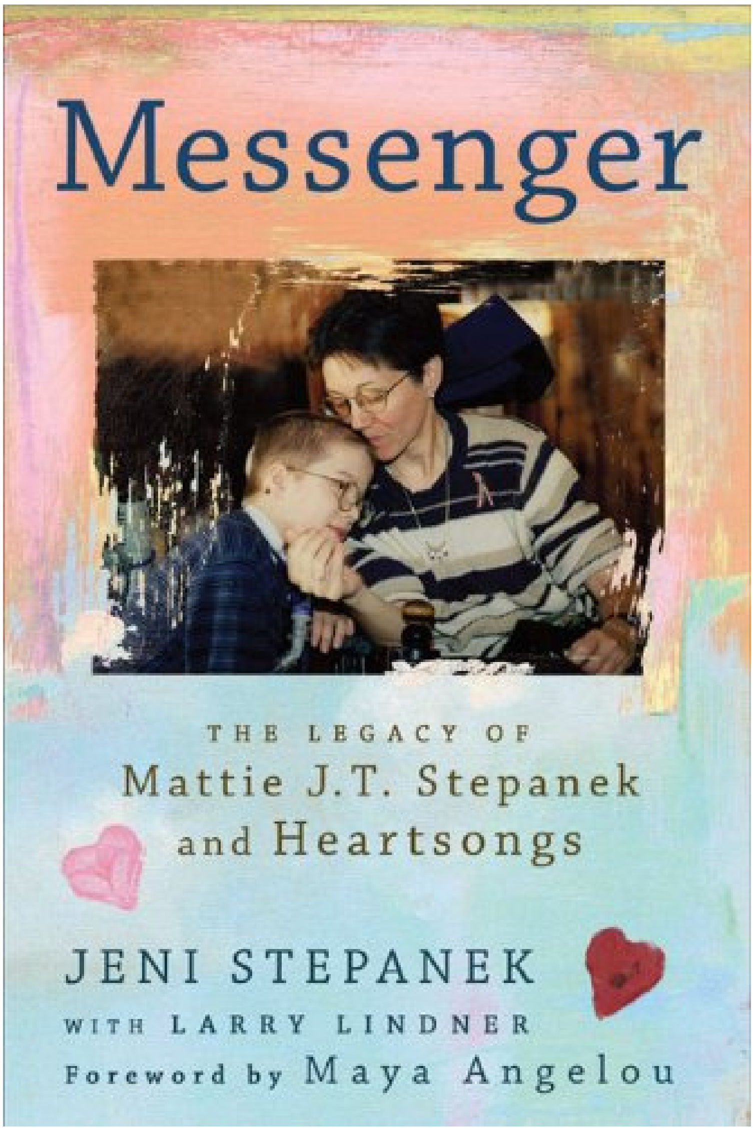
Messenger: The Legacy of Mattie J.T. Stepanek and Heartsongs

Jeni Stepanek



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Jeni Stepanek : Messenger: The Legacy of Mattie J.T. Stepanek and Heartsongs before purchasing it in order to gage whether or not it would be worth my time, and all praised Messenger: The Legacy of Mattie J.T. Stepanek and Heartsongs:

20 of 20 people found the following review helpful. Another Angel at the side of JesusBy Lovin my kindleI read this book in two sittings. Having a hard time reading it through the tears. These tears are mostly from the overwhelming joy I felt from Jeni (Mattie's Mom). How proud I know that she is of not only Mattie but also of her other three

children afflicted with this fatal disease. I felt her pain, her Joy, and her love as a mother. I sat with our nine year old son and read some of Mattie's poetry and explained what message Mattie was spreading. Again, crying and knowing how fortunate I am to share this story with all our children. I will teach our children Mattie's message of peace, love, and of course playing after a storm. Mattie will live in our hearts forever and we are so blessed that God let us borrow Mattie long enough to hear his message. My children will be taught to always be kind to their school mates; especially the children that might need a friend. Mattie is a true inspiration to anyway willing to open their hearts and share their "heart songs". I also pray that Jeni realizes how blessed her children are that they had her to call "Mom". I hope that everyone is lucky enough to read this book; as it is a true honor to know Mattie and his mom. Thank you from the bottom of my heart for sharing Mattie and this beautiful story.16 of 16 people found the following review helpful. "Let there be peace on earth and let it begin with me."By Robert M. Balkam"Messenger" is the message of Mattie Stepanek's life by his mom, Jeni, and, it is also the message of Jeni's life with Mattie. There are, in fact, two messages which are clearly recognizable. They each have the same goal: Peace.The most recent Mattie book was Just Peace: A Message of Hope In it, Mattie described "The Mosaic Vision of Peace" "Messenger" describes the lengths to which he went to spread his message, to the point of giving his life for it, one might say.In the process, Jeni was inevitably involved. Her commitment is no less than Mattie's was -- probably even more now that she feels the total weight on her shoulders. This, notwithstanding the frailty of her own health.Yet, listening to her at a book signing or watching her in any of number of television appearances, she seems to draw on limitless resources to retell the story and its significance while drawing her listeners and viewers increasingly into their own participation.Jeni describes Mattie's faith and her own as well as the importance that it plays in the successful distribution of the message of peace. Peace after all is a major component of religion.It is difficult to imagine anyone reading this extremely well-written book without coming away with a deeper commitment to peace, at least in his or her own life.To the degree that it happens, Jeni I feel sure will believe that her efforts are successful. You are cordially invited to contribute to Mattie's and Jeni's goal.One of Mattie's favorite songs was: "Let there be peace on earth and let it begin with me." -- a modern version of "Make me a channel of thy peace." by St. Francis of Assisi.Bob Balkam Rockville,MD5 of 5 people found the following review helpful. This is a life changing bookBy SweetPeaI watched an interview with Jeni and immediatly went to to order the book. I read it almost in one sitting the day I received it and am in awe of this woman. I liken her to Mother Mary. She is filled with grace and poise and love as I've never witnessed before. She has endured more than any one person has ever had to endure and she has done it beautifully. Her honesty is breathtaking. Mattie is a boy like none other. He was such a joy - I should not say "was," as he continues to be a joy. I have a new respect for Oprah, Jimmy Carter and well, Christopher Cross, a man whom I've never held much of an opinion on before. Jeni has made these people, (and Maya Angelo), real in a way that only she could as they are real to her and have been angels to her son, Mattie. Mattie has been and will continue to be angles to them and to me. When I think I can not handle something, I think of Jeni and Mattie and smile. I wrote an email to Jeni not expecting a response, or if I did receive one, a "canned" one. I received a very thouthfully written one by Jeni and was humbled. I love this family as much as one can love semi-complete strangers. Please - do yourself a favor and buy this book. I just ordered 15 of the to give as gifts. Everyone must hear this story of the fabulous life of Mattie. It matters not what your religious beliefs are. Mattie is as close to Jesus as any one person can be. He was a devout Catholic, but did not judge anyone. He accepted everyone and their beliefs and did not belittle or try to change them. Jeni was an amazing mother to guide him to be the wonderful light/messenger he is. Thank you, Jeni. I am blessed to know your and Mattie's stories.

Oprah Winfrey has called him "an inspiration," Maya Angelou saw him as a kindred spirit and fellow poet, and Jimmy Carter described Mattie Stepanek as "the most remarkable person I have ever known." When Jerry Lewis received his lifetime achievement award at the Oscars, footage of Mattie played behind him. Five years after his death from a rare neuromuscular disease, Mattie is still being celebrated for his indomitable spirit and message of hope. Now the world will get to know the full story of the poet, the peacemaker, the philosopher, and New York Times bestselling author in the first book to share all of the intimate details of his incredible life. In Messenger, Mattie's mother, Jeni Stepanek, recounts the years before Mattie got sick; how he handled the loss of his siblings from the same disease he had; his decision to spread the message of peace and hope; and how, when he became a celebrity, Jeni helped to keep him grounded, and remember to embrace being a kid. Including never-before- seen poems, journal entries, photos, and correspondence with famous friends, Messenger is an inspirational book about a life lived to the fullest. "Not a day goes by when I don't receive e-mails and letters saying that Mattie's poetry and speeches are not enough-people want to know about him directly and intimately. I am thrilled to have joined with Dutton so that I can now tell all his fans the full story behind my son." - Jeni Stepanek,Good Morning America.

