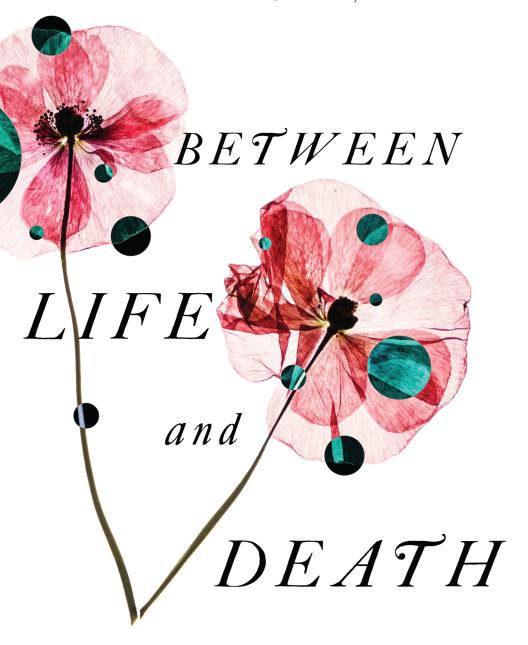
KATHRYN BUTLER, MD



A GOSPEL-CENTERED GUIDE TO

END-OF-LIFE MEDICAL CARE

"If I face a critical, life-threatening illness, I will want an experienced clinician who is well versed in the most recent medical studies, who is kind and compassionate, and who respects my faith in Jesus. I will want someone who can coach me on the right questions to ask my medical team and help me make practical decisions. In short, I will want Dr. Butler. She will guide me to come to the end of life in a way that commends the gospel and brings glory to God. If she is not available, I will want to reread this book."

John Dunlop, MD, Internal Medicine Doctor, Geriatrics, Yale School of Medicine; author, Finishing Well to the Glory of God

"Dr. Butler has done a masterful job in giving us a clear and comprehensive guide to navigating the difficult and complex waters of end-of-life care. Although *Between Life and Death* is written with patients and their families in mind, this book is a welcome and valuable resource for guiding Christian healthcare students through these challenging issues, in addition to providing the necessary biblical grounding and foundations."

Bill Reichart, Vice President of Campus and Community Ministries, Christian Medical & Dental Associations

"It is inevitable that at some point, each one of us will face difficult or even heartbreaking medical decisions. We may have to make decisions related to our own care or, even tougher, the care of someone we love. To prepare to make such decisions in a distinctly Christian way, you won't do better than to read *Between Life and Death*. It will inform, encourage, strengthen, and equip you to act in ways that honor our humanity while bringing glory to our God."

Tim Challies, blogger, Challies.com

"Some of our weightiest decisions wait until the end. When death draws close, what medical treatments will we embrace or reject? Even Jesus-loving Christians struggle to know how to answer these questions, and we need a seasoned doctor to educate us on the options and their pros and cons. Dr. Butler educates the mind, answers the questions, and takes the imagination on an unforgettable ride, made vivid with the descriptive prose only a gifted writer and experienced trauma surgeon could offer us. This remarkable, Christ-centered book is loaded with reality checks and soul checks, and it will serve Christians and pastors for many years to come as they make these final decisions out of faith and not fear."

Tony Reinke, journalist; author, 12 Ways Your Phone Is Changing You

"Dr. Butler has written a remarkable, unique, and timely book. Combining her medical expertise with biblical compassion and moral evaluation, she lucidly explains what we need to know about life-and-death medical situations. She does not offer vague advice, but grounds her counsel in medical facts, legal realities, spiritual principles, and real-life illustrations."

**Douglas Groothuis,** Professor of Philosophy, Denver Seminary; author, Walking Through Twilight: A Wife's Illness—A Philosopher's Lament

"This is a marvelous book. Dr. Butler, a Christian intensive-care specialist, has woven together a clear explanation of detailed and complex medical issues with an intimate knowledge of Scripture to bring forth a book of immense value for patients, loved ones, and clergy as they face the seemingly insurmountable questions of ICU and end-of-life care. It is well written, illustrated with real-life dilemmas, and oozing with compassion, both her own and that of our Savior."

