing clinicians (typically Medical Doctors (MDs), Nurse Practitioners (NPs), and Physician Assistants (PAs)) who are the ones to usually guide patients through medical decision-making in advanced illness, everyone who sees patients should benefit from approaches that help defuse conflict, support patients, and learn from patients what matters most.

Since the first edition was published, many more readers will have had some communication training, and many more have been formally

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trained in palliative care. Therefore, for some, foundational concepts presented in this book, such as delivering serious news, may ring familiar. Others may be familiar with a great deal of the teaching in these pages. Recognizing that everyone has their learning edge, we've tried to shape this book so that all readers can find valuable take-home points, whether it is a refresher, engaging with an entirely new concept, or simply putting names to skills you already use in practice. By being better able to describe and deconstruct your own communication and that of your patients, families, and colleagues, we hope to help you enhance your own skills and teach others. And by doing so, we hope you can find deeper meaning in your work and even protect yourself against the burnout that comes from feeling powerless in the face of suffering.

What's in This Book?

In this book, we describe a variety of communication tools and “roadmaps” that you can use to find your way through difficult conversations. In our years of teaching learners of all backgrounds, we have found that many have either not seen a really good conversation, or they have not been able to identify what made the conversation work. Expert clinicians in action with patients can be so fluid, so seamless, so responsive, that they make great communication look easy. In fact, these master clinicians are collecting lots of data from the patients, drawing from a large repertoire of skills, and constantly readjusting their gestures and words. This master clinician could be you.

How Will This Book Help Me?

Adopting in your own practice the tools and roadmaps we've laid out will make you a better communicator. What do we mean by better? You'll be clearer about where your patients stand, more skillful at understanding their concerns, and more effective when you make recommendations. You'll be the kind of clinician that people want for

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their family and friends. And you'll develop a deeper sense of what matters to you in your clinical work because you will be talking to patients about what really matters to them.

However, a word of caution. The roadmaps are guides, not rules that must be followed. As you get more comfortable with serious illness communication, it is critical to integrate them into your personality so the result is genuine.

How Did We Develop This Book?

For over 25 years we have been teaching communication courses to students, trainees, and staff clinicians in what has come to be known as the VitalTalk method. Several of us have also been deeply involved in studying communication, audio-recording thousands of conversations, and observing what happens in actual practice. We have also learned from other investigators and master teachers. In fact, some of our greatest influences have come from unexpected places, including athletic coaches and elementary school educators. We've come to appreciate where clinicians typically get stuck, and the power of identifying key skills, providing roadmaps for conversations, and having people practice. We have been amazed at how learning a few key tools can change the way someone communicates. Listening to them talk about difficult topics with patients before and after training has been like observing completely different clinicians. Learners who have attended our courses tell us that these communication skills have changed how they approach patients, how they deal with emotional moments, and, most important, how they feel about their work.

Why Did We Write This Book?

Difficult patient encounters frustrate many of us daily. When we face demanding – sometimes tragic – situations, using communication skills that are “okay” is like riding a bike with only three gears – there are

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some hills we just won't be able to climb. For dealing with life-threatening illness, skills that many consider adequate are just not good enough, and both patients and clinicians are paying the price. To make matters worse, research shows that clinicians are unable to accurately evaluate their own communication skills. And even those who are aware of their shortcomings tell us they don't have confidence that they can change. In this book, we want to show you that change is possible, and you can become a better communicator. First, we describe what expert clinicians actually do when they talk to patients and their families. Second, we show what you can do to improve your practice. We highlight specific skills to emulate and offer suggestions for how to practice these behaviors. We want to raise the bar on communication skills. We want to change your idea of what really good communication looks like.

Where possible, we have grounded these recommendations in the growing literature on communication. Yet we've consciously distilled the communication tools and roadmaps into a reader-friendly format. This is not an academic review of the literature that stresses what we don't know. Our goal is practical – to help you communicate better.

How Is the Book Organized?

After discussing what it takes to become a better communicator (Chapter 1) and outlining foundational communication skills (Chapter 2), we organized the book in a progression that parallels how clinicians frequently work with seriously ill patients and follows them through their illness trajectory, including talking about serious news (Chapter 3), discussing prognosis (Chapter 4), planning for the future (Chapter 5), discussing in-the-moment treatment decisions (Chapter 6), managing life between the big events (Chapter 7), discussing goals of late-stage care (Chapter 8), conducting a family conference (Chapter 9), dealing with conflicts (Chapter 10), and talking about dying (Chapter 13). We've also included tips on talking with colleagues (Chapter 11) and what to do when you're really stuck (Chapter 12).

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The last chapter (Chapter 14) will help you know what to expect as your skills improve, describes what getting better feels like, and offers advice on how to continue to cultivate your skills. In this revision, we have also introduced our awareness of the roles privilege, race, and power play in the medical encounter and offer some tools that we hope will help clinicians navigate this landscape with greater self-awareness and sensitivity. Throughout the text, we include snippets of real conversations, slightly disguised, from our own practice and from the courses we've taught. Our goal throughout is to provide you actual words to use.