About the AuthorJeni Stepanek is the mother of Mattie Stepanek, the New York Times bestselling author and humanitarian, who passed away in 2004 to Dysautonomic Mitochondrial Myopathy. Jeni lost three other children to that same neuromuscular disease and has the adult-onset form herself. She holds a doctorate in early childhood special education and is an award-winning speaker. She lives in Rockville, Maryland. Excerpt. Reprinted by permission. All rights reserved.Chapter 1 Sunrise on the Pier . . . The sky grows Shadows, rising With the passing of time. . . . The sky sighs, Ebbing with tides Of pre-dawn nothingness, And yet, Seas of everything created, Tucked into waves. . . . The sun rises Caressing spirits With the passing of time And the promise of hope And the belief of life That gets better with age As we edge into The day that once was Our distant tomorrow. From Night Light in Reflections of a Peacemaker: A Portrait Through Heartsongs, page 29. Nell was getting more and more soaked each time the water sprinkler circled back around. She had fallen off the boardwalk into the beach grass on her way back from the ice cream shop and was now unable to get up, afraid she might have broken her leg. She also had a painful abrasion on her forehead. Still, she was laughing to herself. While she waited for help getting to the emergency room, the sprinkler system came on automatically, and she knew the sight of her sitting there dripping wet was ridiculous even more so because Mema, who had gone with her for ice cream, kept running off each time the ch ch ch ch ch of the sprinkler circled around. Mema had wanted to stay right by Nells side while others in the group went for help but had her hair done that day and didnt want it ruined. So she would jump back with each spray, apologizing from a distance about her visit to the beauty parlor. This made Nell laugh even harder. We were toward the end of our annual week at the beach on North Carolinas Outer Banks. Mattie and I had been coming every year since 1992, when he was two, courtesy of my dear friend Sandy Newcomb and her parents, Mema and Papa (whose real names are Sue and Henry Newcomb). They always stayed in a two-story condo right by the water a crazy flophouse with red and purple walls and more air mattresses and foldout sofas than bedroomsand they had us down for a week or more every July. The summer of 2000 had been better than ever in the sense that all our kin were able to make it for at least a couple of days. By kin, Mattie and I meant the family with whom you didnt necessarily share blood but with whom youre related through life. These relationships were always wonderful to him, whereas blood relations could be sweet or sour. Our immediate kin consisted of Sandy, who by that point had become more like a sister to me and like a favorite aunt to Mattie; Sandys daughters, Heather and Jamie Dobbins, and her son, Chris Dobbins (all were teenagers or young adults then); and Mema and Papa. We playfully called this group the Stepobbicomb Famcombining Stepanek, Dobbins, and Newcomb into one kinship unit. Some extended kin were also a part of this beach vacation, including Matties best friend, Hope Wyatt; Hopes mother, Susan (Susans husband, Ron, on a peacekeeping mission in Kosovo at the time, was the one who brought Mattie the United Nations flag); and Nell Paul and her husband Larry. Sandy had met Nell in a La Leche class when they were both expecting their first children, and through her I had become good friends with Nell, too. Mattie called us the Three Grannyolas. It turned out Nell hadnt broken her leg after all. And although the gash on her forehead was a nasty one, it wasnt anything time and some pain medication wouldnt heal. Nell had been a source of humor all week. The night we arrived, she explained that she was having health problems that made it difficult for her to stand on her feet too long. But she offered to help Sandy make a chicken tetrazzini dinner that night by calling out, without a hint of irony, that at least while sitting at the table, she could very easily cut the cheese. When we all burst out laughing, she responded with some amount of confusion and indignity that not being able to walk around a lot has nothing to do with my ability to cut the cheesewhich only made us roar. Nell grew up a preachers daughter in the South in the 1940s and 50s and simply didnt know certain idioms and other common wordplays. We had such fun teasing her all week about the T-shirts you see at the beach with suggestive double entendres and such. We entitled that vacation The Education of Nell, playing practical jokes on her as we went. One day I looked sidelong at Mattie with a mischievous gleam and said to her, I suppose youve never heard the phrase duck on the head. Mattie went along and called out, Mom, I cant believe youd even tell her that. Thats, like, rude. I then said to Nell with feigned indignation, Never mind, we arent going to go there. Later in the week, Mattie and Hope staged a tattling scene wherein Hope accused Mattie of saying duck on the head, and Mattie defended himself by responding that he was only telling Hope why she shouldnt say it, and I scolded both of them. Nell felt terrible. She had been repeating the phrase here and there in the belief we had been pulling her leg and thought it was she who got the kids going. We didnt disavow her of this notion. Then, on one of our last days