Robert D. Orr, MD, CM, clinical ethicist; author, Medical Ethics and the Faith Factor

"As a pastor's wife, a parent, a daughter, a granddaughter, a friend, a neighbor, and a member of the church, the issues in this book regularly loom over my life and the lives of those around me. How do we best love the sick and dving? How do we know when to pursue medical interventions and when to allow our loved ones to, as Dr. Butler puts it, 'relax into the embrace of Jesus'? These are complex questions without easy answers. But Between Life and Death provides a helpful framework of biblical wisdom to illuminate otherwise murky scenarios. Dr. Butler explains the dense medical terminology that can baffle already-overwhelmed caregivers. And, with unflinching (but not unsympathetic) clarity, she brings us to the bedsides of the suffering and tells us what it is like to experience CPR, a ventilator, or artificially administered nutrition. The actual impact and likely outcome of such treatments is far from the glamorous glow of TV medical dramas, but we need to know the stark reality in order to make God-honoring and merciful choices for ourselves and our loved ones. Thankfully, this book also has an expiration date. One day, gathered in the near presence of Christ, we will no longer need to know how to make decisions about death. But in the meantime, I'm glad to have this book on my shelf."

Megan Hill, author, *Praying Together* and *Contentment*; Editor, The Gospel Coalition

"For all the blessings of modern critical care, we have not sufficiently reckoned with its dark underside: what happens when medical technology and intervention do not preserve life but prolong death? With her keen medical training and experience on display, Dr. Kathryn Butler parts the curtain on an array of life-threatening situations that might befall us or those we love. In Between Life and Death, Dr. Butler points us to the hope of the gospel, showing what Christian discipleship might look like in some of the most agonizing moments in life. May this book serve as a useful guide and conversation starter as we prepare for death and gaze on Christ."

Ivan Mesa, Books Editor, The Gospel Coalition

"Dr. Kathryn Butler *has ta*ken her Christ-centered life as well as her experiences as a trauma surgeon to give the reader ways to assess end-of-life decisions to the glory of God in Christ Jesus. Her book emphasizes that we live by the grace of God in Christ Jesus. Dr. Butler has included numerous Bible references that are extremely helpful within the context of living and dying in Jesus Christ. It is a must-read for all Christians, church leaders, and medical professionals who are living through end-of-life dilemmas."

Bob Weise, Professor Emeritus of Practical Theology, Concordia Seminary

# BETWEEN LIFE and DEATH

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# A GOSPEL-CENTERED GUIDE TO END-OF-LIFE MEDICAL CARE

KATHRYN BUTLER, MD



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# То

My patients, whose courage inspired this book. And to Scott, Jack, and Christie, who daily remind me of God's love.

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I am sure that neither death nor life, nor angels nor rulers, nor things present nor things to come, nor powers, nor height nor depth, nor anything else in all creation, will be able to separate us from the love of God in Christ Jesus our Lord.

-Romans 8:38-39

# INTRODUCTION

Their nightmare of blood transfusions and emergency surgeries receded into memory with a whisper.

As the respiratory therapist removed the tube tethering him to the ventilator, he sputtered, coughed, and squeezed his eyes shut. Then, with an oxygen mask misting his face, his eyes locked with his wife's. For the first time in two weeks, he spoke, his hoarse voice barely audible: "Hi, Hun."

"We've missed you," she answered. Tears welled in her eyes, and her limbs relaxed, like taut petals unfurling. In that moment, the burden of the car accident, and the havoc that had seized them for so many days, seemed to slip like silk from her shoulders.

The nurses and I beamed. Stories like this had drawn us to critical care. After long nights standing vigil over him, turning dials, adjusting medications, and stilling our frantic hearts, his injuries—his shattered liver, his lungs foaming with blood—no longer threatened him. The laboratory results and the ventilator settings no longer dictated his days. God had reunited husband and wife with a draught of air.

