



# Real-Life Stories of Ordinary People with Extraordinary Bravery

A conversation with the author of *Between Life and Death*

**B**etween *Life and Death* is a collection of real-life stories of ordinary people who displayed extraordinary bravery as they approached the end of their lives. By acknowledging death as a necessary transition rather than an unknown to be feared and avoided, these patients embraced their end days by living each day they had remaining to the fullest. The patients profiled in this book provide guidance not only to other patients with cancer, but also to oncologists seeking insight into how best to help their patients approach the end of their cancer journey.

The book's author, Kashyap Patel, MD—CEO of Carolina Blood and Cancer Care Associates in South Carolina, vice president of the Community Oncology Alliance, former member of the Association of Community Cancer Centers (ACCC) Board of Trustees, and chair of the ACCC Clinical Affairs Committee—says he wrote *Between Life and Death* to capture his 30-year journey as a practicing oncologist across 4 countries and 11 cities.

Dr. Patel explains that his book is a response to the struggle he and his and his colleagues often face when treating patients with cancer for whom a cure is no longer an option. He has come to believe that great harm has been done to patients and their loved ones by framing cancer, the suffering it causes, and its frequent termination in death as a battle to be won or lost. This dominant paradigm, explains Dr. Patel, has led to the inevitable

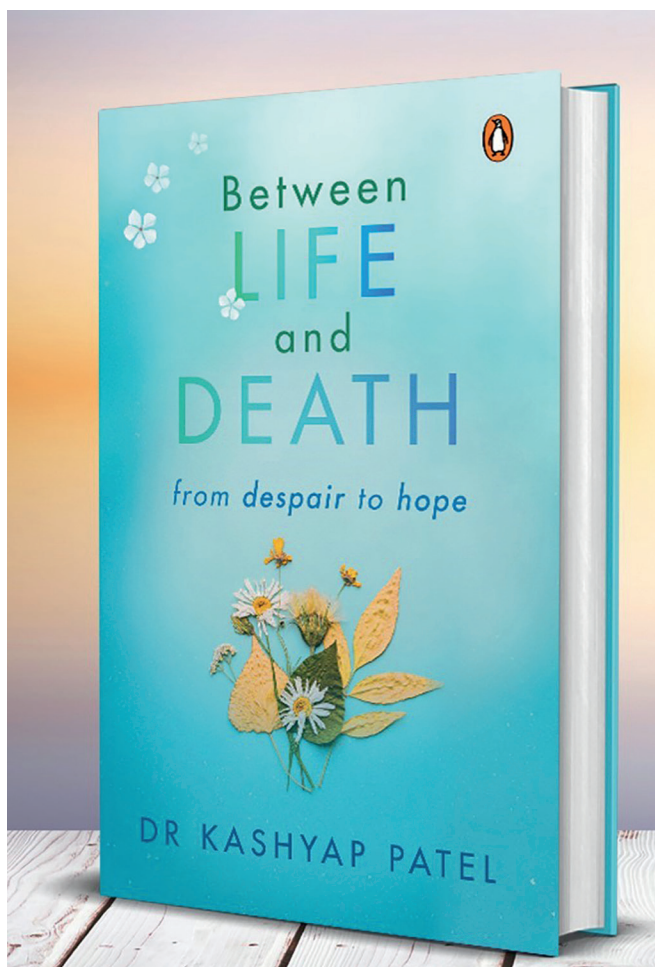
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conclusion that cancer creates winners and losers, and death is an enemy to be battled until the bitter end.

Dr. Patel explains in his book that while death is indeed inevitable, fear of it is not. “While most published literature focuses on cancer as a battle and celebrates stories of cancer survivors, this compilation highlights the altruistic and humanistic aspect of the struggle against cancer,” he says. “My book reveals that the true reason death causes so much insecurity is our fear of it.”



Dr. Patel's book narrates the stories of individual patients with cancer who have chosen to approach death as a transition on a longer journey rather than as a terminus to be feared. "We have the capacity of choosing how we react to the fear and challenges death brings," explains Dr. Patel. In *Between Life and Death*, he shares his conversations with several extraordinary patients about their attitudes toward death as they approach the end of their lives. Through those conversations, Dr. Patel seeks answers to questions such as: How do people perceive their own death? What impact does their fear of death have on their cancer journey? How can we best spend the end of our lives with our loved ones? Is there an afterlife or a soul?

Below, *Oncology Issues* talks to Dr. Patel about the origins and aims of his book.

**OI.** How do oncologists generally learn to help their patients deal with death and dying?

**Dr. Patel.** In all the places I've practiced, I've seen very little training in death and dying for physicians. In U.S. medical schools, there still is no curriculum. Less than 10 percent of U.S. medical schools offer any classes in death and dying. Students may have 10 hours total in their five years of medical school, which is hardly sufficient.

Why is this? It may be because physicians have a sense of guilt about "failing" their patients who have not gotten well. Patients may pick up on that and feel that they are disappointing their physicians. It's like the relationship been a coach and his players. Even though the players may know that they are losing the game, they do not want to disappoint their coach.

But we have an obligation as physicians to help patients make their transition. It's a comfort for patients when they realize that death is an inevitable part of their life journey. This book is a telling of stories about life and death from the point of view of patients who have encountered their own mortality. It's a complex issue, and the more we shy away from talking about it, the more complex the problem becomes.

**OI.** What do you perceive as the most problematic ways oncology deals with the death and dying of patients with cancer?

**Dr. Patel.** We are consistently taught that our goal is to stop death through any means possible. When we develop new medications for cancer, we talk about them as a new way to defeat death. So, when a patient improves or recovers, we brag about stopping death. When death becomes inevitable, we feel like we have failed. Little attention is given to end-of-life care, as we have been programmed to believe that when our patients reach that stage, there is little we can do.