there, we all tied tiny stuffed ducks to our heads and went around the side of the pool where Nell was sitting, quacking at her. Mattie was having the time of his life. Chris would throw him into the deep end of the pool, and hed soon be bobbing to the surface, yelling to be thrown in again. He also began interviewing all the kin for a fun book he and I were envisioning, The Unsavable Graces. He wrote goofy poems and went to the top of a giant sand dune called Jockeys Ridge. He went with me to Mass recited in Spanish, which we did every summer; doing so allowed us to really think about the essence of God in rituals rather than just recite prayers from rote. He and Hope, both blond, ambushed Chris, also blond, while Chris was trying to flirt with a pretty girl in an orange-pink bikini, saying, Daddy, were hungry, and Mommy said its your turn to fix us lunch. Chris later married that girl, Cynthia, and Mat-tie was best man at their wedding. Matties disability had progressed since the previous summer, but we were used to that and always found ways to accommodate his condition without letting it ratchet down the fun. For instance, when Mattie was six and seven, he could walk to the pool, do backward flips into the water, swim laps, and dive down ten feet to the bottom to grab pennies. As long as he remained attached to a tank of oxygen, he would be fine. We would rig a twenty-five-foot tube that connected the nasal cannula in his nostrils to the tank so he could swim anywhere in the pool and never be without the supplemental oxygen. When he wasnt in the water, he would drag the tank behind him on a cart, sometimes using his cannula and tubing as a jump rope and letting other kids take turns as he swung it. When Mattie was eight, he needed a wheelchair with the oxygen on the back of it to get to the pool but could still move around pretty well once he was in the water. The summer he turned nine, he went from one oxygen tank to two, but as long as he had the extra oxygen, he didnt have the frequent feeling that he was suffocating. This time around, Mattie was too weak to swim muchhe would come up gaspingbut he could still enjoy Chris throwing him into the deep end. To compensate, we bought a ten-foot blow-up alligator float that Mattie could hang on to in the water. The object was always to continue the fun no matter the challenge. There was always another solution, another fix. Granted, this year there had been changes that were more marked than in previous summers. At night, Mattie now had to be on a BiPAP machine, short for bi-level positive airway pressure. It involves wearing a mask over your nose or mouth or, in Matties case, both, that helps you breathe easier when youre short of breath. Mattie also had to wear it during the day if he felt exhausted, such as right after pool time. This was in addition to the pulse oximetry and cardiorespiratory monitors to which he was connected anytime he was sitting or lying at rest since the day he was born, which would let us know if his heart or lungs werent doing what they were supposed to. The dysautonomic in dysautonomic mitochondrial myopathy means things in the body that should happen automatically dont always. For example, when someone switches from physical activity to sitting, the heart self-regulates by beating more slowly. But Matties heart could overshoot the mark and start to forget to keep beating while he was at rest rather than simply slow a bit; the fine-tuning just wasnt there. If his heart rate fell too low, the machine triggered an alarm that would signal someone to jiggle him or provide other tactile stimulation or remind him to breathe more deeply for a minute until his heart could receive the signal and get its pumping back in sync with his bodys needs. Understanding this condition and how to deal with it came slowly, across the lifespans of all four of my children. The medical community didnt even have a name for it until my two eldest had died. It was simply called dysautonomia of unknown cause, and early on I was told that subsequent children would not be affected. Not until Mattie was two years old and my third child was months from death did doctors understand that it was a condition of faulty mitochondriaan essential component of every cell in a persons body. I was actually diagnosed firstwith the adult-onset formthen the children. Two years later, after my third child died and Mattie was only four, I was in a wheelchair. Now we were all too familiar with the conditions devastating effects. We were used to adding supports and medical machinery to compensate for the detrimental effects of this progressive condition, and then we would keep going. But that summer, the changes werent just in the BiPAP machinery or even in the fact that Mattie didnt have the energy to really swim. Hope, who was two years his junior, was now several inches taller than he was. Matties shoe size, in fact, was the same as in kindergartena childs 11. Growth taxed Matties autonomic system, and somehow his body knew that. In addition, he could not walk across the beach to the ocean. Mattie didnt need his wheelchair because he was incapable of walking; he needed it in large part because he would tire so easily. In previous years, he had the energy to walk across the sand to the waves so he could bodysurf (always attached to his oxygen). He had to. We didnt always have a special beach wheelchair that could get traction over