While the nurses still reveled in his recovery, I walked into an adjacent room to check on another patient. My joy ebbed as I stepped through the doorway and laid eyes upon the elderly gentleman who withered into his mattress. He relied upon the same battery of machines that had rescued our car accident survivor, yet

his illness had assumed a starkly different trajectory. A massive stroke had paralyzed him and obliterated his capacity for language. Jaundice yellowed his skin to the color of turmeric. Bruises mottled his arms as blood leeched into his tissues. Although a formidable array of lines and tubes pumped and churned, his organ function dwindled. He was dying.

As I stood at the doorway, his wife sat beside him with her gaze distant and her hands limp in her lap. We had already spent hours poring over numbers and statistics. We had discussed prognosis, outlook, disease processes, and research. Yet during those long hours, I had failed to address the anguish twisting in her heart.

"Do I have any right to make decisions about his living or dying?" she would ask, as my team and I inquired about whether to continue life support. "Isn't that God's place, not mine? I don't think [my husband] would want any of this, but I don't know what's right." She would search our faces for the reassurance she lacked, and when we offered none, she would place a hand over his to stroke the contours, once so familiar, that disease had bloated beyond recognition.

As I stood in the doorway this time, she did not raise her eyes to greet me. In the dim light, I barely discerned the silvery lines staining her cheeks. She had been crying for a while. "He's the one who usually helps me with hard things like this," she said, with her gaze still fixed on the past. "I miss being able to talk to him. I feel like I'm the one dying." Finally she looked at me, her expression weary and pleading. "I wish God would just tell me what to do."

In the right circumstances, modern critical care saves lives. The moments when I have lifted my most raw and heartfelt praise to the Lord have occurred within the walls of the intensive care unit, when I have witnessed his grace and mercy made manifest in the recovery of a child battling a widespread infection, a man fight-

ing for his life after a motorcycle crash, or a woman whose heart strains in the throes of a heart attack.

Yet medical technology harbors a dark side. When an illness cannot be cured, aggressive interventions prolong dying, incur suffering, and rob us of our ability to speak with loved ones and with God in our final days. Ventilators steal both voice and consciousness. Resuscitation looks a lot like assault. In the ICU we often awake in panic and find ourselves physically strapped to a foreign bed, deprived of the familiarity and comfort of home. We clamber for air, only to find we have no freedom and no voice.

When our critically ill loved ones cannot speak to us, we wrestle with impossible decisions of whether to press on or to withhold treatment, all while we yearn to hear a beloved voice again. Like the wife holding my dying patient's hand, such dilemmas thrust us into grief, doubt, fear, anger, and even guilt as we struggle to reconcile a web of hospital instruments with a mother's voice, a father's laughter, or a child's smile. While we wrestle, concerns about faith also haunt us. Death is a profoundly spiritual event that rips from us the people we most cherish and pitches us into doubt about suffering, mercy, and the God whom we serve. What is God's will? we ask. Why is God allowing my loved one to suffer? What does the Bible allow in this scenario? Such questions tap into our deepest anguish, a pain that echoes from our origins as image bearers torn from God. Death is the wages of our fallenness, and the final enemy (Rom. 6:23; 1 Cor. 15:26). Even Christ wept in the face of death (John 11:35).

Yet when they deliver devastating news, too often physicians—and I include myself among the culpable—ignore these concerns and suggest chaplaincy services as a conciliatory afterthought. We focus solely on monitors and machines, and, in so doing, we transform death from a process directed heavenward to one steeped in nomenclature and obscurity. Percentages soothe little when we pine for hope. Medical terms offer no solace when the soul thirsts for God (Ps. 42:1–2). When it so heaps decisions of life and death

upon us without a grounding in faith and Scripture, medicine casts us adrift, rudderless. We stumble forward under duress, without understanding how the lines, tubes, and numbers equate with the truth that "death has been swallowed up in victory" through Christ (1 Cor. 15:54).