A big problem is that our medical system does not give patients adequate time to prepare to die. The average length of stay in hospice is three days, which is considered adequate. I think we should enable patients to spend six to nine months in hospice, so they have time to come to a peaceful end of their lives. We celebrate many things in life: weddings, birthdays, major milestones. The one thing we don't celebrate is saying goodbye to our loved ones by enabling them to transition to the unknown.

**OI.** What roles should members of the cancer care team outside of physicians (e.g., nurses, social workers, navigators) play when working with terminal patients?

**Dr. Patel.** I spend approximately 20 minutes with my patients in the consulting room, but my infusion nurses might spend 6 hours at a time with them. Nurses and other caregivers in the office can take that time to engage patients in conversation and share examples of how people can have excellent quality of life, even if they decide not to receive curative treatment. They can explain to them how their relationships with their family members continue. Together, we are a team caring for all of our patients' needs.

**OI.** Do you want to highlight any of the specific patient stories you relate in your book?

**Dr. Patel.** In my effort to better care for my terminal patients, I studied different spiritual practices, religions, and perceptions of death and dying, going back to ancient Egypt and Rome. I studied Christianity, Judaism, and Islam. And I saw a commonality in beliefs about death and the process of dying.

Then, I met a patient who changed my way of perceiving death. He had been perfectly fine when he was diagnosed with Stage 4 cancer. He told me that he did not want treatment, but he did want me to help him and his family prepare for his death. He said he had read about dying, but he didn't feel fully prepared for it. During the next three months, our team had continual conversations with this patient and his family about death and dying, and we prepared him to leave.

My experience with this patient taught me so much. I decided to tell his story, as well as the stories of several other patients, in my book. All these patients are real people I met in my practice in South Carolina. From my interactions with a 29-year-old woman to an 85-year-old man, I was able to help these patients in their spiritual journeys and help them prepare for their transitions, and it was an incredible journey for me as well.

Another patient of mine had multiple myeloma. She was 85 years old, and she used to jokingly call me "her boyfriend." When she was ready to transition to hospice care, I placed her there. One day, her son called me and said, "I know that you're not on call, and forgive me if I entered into your personal life. But my mother is dying, and she keeps muttering your name." She had been in a coma for the past three days, and she just opened her eyes and said, "Dr. Patel, my boyfriend, where is he?"

I was going to attend a wedding that evening, but I told my wife that I had to go and see this patient. I went to the room she was in, and she was surrounded by her son, daughter-in-law, and grandchildren. I put my arm around her, and she opened her eyes, almost like she was waiting for me. And then she died in my arms. Her son told me he could not believe what he witnessed. "It's almost like if you did not come, she would have continued to suffer," he said. "She would have continued to struggle, and eventually she would have died. But you helped put closure to her life."

**OI.** What do you most want people to take away from this book?

**Dr. Patel.** We need to better prepare our patients for death. When I see advanced patients for their first consultation, I explain to them that palliative care will be an option at some stage, that, at some point, we'll have to sit down and talk about changing gears from trying to prolong life to focusing on quality of life. That sets the expectation that the aim is not a cure, that the aim is to extend quality of life. To say that, at some point, it will become necessary to make a compromise between quality and quantity is just ridiculous. I want this book to serve as a guide to teach all providers across all tiers how to effectively communicate with patients about end-of-life care.

This book is for everyone because all of us are going to die. Even though it's focused on stories of cancer patients, it's for anyone who wants to know about their ultimate journey toward the finish line. It's for anyone who does not want to approach dying as a hopeless situation. We all have a choice to make: Do I want to be afraid of death and lose every moment to fear, or do

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We all have a choice to make: Do I want to be afraid of death and lose every moment to fear, or do I want to live life to the fullest?

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I want to live life to the fullest? I don't know when my time will come, but I do know that I can choose to live my life to the fullest, and I can make that choice today.

**OI.** I've heard that you intend to donate the royalties from this book. Can you talk about the charity you selected?

**Dr. Patel.** I am giving it to a foundation that helps the marginalized, orphaned children of India learn acting skills. I have a friend in the theater in Mumbai, and I donated a small amount of money to this foundation several years back. Later, my friend invited me to see the impact of my donation. I saw a child perform, and he was dressed in rags because he had no money. He told me afterward that he saw water come out of a faucet for the first time that day. In the slums, they have shantytowns, and there is no plumbing.

I was moved. In general, these kids have no future other than begging on the street. But one child who was trained there did actually go on to Hollywood to act professionally. That is an inspiration for so many, and I want to help other children believe they could also do that. It gives them some sense of hope. All proceeds from this book will support this foundation for orphaned children in Mumbai who may have no hope of living beyond the slums they grew up in. I will also match all proceeds with my own personal savings. 

*Kashyap Patel, MD, is a practicing oncologist and has been working directly with cancer patients for the past 20 years. He is the CEO of Carolina Blood and Cancer Care Associates; vice president of the Community Oncology Alliance; former member of the ACCC Board of Trustees; chair of the ACCC Clinical Affairs Committee; medical director at the International Oncology Network; and past president of the South Carolina Oncology Society. A certified trainer for physicians with Education in Palliative and End-of-Life Care (EPEC), Dr. Patel has been a speaker at several continuing medical education events. Dr. Patel has led committees in numerous South Carolina hospitals and has extensive research experience in the field of oncology. In August 2020, Dr. Patel published Between Life and Death. Read more about Dr. Patel and his book at [betweenlifeanddeath.org](http://betweenlifeanddeath.org).*

*Barbara Gabriel, MA, is associate editor, Oncology Issues.*