the sand. But this summer, after the first day of walking out to the water, he said he couldnt go back; it took too much out of him. We did have a rented beach wheelbarrow that got me down to the waves that first day, and I told him he could hop on while someone pushed. But he said no. He was aware that he lacked the energy to handle the waves. And he knew he wasnt up to getting overheated on the hot sand; his condition also compromised his temperature stability, so that once he became too hot or too cold, his body had a hard time readjusting to normal. Mattie didnt have the strength to climb Jockeys Ridge, either, a massive sand dune in the middle of the Outer Banks that offers stunning views of the barrier island chain from the top. Park rangers drove us up in a jeep that year. He was still his charismatic self, chatting up the rangers and people who had hiked up to fly kites. But instead of turning cartwheels at the top, as he had done the year before, he sat on a lawn chair. We treated all of Matties limitations as challenges to be gotten around rather than game changers. Of course anybody could see that they were. But my aim was to help Mattie live on a day-to-day basis as though the assaults on his body could always be taken in stride, that any new weakening or new machinery were just part of life rather than shifts that called life into question. I even managed to convince myself much of the time that no symptom of illness was something a combination of medical help, ingenuity, and prayer couldnt overcome. Mattie was ahead of me, though. Even on the first day of that vacation, he let me know. For fun, he went around asking everyone why they had come to the beach house that summer, either videotaping their responses or writing them down. It was all note-taking for the Unsavable Graces book. Everyone gave silly answers. Sandy said she came to learn Braille for a course she was taking and not get sick; the summer before, she had come down with an awful case of bronchitis and was laid up most of the time. Nell said she had been planning on thinking three deep thoughts but had already done that in the car so was at a loss as to what she was going to do the rest of the week. Chris said he was a plumber and had come to fix the sink, code for being on the hunt for pretty girls. Then I turned the tables and asked Mattie what he was there for, figuring hed give as ridiculous an answer as everyone else. But he just looked at me and said, I really need to consider the meaning of life this summer, because life is changing. Caught off guard and wanting to keep away from that subject, and not wanting to spoil the others fun, I chided him. Mattie, were all clowning around, and youre being serious and philosophical. Immediately, I saw the hurt in his eyesand have regretted to this day the words that fell out of my mouth at that moment. He was headed someplace else, even on day one. Mattie remained ahead of me, however. After that exchange, he kept what he needed to say bottled up throughout the week, making sure his words mirrored the general festive mood. He jumped into as much physical activity as he could handle. He participated in the practical jokes. He played board games with the rest of us. Even when he had to take breaks more frequently than he used to, he would beg off joining in some group fun as casually as possible and go to his room to read or write poetry (and then end up falling asleep, even in the middle of the dayhis fatigue was that overpowering). Not that he didnt truly enjoy himself to the hilt. He did. But it wasnt until our sunrise on the pier that he spoke his heart. Sunrise on the pier was a ritual Mattie and I engaged in, without fail, the morning of our last full day at the beach every year. It was our thin space. A preacher once described thin space to me as that place where your spirit and God are in closest contact. Generally, were all aware we have a spirit, an essence, thats deep inside us. At your thin space, the veil separating your essence from your being becomes transparent enough that the spirit becomes undeniable. Instead of being a silent voice, your spirit more or less shows itself to you; you know it intimately rather than simply being aware of it. All of the beach was thin space for Mattie and me. Where we stayed on the Outer Banks was not an arcade-laden, honky-tonk resort spot with some sand and waves that happened to be nearby. It was where, on an island jutting into the ocean, the sea met the sky and the earth; past, present, and future converged in an absence of measured time; and what we felt actually became something we could behold. I had been coming to this stretch of beach since 1976, long before Sandy invited me to join her on family vacations. I didnt meet Sandy until 1989, but by coincidence, we had both fallen in love with the same place. After my first two children died, I even pitched a tent down on the sand near the pier to try to catch my spirit up to my life. When you lose a child, your body keeps moving, but your spirit doesnt want to come along. It drifts behind. At the beach, my spirit told me theres still more there. It allowed me to feel the essence of my children and the presence of God, which put it back in sync with my body and allowed me to go forward. Now the beach, this pier, was the place where my spirit and Matties could talk to each other directly, without anything muffling what got said or what