The idea for this book arose in my heart during my ten years caring for patients in the intensive care unit (ICU), first during my surgical and critical care training and then as a trauma surgeon who worked extensively in the surgical ICU. Over the course of that decade, I had the privilege of partnering with people during their most vulnerable moments, and I loathed the disconnect between the technical details that I laid out and the pain tearing them apart. As I would lean forward in my white coat to inquire about resuscitation and feeding tubes, the weight of unvoiced questions bore down upon us—questions of God's authority, of his goodness, of sanctity of life, and of suffering. These questions sprang from concerns fundamental to our Christian faith, but they hid beneath the trappings and decorum of a secular medical system.

To honor God in the bleak setting of the ICU, we must clarify the expanse between life and death that our medical advances have blurred. The shift of dying from the home to the hospital challenges us to acknowledge the capabilities and limitations of the technology upon which we lean, and to embrace it in a fashion that keeps the gospel in focus. Compassionate, gospel-centered guidance in end-of-life care requires a consideration of medical technology through the lens of heaven. We must unravel the jargon and the statistics and appraise them against the clarifying light of the Word.

When I speak of "life-prolonging," "life-sustaining," or "organ-supporting" technology, I refer to the array of medical interventions that augment or replace failing organ systems, e.g., ventilators for failing lungs, and dialysis for failing kidneys. Doctors usually implement such measures in emergency or ICU settings, when organ failure is life threatening. The introductory

chapters of this book provide a framework for understanding such treatment in broad brushstrokes, coupled with a discussion of the biblical principles that undergird Christian medical ethics. Thereafter, chapters focus on specific categories of life-sustaining technology. These discussions revolve around individual patient encounters and include in layman's terms candid explanations of the interventions, their limitations, and their curative potential.

I have changed identifying details, including gender and diagnosis, to protect the privacy of the patients and families who inspired this book. Additionally, in some places I have combined narratives into composite accounts to more effectively highlight key issues. Throughout, however, I have endeavored to preserve the rawness of the struggle that patients and families face as they navigate end-of-life dilemmas. In particular, the conversations are accurate, taken in many cases from my own notes over the years of encounters I dared not forget.

My hope is that through this book, Christian believers grappling with decisions about life-prolonging measures can confront their situation with peace and discernment. Although clergy and healthcare professionals will find Between Life and Death useful, I wrote it for patients and their loved ones as they face the unthinkable. If you are facing terminal illness or discussing endof-life wishes with a physician, I recommend reading this book in its entirety. On the other hand, if the tempest of critical illness pressures you into urgent decision making, with little time to read and digest, I suggest reading the chapters "Framing the Issue" and "Wisdom Begins with the Word," and then referencing the sections pertaining to your specific situation. "Advance Care Planning" and "Being a Voice" will offer guidance in making decisions for yourself or your loved ones. Key points at the end of each chapter provide quick reference, and relevant resources, including a sample advance directive and suggested reading, appear in the appendices. Throughout, I have endeavored to write in plain language; however, I have included medical terminology in parentheses throughout the book, and definitions of these terms appear in the glossary.

I have no intention of dictating how to proceed clinically in every case. Any medical decisions should occur on an individual basis, in collaboration with a trusted doctor and with your unique attributes, values, and circumstances central to the discussion. Rather, I seek to inform, to decode the jargon, and to provide a biblical framework for key issues you may encounter in an ICU setting. I hope to provide clarity and solace to the son at the bed-side, the grandmother weighing her options, and the patient whose life flickers and wanes before the life to come.

I never trained at a seminary. I write as a follower of Christ and a specialist in critical care who, after becoming a believer during her ICU training, found herself counseling patients and families through heart-wrenching dilemmas on a near-daily basis, and who found dialogue about medical choices in the context of Christian values glaringly absent. Mentors among pastors and ethicists kindly guided me in the writing of this book, and I am sincerely grateful for their insights.