Finally, we congratulate you for wanting to improve your skills. The first step in the journey is the hardest one. You have made that commitment by picking up this book.

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Acknowledgments

This book rests on the shoulders of prior leaders in palliative care and clinician–patient communication. We want to particularly acknowledge Bernard Lo, Richard Frankel, Phyllis Butow, Susan Block, Mike Rabow, Timothy Quill, and David Weissman, from whom we have learned so much about communicating with seriously ill patients. Kelly Edwards had a crucial role in developing our pedagogy, and Walter Baile helped Bob, James, and Tony start VitalTalk.

The first edition of the book was written by Tony, Bob, and James. We feel blessed to have worked together for over 20 years in developing the book’s core concepts. It has been a wonderful partnership in which the sum is better than the parts. Our countless discussions, while often heated, focused on the work and made our thinking better. We cannot imagine better collaborators and our shared effort has been a crown jewel of our academic lives. Having Elise, Gordon, and Holly join us in the second edition has brought both fresh ideas and delight at the work’s generative power.

This book also benefits from the wisdom and collective experience of our VitalTalk family. These talented clinicians, who inspire awe as they bring their whole selves to this difficult work, have helped us refine our ideas and given us feedback about what works (and does not) in practice. Without the VitalTalk staff, no courses would have ever materialized, and we would never have been able to write this book. Their dedication and passion for the mission have made our jobs easier and their insights have continually improved our teaching. Special kudos go to Jennie Dulas and Lynsey Seabrook – previous and current VitalTalk leaders, and our very first staff persons – Jackie van Allen, Rose Schulte, and Lisa Barrett. We would like to thank Angie Jabine for her careful editorial review and Jessica Papworth at Cambridge University Press for her patience through many delays.

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Writing books require the support of both one's work and personal families. Bob wishes to acknowledge Wishwa Kapoor, Alan Meisel, and Missy McNeil for their support and encouragement of his scholarly career. Colleagues in the Section of Palliative Care and Medical Ethics at the University of Pittsburgh, particularly Julie Childers, Rene Claxton, and Jane Schell, helped him refine his thinking on many of the concepts in the book and become a better clinician. Colleagues such as Doug White and Gretchen Schwarze helped him understand emotions, shared decision-making, and bioethics; Doug Lemov and the Masters of Science in Medical Education focused his learning on how to teach. Finally, his children, Brandon and Kirsten, dealt with his absences and distractibility and still became amazing adults.

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Elise is grateful to her whole VitalTalk family for the continuous cycle of mentorship, learning, collaboration, and friendship that makes the VitalTalk community what it is. Particular thanks go to the coauthors of this book, along with Kelly Edwards, Lynn O'Neill, Steve Berns, Jillian Gustin, Justin Sanders, Lynn Aliya, and Jennie Dulas. She also would like to thank mentors, friends, and colleagues who have influenced her path to and in this work – Mike Rabow, James Hallenbeck, Seth

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Acknowledgments

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James grew up hearing his father's dinnertime stories about patients' lives and from them learned that sacred moments emerge when we listen deeply. He is grateful to both his parents for the values by which he strives to live. As a resident and fellow, he learned from too many young men with HIV/AIDS how to sit quietly with loss, and Bernie Lo and Margaret Chesney set him on the path to communication research. At Duke, he is grateful to Harvey Cohen for support and guidance, and to amazing research collaborators Kathryn Pollak and Karen Steinhauser, who gave interdisciplinary insight and methodological rigor, and made it all fun. For the past eight years, Dana-Farber Cancer Institute has offered an enormously generous and collegial environment in which to set his ideas into practice. Throughout, James' sons Noah and Zeke have kept him humble and laughing. And this book, as well as all that came before it, would never have happened without the love, encouragement, and nourishment from his wife Ilana Saraf.

Gordon is forever grateful to Stephen McPhee, Joshua Hauser, Michael Preodor, his coauthors, and all the VitalTalk faculty and staff for their friendship, mentorship, and partnership over the years. He would also like to thank Diane Wayne, Marianne Green, and the Department of Medical Education at Northwestern University for supporting this work. He would like to express special gratitude to his Northwestern teaching team, including Melanie Smith, Laurie Aluce, Eytan Szmuilowicz, and, in particular, Julia Vermylen, who codirects the program and has been an amazing partner since the very first course. Finally, none of this would be possible without the love and support of his wife, Czarina, and daughters, Eva and Penelope.

In addition to her coauthors and Kelly Edwards, who have indelibly changed who she is as a teacher and human, Holly wants to express her love and gratitude for Laurel Herbst, Charles von Gunten, Frank Ferris, Suzana Makowski, and Gary Buckholz. Among so many incredible

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