got heard, even between parent and child. It never mattered whether it was a cloudy sunrise and the sun didnt show. An unrise, as we called such mornings, was just as significant. We always came down to the pier before five A.M., at least a full hour before the sun actually rose. We had to start when the stars were still out, when it was still dark and time was taking a last look backward before moving forthward, as Mattie called it. That morning, no breeze stirred as we made our way to the edge of the pier. The two of us wheeled out together across the warped wood, slowly, slowly, sounding a soft, almost rhythmic bumpedy-bump on the weathered planks, so we wouldnt be jolted out of our seats. Matties ability to handle the chair on the rickety wood slats was something of a small marvel, considering his wheelchair beginnings. Fine and visual motor skills were never his strong suit, and he had to learn little by little how to navigate with the chairs joystick. When he first started using it, I took him to the first floor of a mall department store and had him circle around while I waited at the juncture of mall and store. I told him not to move out of anybodys way, to just stop where he was if someone came toward him, because he wasnt ready to back up or steer to the side. After a few turns around the bank of escalators that stood in the middle of the floor, he said he had the hang of it and was ready to step aside should anyone come toward him. I said okay, with misgivings, and the next thing I knew he was wheeling gleefully from the store into the mall exclaiming, Mom, Mom, I did it! I backed out of someones way! At the same time, however, alarms were going off. It turns out that in backing up, he had hooked on to a lingerie cart and had left the store with a bevy of unpaid ladys undergarments in tow. Because the pier was so long and because we had to go so slowly, it felt like we had been rolling hours out to the middle of the ocean by the time we reached the edge. In previous years, wed make our way to the end of the pier holding hands and laughing, but not that day. In the dark that morning, Mattie started out quiet. We began our talk the way we always did, with Mattie asking about his sister and brothers. Tell me about Katie, he would implore. Tell me about Stevie, about Jamie. Tell me about how Jamie took care of me, how I took care of him and became the big brother to him when he got sick. Mattie used to read to Jamie. Mattie couldnt speak when he was a toddler because the trach tube he had in his neck at the time limited the use of his vocal cords. But he got around it by communicating with American Sign Language. Jamie, for his part, couldnt see what Mattie was signing because two years before he died, he lost meaningful use of his vision. Yet Jamie would sit there and smile as Mattie signed for him the illustrated stories in childrens books. They had found their own thin space between them. These reminiscences were crucial to Mattie. When he was about seven years old, he started crying hard, seemingly out of the blue, and when I asked him what was wrong, he told me he was beginning to lose his memories of Jamie. He remembered sitting in Jamies bed and squeaking his little yellow caterpillar in his brothers ear after Jamie had lost use of his sight, Jamie smiling in response. And he remembered the two of them sitting in each others chairs for fun and my reading to the two of them together, and Jamies little white casket with the contents I put in that he would take with him to Heavenbut not much more, and it frightened him as well as saddened him to be losing touch with memories he held sacred. He was saddened, too, about not having known Katie or Stevie, and would tell me on the pier that he missed not ever getting to hear them laugh, or to kiss or touch them. In 1993, when Stevie would have turned six, Mattie told me he did not know whether to sing a nursery rhyme for the baby Stevie was when he died, or to talk about fishing and other life discoveries that would have interested the little boy Stevie would have become by then. Mattie was three at the time. When Mattie finished talking about his siblings, he asked me what I wanted to be when I grew up. It was part of our pier ritual, our way of moving by degrees from what was to what will be. And I always told him the same thingthat I wanted to be eighty-three. He would laugh and respond by saying that you couldnt be a number, and Id answer, Okay, then, I want to be a beach chair philosopher, thinking deeply by the ocean and sharing thought-provoking stories. This would lead to my asking Mattie what he wanted to be. In years past, Mattie always talked about wanting to be a daddynot simply a father, who wasnt necessarily close, but a daddy. He was going to have seven children and had already named them. The oldest was a namesake, Matthew Joseph Thaddeus Stepanek, Jr., who would be called Tad. Second would come Kathryn Hope, to be called Katie Hope after his sister, Katie, and his favorite word (and also his friend Hope, who he was fine with being his childrens mother). Third and fourth would be Steven Blaine and Jamie, after his brothers, Stevie and Jamie. Since Jamie was not just his brothers name but also one of Sandys daughters names, shed be a girl. Her middle name would be Margaret after his great-aunt Margaret, who died around the time he was born but had been very good to me while I was growing