

Messenger

The Inspiring Story of
Mattie J.T. Stepanek
and **Heartsongs**



JENI STEPANEK
with Larry Lindner

Foreword by **MAYA ANGELOU**

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First published by Dutton, a member of Penguin Group (USA) Inc.
375 Hudson Street, New York, New York 10014, U.S.A.
Penguin Books Ltd, Registered Offices: 80 Strand, London WC2R 0RL, England

First published and distributed in the United Kingdom by:
Hay House UK Ltd, 292B Kensal Rd, London W10 5BE. Tel.: (44) 20 8962 1230; Fax: (44) 20 8962 1239.
www.hayhouse.co.uk

Published and distributed in Australia by:
Hay House Australia Ltd, 18/36 Ralph St, Alexandria NSW 2015. Tel.: (61) 2 9669 4299; Fax: (61) 2 9669 4144.
www.hayhouse.com.au

Published and distributed in the Republic of South Africa by:
Hay House SA (Pty), Ltd, PO Box 990, Witkoppen 2068. Tel./Fax: (27) 11 467 8904. www.hayhouse.co.za

Published and distributed in India by:
Hay House Publishers India, Muskaan Complex, Plot No.3, B-2, Vasant Kunj, New Delhi – 110 070. Tel.: (91) 11 4176 1620; Fax: (91) 11 4176 1630. www.hayhouse.co.in

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A catalogue record for this book is available from the British Library.

ISBN 978-1-8485-0251-2

Printed and bound in Great Britain by CPI William Clowes, Beccles, NR34 7TL.

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For Sandy Newcomb

Mattie's "VFABF"

—Very Favorite Adult Best Friend—



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Maya Angelou and Mattie, April 2002

Foreword

by Dr. Maya Angelou

There is an old African American gospel song which asks the Creator directly, “Lord, don’t move your mountain, just give me strength to climb it. You don’t have to move that stumbling block, just lead me, Lord, around it.”

In essence that was the theme of Mattie Stepanek’s life. That person, young in years, small in stature and challenged physically, dared to say of life—“However you press me, and pain me, and dare me, I shall live you fully. I shall find peace in the storm of disease. I shall find joy in the heart of pain. My name is Mattie Stepanek and I shall be an ambassador of love.”

This young poet asked to speak to me, and at first I was simply pleased. As I came to know him, his life, his mother and his poetry, I was honored to be a person who had encouraged and inspired him. Mattie Stepanek did not come from the ground like grass, he grew like a tree. He had roots.

Jeni Stepanek, who has seen all of her children succumb to the ruthless disease and watched her son, the poet, fight valiantly for each day of his life, for each ray of sunshine, and has, herself, been assailed by the same illness, is a root. She is planted deep in the earth. She has given strength to all her children, nurture and admiration to her son, the poet, and now she has given us this book, *Messenger: The Legacy of Mattie J.T. Stepanek and Heartsongs*.

I commend Jeni Stepanek for daring to live, for daring to give, and above all for daring to love.

Messenger



Prologue



International Association of Fire Fighters honoring
Mattie at his funeral, June 28, 2004

*. . . I will revolve seasonally
When my death comes,
And children will remember
And share their Heartsongs,
Celebrating the gifts in the circle of life.¹*

A jar of jawbreakers, a crucifix, a SpongeBob pillow, a copy of *To Kill a Mockingbird*, the noisy half of a remote control fart machine. These were among the items Mattie had with him in his casket.

We had begun discussing what he would “take” nearly a year and a half earlier, in February of 2003. Mattie was in the Intensive Care Unit of Children’s National Medical Center in Washington, DC, clearly having crossed the line from being a child with a life-threatening condition to a child who’s going to die, probably sooner rather than later.

¹ From “Eternal Role Call” in *Celebrate Through Heartsongs*, page 52.

I was about to open the game box with the Yahtzee dice and UNO cards when he looked straight at me and asked, “Mom, do you think people are going to come to my funeral?”

He was finding it difficult to breathe. In this latest health crisis, his airway had eroded; at times he felt like he was suffocating. His fingers bled, he coughed up blood and tissue from his tracheal lining, and a tracheostomy tube came out of the hole in his neck—ventilator and oxygen line attached.

Mattie had had life-threatening episodes before, but I had avoided having direct conversations with him about his death up until that point. “You know,” he continued, “I’m going to be young when I die, and maybe people won’t feel comfortable coming.”

“Of course people will be there!” I answered reflexively. I hadn’t actually thought about people coming to his funeral before that moment. Mattie was going to be the fourth child I buried as a result of a rare disease called dysautonomic mitochondrial myopathy, and I was, I suppose, trying to keep my distance from that inevitable day even while I was preparing for it somewhere within.