As we delve into a shadowy realm, I pray for those of you struggling with the heart-wrenching dilemmas touched upon in these pages. I pray that whatever the outcome, the Lord may grant you strength and peace, even in the grim hours when life dwindles. In end-of-life care, the best answers are not about right or wrong but about God's grace, manifest in Christ (John 3:16). May we rest in the assurance that however total our heartbreak, and however devastating the path before us, God has triumphed over sin, his love for us surpasses understanding, and this broken world is not the end. As Paul writes, "Neither death nor life, nor angels nor rulers, nor things present nor things to come, nor powers, nor height nor depth, nor anything else in all creation, will be able to separate us from the love of God in Christ Jesus our Lord" (Rom. 8:38–39).

# PART I

# DYING, but ALIVE in CHRIST

# FRAMING the ISSUE

She reminded me of a sparrow buffeted by wind. Her diminutive frame trembled, and a nurse placed a hand on her back to steady her as she teetered beside her husband's bed.

Her husband watched through glazed eyes. His chest rose and fell with a sickly cadence, like that of a maimed bird beating its wings to take flight. He seemed remote, his mind wandering through forgotten country. He had developed pneumonia after a difficult surgery, and as infection clogged his lungs, delirium seized him. His bleary gaze searched a space none of us could see.

"He doesn't want it!" his wife insisted.

The surgeon drew nearer to her. "I don't think you understand me. He's already gotten through the surgery. He's made it this far. I think he would want the breathing tube."

"No, doctor, he wouldn't," she retorted, her voice cracking. "We talked about this so many times, and he was crystal clear. He's always said, 'When God calls me home, let me go.'"

The surgeon folded his arms. "But how can you be so sure that God is calling him home right now? You realize he'll die without the tube, right?"

Her face reddened. She opened her mouth to speak, but for several moments words failed her. Veins swelled in her neck. "No tube!" she finally managed.

The nurse's eyes met mine, and she pleaded with me to intervene. I urged the surgeon to allow me to speak with the patient's wife in private.

"Please, help her to understand," he urged me as he left the room. He shook his head as he walked toward the ICU double doors.

I sat beside my patient's wife and cupped one of her hands in my own. With her free hand, she clutched her husband's fingers. In contrast with her broken spirit, her grasp seemed forged from iron.

"Please," I ventured, "can you tell me about your husband? What is he like?"

A thin smile graced her face, and her demeanor softened. She described for me their sixty-year marriage, the partnership they shared, the tenderness, the trust. She outlined his declining health over the last year and his inability to engage in the things that set his mind and heart afire. Pain, immobility, and shortness of breath confined him to the house. Visits with friends, once life giving, now exhausted him. The fog of pain and medication so clouded his thinking that he could no longer concentrate long enough to read, not even to skim the Bible that sat on his bedside and which for decades had steered him through tempests. His own father had suffered a slow, painful death in the ICU, and he had pleaded with her to shield him from the interventions he witnessed. The very idea of a ventilator horrified him.

"He didn't even want this surgery," she related to me. "I persuaded him to go through with it because I wasn't ready to give up time with him. On the way to the hospital, he made me promise I'd say no to tubes or CPR or anything like that. He couldn't stand the thought of it. He's always said, 'Let me go home to God.'" Her voice cracked again. "He's going through all this out of love for me. The breathing machine would be too much."

I squeezed her hand. "I think he's made the decision for us."

Afterward, we reinstated the do-not-intubate order that he had established prior to surgery. His breathing would fail without a ventilator, but to force him onto one against his wishes, when its efficacy was dubious and his suffering certain, lacked all semblance of compassion. We changed our focus from cure to comfort. His surgeon, although disappointed, understood.

His nurse remained at his side around the clock to provide medication to alleviate pain and anxiety. When I left the ICU that evening, his wife rested beside him with her head in his lap. Although his gaze remained distant, he stroked her arm with his hand.

The following morning, I again found his wife in tears. Overnight their son had rushed to the hospital in a rage over the decision against a breathing tube.

"You're not going to kill my father!" he had bellowed at the staff. "I know my dad. He was a God-fearing man who until six months ago went to church every single Sunday. He would *not* be okay with this." He threatened to call the police before he stormed out.