up. Mattie liked that he and I played Parcheesi with the same dice Margaret and I had rolled when I was a child. Fifth came Patrick Noah (Patch, for short), followed by Theresa Rose, or Tessie, which was going to be Matties name had he been a girl. Mattie planned on giving Tessie to me, and when Id tell him his wife wasnt going to like that, he always explained that hed make it up to her by letting her name the seventh child whatever she wanted, with the proviso that if she didnt choose a name within thirty days, the right to give a name would revert back to him, and in that case he would choose Sophie and Sadie since the youngest children would then be twin girls. Pure fun as all this was, the idea of Matties fathering children wasnt totally in the realm of fantasy, and he knew that. Mitochondrial diseases like his are invariably handed down through the mother because virtually all of a persons genetic code for mitochondria comes from the egg theres essentially none in the sperm. Thus, Mattie knew that if he made it through adolescenceand one doctor had even told him that adolescence would be a make or break point for him because the body goes through so many changes at that timehe could have children and not risk passing on his disease. But as night shifted toward dawn that morning on the pier, Mattie didnt talk about having children. Instead, he went off script and said that sometimes he worried about what he would do if I died before him. He told me that if something happened to me first, hed go into his room and stay there until he could come out and cope, that hed end up having to shave a very long beard because thats how long it would take him to be able to move on. But he would move on, he said, because you cant lie down in the ashes of another persons life. He talked about how after a time it would be okay to laugh again, to play with friends, to have fun. Of course I nodded in agreement while he spoke, and did what a mother does in my situationtold him that Id stay here as long as I could. While a prognosis is something of a moving target, the one I had been given left me with a vague six months to ten years. But Mattie wasnt looking for an answer from me. He was setting me up. If I die first, he said, you have to do the same thingmove on because I could go before you, Mom. I wanted to pull Mattie away from this line of thinking. His whole life was spent on the edge, yet we had always managed to skirt it, to find some semblance of stable footing and keep our focus on daily living. Now here he was looking over the edge, but he was just a boy; it was my responsibility to keep him looking in the other direction. Mattie, I joked with him, you have at least until youre seventeen. Weve had the signs. Mattie was born on the seventeenth day of the month, in the seventeenth minute of the seventeenth hour (5:17 P.M.), measuring seventeen inches and weighing 2,017 grams, and I had always used that to calm his fearsnot to mention hang on to it myself as if it were a prophecy. Mattie nearly died minutes after he was born. Seventeen years of age sounded pretty good. He wouldnt let it go, though. Maybe I wanted to have kids, he said, because you want to leave behind lessons, leave behind everything that matters to you. Thats how you touch the world. But I have to reconsider what its like to leave a legacy. I think my life is the opposite of what it says on your coffee mug. On my coffee mug it said, I may have to grow old, but I dont have to grow up. Mattie said, I think I may have to grow up without growing old. He went on: I think were going to have to define differently what Im going to be. Were going to have to define my growing up differently. I want to be remembered as a poet, a peacemaker, and a philosopher who played, he added after a pause. He had mentioned those things before in various contexts, and even at the pier in prior years. But that was the first time he had strung them together in a definitive way, underlined them, so to speak. I didnt want to hear Mattie creating an epitaph. At the same time, I had to let him talk. His mortality was facing him, and I couldnt pretend otherwise. I had already shortchanged him earlier in the week. Now I understood why he reacted so strongly a few days earlier when Nell had to go to the emergency room. He had been really worried, crying and praying for her, afraid that something was very wrong. I felt I understood at the timeMatties whole life was filled with loss, with visits to emergency rooms that ended with long stays in the hospital and life-altering compromises. But what I realized on the pier was that even while I was aware he was losing ground, he was sensing it in a way I wasnt able to see. As close as I could possibly be, I was an outsider looking in. It wasnt as if once he brought up living a truncated life, we abandoned all that was ritual in our visit to the pier. We still spoke, as we did every year, about choiceabout how you cant choose whether youre going to have a disability, or your mother is going to be in a wheelchair, or your parents are going to be divorced, or youre going to be so without means at times that you have to stand in line for handouts at a church food pantry. Mattie lived a life in which these and so many other things happened that would never have been anyones choice that we made it a point to list the things you could choose: whether to talk about someone behind his back, whether