When I entered, I found the patient's wife crumpled and broken at her husband's bedside, his hand still clasped in her own.

"Doctor, I don't want to upset anyone," she said. "Maybe I'm not supposed to argue about this, and just do what everyone else says. But I *promised* him. I know he wants to go when God calls him. He trusts in God, not in all these machines. What else am I supposed to do?"

# A Foreign Landscape

As dramatic as it may appear, the turmoil this family endured occurs commonly in our era of intensive-care medicine. Next of kin find themselves in the unfathomable position of advocating for their loved ones in a foreign environment, complete with an undecipherable vocabulary. Among themselves, families bicker

and disagree. Nurses fight tears as their patients grimace with yet another turn, yet another dressing change, yet another needle stick. At the center, heavy within the room but often unspoken, is the question of how faith informs the heart-wrenching, convoluted process. Openly, healthcare practitioners, patients, and families debate about prognosis, percentages, and advance directives. Inwardly, we all cry, *How long*, *O Lord?* (Ps. 13:1)

The tumult seems incongruous with our vision of life's end. For centuries, Western culture has conversed about death in euphemisms and poetry. We all long to "go gentle into that good night," and "to die, to sleep. "We soften the vulgarity of death with the phrase "pass away," as if life were a gauzy breeze, a zephyr that pirouettes in the air before vanishing into silence. Literature, philosophy, politics, and next-door neighbors depict death as a subdued stepping over a threshold, replete with quiet resignation, as subtle as a passing whisper.

Even while we cling to such metaphors, the landscape has shifted beneath us. In 1908, 86 percent of people in the United States spent their final days at home, among family and cherished friends, in the spaces that forged their memories.<sup>4</sup> The particulars of dying reflected its spiritual reality as a passage from captivity to sin to renewal in Christ. It was profoundly personal and relational.

A century later, Americans still treasure this understanding of death and cite the home as its rightful domain. Over 70 percent of us in the United States wish to spend our final days as our predecessors did—at home, among those we love. Yet in our era, *only 20 percent do.* Death has passed from the purview of families, pastors, and the quiet of home to sterile rooms that resound with alarms. The majority of us now die in institutions, facilities that run the gamut from nursing homes to acute-care centers. Up to 25 percent of people over the age of sixty-five years spend their final days in an ICU, far removed from adored friends and glimmers of the past.

Medical progress over the last fifty years has equipped doctors with technologies that, under the right circumstances, can save lives but also transmute death from a finite event into a prolonged and painful process. Death now commonly occurs in fits and starts, in a slow, confusing fragmentation of a life. It occurs within institutions, among medical personnel, distant from the view of families and the consolation of home. When technology so degrades a natural event into a complicated ordeal, our comprehension falters. Poetic constructs, while they appeal to our hearts, break down when death involves a mechanical ventilator, chest compressions, and feeding tubes. Even as Christians, we strive to understand how the numbers and equipment reconcile with the truth that "my flesh and my heart may fail, but God is the strength of my heart and my portion forever" (Ps. 73:26). God's perfect timing seems less distinct when machinery blurs the boundaries of life and death. His will may seem elusive to us when decisions about ventilators and resuscitation confront us with check boxes. We embrace an understanding of death rooted in hope—in the gospel—that does not align with the distressing decisions that subsume our final moments.

# An Unsettling Silence

The transition of death from the home to the hospital hides the realities of dying from an entire culture. As time passes, those of us who know death before it strikes us personally shrink in number. Our fear of dying, already inherent, deepens when it lurks beneath the unfamiliar. Even physicians admit to avoiding discussions about end-of-life care with their patients, out of concern for inciting emotional distress.<sup>8</sup> The topic unsettles, and so few of us openly discuss our final days. We prefer to displace the issue from our minds until the need arises.