to be your best self and do your best work, whether to focus on what you do have instead of what you dont, whether to go forward despite challenges or sink into despair. We also assessed our week as we always did, reviewing all the practical jokes and shenanigans with everyone. We talked, too, about Matties poetry, which was so important to him. But there was a new urgency about it, about the poetry and about the future. He said he needed to get his books of poems published. He had written several volumes of Heartsongs poetry by that point, Heartsong being a word he coined for himself to get at a persons essencethe longings and hopes and feelings that both describe and stir each of us. It is our charge, Mattie said, to take what we wish for in our Heartsong, package it in the best way we can, and offer it to others. In giving the gift you want most, he felt, you get it back. Matties package was his poetry; his Heartsong, a passion for hope and peace that grows from happiness, in a life that medicine kept dictating held no promise of hope. Mattie also said he needed to talk to his role model, Jimmy Carter, to find out if Im doing peace right, and that he needed to get his message of hope and peace on Oprah so that it could be spread. He had been talking about these things for a while, but previously they had seemed like the kind of yearnings all kids feed off of sometimes. Now they sounded like goals for an adult who needed to figure out how to make them happen. Mom, he said, I need to live everything that matters to me quickly. I need to do everything I want without growing old. If I can get my poetry published, itll be like Im having children. Mattie and I had talked in previous years about a persons creating something that lasts beyond his life spanhis echo, his silhouette. That day, he was addressing it more as a plan than a philosophical musing. Then he said, I dont think Im ever going to be back here. March thirtieth is a dark day for me. I felt a kind of nauseating ache start to rise. My daughter, Katie, was only twenty months old when she died, but the day before, she put away all her toys and refused to play with them. Bye-bye, she said. All through. What are you talking about, Mattie? I said. Youve always been on machines. There are tons of things that can still be done. No, Mom, he answered. I dont see next July. I dont see this pier in my future. The pier marked time for us. It was a kind of punctuation mark to our lives, a breather to go over where we were at that point and how we were going to move forward, how we were going to celebrate. It was where we planned our what nexts. The pit in my stomach rose higher. Youve got summer camp next year, I told him, although it was more like pleading. Youve got holidays. After a moment, I added, Do you think youre going to die on March thirtieth? Because well watch. Well take extra care to watch you around that time. I had debated whether to say it out loud, considering that if the thought remained unspoken, I might be able to hide it, keep it from having a chance to become reality. Im just saying I cant see past March thirtieth, he said. I cant fit anything after that into a context. Dont you see anything at all after that day? I asked. Easter? Your birthday? Maybe Thanksgiving at Sandys house, he answered finally. But Im not sure if Im seeing it, or just wanting it. Well, what do you see? Do you see people? The table? Do you see Christmas after that? Mom, please lets hush. Lets just sit here. I have to memorize this. But, Mattie, were videotaping this, I said. Mattie always liked to tape a minute of sunrise, shut the camera for ten minutes, then tape another minute so that everyone back at the beach house could see what they had missed. No, Ill remember what this looks like, what it sounds like. I have to memorize what this feels like, he countered. His voice had no trace of sadness or melancholy. It was more like an expression of Wow, Im really going to miss this, an anticipatory loss. By now the sun was almost fully risen. It was one of the gorgeous, brilliant sunrises, not at all a gray and muted shift into the day but a ruby pink with shades of orange. Mattie commented that it looked more like a sunset than a sunrisea gift from God, he said, because it combined his favorite color, the color of sunset, with his favorite time of day, sunrise. I stopped trying to reassure myself, and we just sat quietly and looked out to the horizon. I put my hand on top of Matties and told him I loved him. We said that to each other a hundred times a day, every day, and we meant it; it wasnt just words. But it especially needed to be said then. Everything looked as wonderful as it ever didblue, cloudless sky; sun sparks dancing on the waves; strong, bright light. We even began to see movement in the waterdolphins. It was a common sight on the Outer Banks, but one that always delighted us. Except this time we saw water spouting up. It wasnt dolphins but whales! Water was spouting out of their blowholescalves and their mothers. We could even hear their beautiful, haunting song. We watched the whales as they moved farther and farther away from land and finally swam out of sight. Then we sat just a minute more before slowly turning around to roll back. The next morning, after a last day of diving into vacation giddiness with the others, we loaded our things into the van and headed for home. It was Matties tenth birthday.