Unfortunately, most of us will be unable to articulate our wishes when the time comes, let alone prayerfully consider God's will. Severe illness frequently alters consciousness, creating delirium and encephalopathy that render us disoriented, paranoid, and even hallucinating. The silicone tube required for support on a mechanical ventilator obstructs the vocal cords, eliminating the ability to speak. To tolerate a tube within the airway, we require sedating medication, which inhibits even nonverbal communication. In addition to enshrouding sufferers in confusion, critical care deprives us of a voice.

When trepidation disallows us to discuss our mortality ahead of time, we strand those we love with impossible decisions. In a recent national survey, only 26.3 percent of adult respondents had completed an advance directive, i.e., a document to guide treatment preferences when we cannot speak for ourselves. When doctors cannot communicate directly with us, and we have no advance directive to guide them, they will seek out our healthcare proxy or next of kin for management decisions. Yet many family members and friends feel ill-equipped for this role. The same fears that prevent us from talking openly about death obscure our wishes from those who eventually make hard choices for us.

Even when we complete an advance directive, such documents often oversimplify the realities of end-of-life care. 10 Standard forms reduce complex and highly nuanced issues to a series of check boxes. They require us to project our thoughts into the future concerning subjects about which we have little knowledge, and to pass judgments using a polarizing metric without middle ground. We declare on such forms that either we will accept a mechanical ventilator, or we will not. We indicate we will accept chest compressions, or we will not. Such a stark, concrete approach disregards the messy realities of intensive care, a field that abounds with caveats. If you have declared "no ventilator" on an advance directive form, would you refuse such an intervention for a completely reversible event? What if you require a ventilator for only twentyfour hours? What if support lasts two weeks, but afterward you can recover and return home? A check box can scarcely delineate such subtleties. The efficacy of an advance directive hinges upon the conversation with your physician during its completion and explicit documentation of your values, not upon the form itself.

#### The Value of Discernment

When we have not communicated our wishes about life-sustaining measures, family members have little to guide them. From the doorway of a hospital room, a patient who will recover may appear identical to one fighting for his life. In both scenarios, we may require a mechanical ventilator to breathe, and sedating medications may plunge us into unconsciousness. An array of poles with intravenous (IV) bags and pumps will surround us. Wires from monitors may coil from our chest and scalp. For the aggrieved spouse at the bedside, such foreign trappings render looming death indistinguishable from steady recovery.

Differentiating between life-threatening illness and self-limited conditions that require only transient support involves an educated interpretation of numbers: the ventilator settings, medication dosages, laboratory values, radiography studies, and vital signs. The specific disease processes at work, and their treatability, are paramount. Understanding requires, at minimum, a detailed discussion with a physician who is adept at translating the numbers and statistics into laymen's terms and can frame the situation into a picture that families can comprehend.

Unfortunately, experience communicating with clinicians can vary. Physicians without a background in palliative care report discomfort in discussing end-of-life issues and cite concerns over unclear prognosis, time constraints, patient emotional distress, and inadequate training as factors inhibiting such encounters. In acute scenarios, we must place immediate trust in a physician with whom we have no prior bond. Studies show that during such situations, doctors are more likely to pursue aggressive treatments that may not align with our wishes. <sup>11</sup> One in ten Medicare decedents have surgery during their last week of life, despite the fact that only 10 percent wish to spend their last days in the hospital. <sup>12</sup>

When unfamiliar medical details muddy understanding, we need to lean ardently upon our assurance in Christ. Yet in one study of the dynamics between physicians and the loved ones of dying patients, only 20 percent of discussions touched upon spirituality, despite the fact that 77.6 percent of surrogate decision makers reported faith as important to them.<sup>13</sup> In this same study, loved ones raised the topic of spirituality in the majority of cases, and in only 20 percent of these instances did physicians inquire further. Surveys with physicians and nurses suggest that although most value the spiritual needs of their patients at the end of life, few feel comfortable engaging in conversations about faith.<sup>14</sup> Healthcare practitioners report inadequate preparation for spiritual dialogues and suggest that such conversations fall outside their scope of practice.<sup>15</sup>

Thus, despite their currency in the most fundamental of spiritual issues—life and death—modern medical systems offer scant context for a faithful response. Meanwhile, faith directly informs the care we pursue. Research shows that those of us who report significant support from a religious community are less likely to receive hospice services, more likely to pursue aggressive interventions at the end of life, and more likely to die in the ICU.<sup>16</sup> The confusion—and anguish—of end-of-life care deepens when we divorce the technicalities of dying from its spiritual origins.

In the case scenario at the start of this chapter, Christian faith informed the perspectives of my patient's wife and son, yet they arrived at diametrically opposed conclusions. According to his wife, aggressive measures repulsed my patient because he wholeheartedly accepted God's authority over his life and death, and he saw his worsening physical and cognitive impairments as hindrances to a life of faith. His son, however, reasoned that his devotion to God would compel him to pursue every intervention possible to extend his life.

To provide compassionate, gospel-centered care at the end of life, we must tease apart both the theology and the medical insight

that fuel such discrepancies. Dogmatic responses usually worsen confusion and heartbreak and dismiss conflicts that strike to the core of our faith. Our priorities run deep. In this disconcerting era that blurs the boundaries between life and death, we must strive always to respond with love and mercy, and to walk humbly with our God (Mic. 6:8). In the following chapter, we embark upon our journey through an exploration of God's Word.

#### **Take-Home Points**

- Although the majority of Americans would prefer to die at home, only 20 percent of us do. Most of us now die in institutions, and many in the intensive care unit.
- The changing landscape of death places us and our loved ones into heart-wrenching situations when we must make decisions about advanced medical options that we do not understand.
- Life-prolonging technology robs us of the ability to communicate, and few of us outline our wishes regarding end-of-life treatment before catastrophe strikes.
- Life-sustaining measures can save life, but when administered indiscriminately they can prolong suffering and death without benefit.
- Although our Christian faith is central to our approach to death, healthcare practitioners rarely offer spiritual support.
- A gospel-centered response to end-of-life critical care mandates consideration of the Word and acknowledgment of the potential benefits and limitations of intensive-care technology.

"To prepare yourself to make difficult medical decisions in a distinctly Christian way, you won't do better than to read *Between Life and Death*."

TIM CHALLIES, blogger, Challies.com

Modern medical advances save countless lives. But for all their merits, sophisticated technologies have created a daunting new challenge, namely a blurring of the expanse between life and death. The dying process is often hidden behind a complex web of medical terminology, statistics, and ethical decisions, making it difficult for patients and loved ones to know how to approach the end of life in a dignity-affirming, Godhonoring, faith-filled way.

This book offers a distinctly Christian guide to end-of-life care. It equips readers by explaining common medical jargon, exploring biblical principles that connect to common medical situations, and offering guidance for making critical decisions. In these pages, readers will find the medical knowledge and scriptural wisdom they need to navigate this painful and confusing process with clarity, peace, and discernment.

"Dr. Butler has woven together a clear explanation of detailed and complex medical issues with an intimate knowledge of Scripture to bring forth a book of immense value."

ROBERT D. ORR, MD, CM, elinical ethicist; author, Medical Ethics and the Faith Factor

"This remarkable, Christ-centered book will serve Christians and pastors for many years to come as they make these final decisions out of faith and not fear."

TONY REINKE, journalist; author, 12 Ways Your Phone Is Changing You

"Dr. Butler has done a masterful job in giving us a clear and comprehensive guide to navigating the difficult and complex waters of end-of-life care. Although written with patients and their families in mind, this book is a welcome and valuable resource for guiding Christian healthcare students through these challenging issues."

BILL REICHART, Vice President of Campus and Community Ministries,
Christian Medical & Dental Associations

KATHRYN BUTLER (MD, Columbia University College of Physicians and Surgeons) is a trauma and critical-care surgeon who trained at Massachusetts General Hospital and Harvard Medical School, where she then joined the faculty. She left clinical practice in 2016 to homeschool her children, and now writes regularly for desiring God.org, *Christianity Today*, and the Gospel Coalition on topics intersecting faith and medicine.

END-OF-LIFE CARE



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