But this was going to be different. My other children died very young, all before the age of four. Mattie, on the other hand, was already twelve. He could participate in his own funeral arrangements. It was different, too, because Mattie had achieved renown. He had been on *The Oprah Winfrey Show*, *Larry King Live*, *Good Morning America*; he had written several books of poetry that had reached the *New York Times* bestseller list and sold millions of copies; he had become the National Goodwill Ambassador for Jerry Lewis’s Muscular Dystrophy Association; he knew his heroes—Jimmy Carter and Maya Angelou—personally; he had given inspirational talks to thousands about peace, about being true to yourself and following your Heartsong, as he called it. My grief and the grief of those close to him was going to be private, but many others were also going to grieve and want to pay respects.

Most important, however, was that Mattie’s funeral go the way he wanted. He asked if he could tell me some things he would like. I took out a piece of paper and a pen. He talked about what he wanted mentioned in various prayers, songs he wanted sung, who he wanted to do

the readings, who he wanted to say his Mass. In the Catholic Church, a funeral Mass is a celebration, a spiritual send-off, and he wanted his celebration to go just right.

Mattie then went on: “Please don’t send me to a morgue,” which is standard procedure after someone dies. “I don’t want my face covered with a shroud. I don’t want to be put in a drawer. I know I’ll be dead and it’ll be meaningless then, but I’m alive now and I’m afraid of the dark. Please keep a light on in the funeral home, too.”

He added that he didn’t want to go from the funeral home to the church in a hearse, if that was in any way possible. In a hearse you’re alone, with just a stranger driving.

I was thinking of Mattie’s requests as we drove to his funeral, which occurred sixteen months later, on a warm day in late June 2004. I was going down a mental checklist to make sure I had honored all of his wishes. I don’t know what Heaven is, but it has got to be good, and I was wondering, from that good space, is my son happy? Does he know I have done everything to make this the celebration he wanted?

I suddenly realized that I had forgotten to put his Black Belt in the casket. Before Mattie became too sick, he had earned a Black Belt in a Korean martial art called Hapkido, and he wanted the reward for that triumph with him. I felt horrible that I hadn’t remembered.

Everything else that he requested was there, though—a photograph of him with his older brother, Jamie, the only other sibling alive by the time Mattie was born; a photograph of his other brother, Stevie, and his sister, Katie, both of whom he planned to meet for the first time in Heaven; a photo of Mattie and me; the baptism rosary of our little friend Kaylee, who called him “Uncle Mattie”; a camera with a flash because Mattie wasn’t sure about “the lighting situation after death”; a small tape recorder “with extra batteries”; Mr. Bunny, a fleece puppet he had from the day he was born; his Muscular Dystrophy Association (MDA) business cards; a *Lord of the Rings* bookmark; Austin Powers memorabilia that Mike Myers had sent to him; some Legos; and a number of other items. Despite being Catholic, I bury my children like little Egyptians departing for the next life with their worldly goods, and Mattie, aware of that, wanted as much tangible that mattered to him as the casket would hold.

Others put in gifts of their own. There was the Native American offering of feathers; a white rose from the flower arrangement sent by Oprah Winfrey; a photo of Mattie and his friend Hope, whom he had known since he was five; a wooden plaque with a picture of Hermione from *Harry Potter*; other tokens of affection; and yes, the noisy half of his remote control fart machine.

I had refused to place it in myself, even though it was one of the last things Mattie asked for when we talked about his funeral. “You have to take it,” he said. “Put the noisy half in the casket with me, keep the trigger half, and, before I’m actually buried, press it, so I get the last laugh.” Mattie believed people should “remember to play after every storm”—this was his personal philosophy for life—and he felt this would allow mourners to begin playing again.

I told him I couldn’t do it, that I was his mother and that I would be grieving and it wouldn’t be right. So Mattie asked Devin Dressman, a research doctor who he had become close friends with, to do it.

A lot happened in the sixteen intervening months between Mattie’s conversation with me and his death, even though we had not been optimistic that he would make it out of the hospital when we had that discussion. He published a fifth bestselling book of poetry. The Iraq War began, just weeks after then-President and Mrs. George W. Bush called Mattie to thank him for all he did for our world in the name of peace. He panicked new doctors on his team by drinking from a urinal that he had filled with apple juice. He started going to the hospital every other day for blood and platelet transfusions. He attended MDA Summer Camp and had the time of his life, mourned the death of his friend Racheal, turned thirteen, ate Maryland crabs with Christopher Cross, delivered a keynote speech for Rosalynn Carter’s Intergenerational Caregiving Conference. His interest in girls went from prepubescent to adolescent. He discussed the concept of angels on *Larry King Live* as part of “an expert panel,” slept at the local firehouse during a hurricane, underwent treatments to try to strip toxic levels of iron from his blood, did book signings, went into cardiac arrest—three times—fell into a coma, came out of it, saw the latest *Harry Potter* movie. . . .

The day he died, June 22, a terrific rainstorm kicked up in the mo-

ments after his heart stopped, with blasts of thunder and lightning. Afterward, as improbable as it may sound, a giant rainbow stretched itself across the sky and could be seen from different locations. I wasn't looking out the window, but kids at his summer camp three hours away saw it. Staff in the hospital saw it. Someone I don't even know wrote about it in the guest book at the funeral.

The storm delayed a visit to the hospital from Mattie's service dog, a golden retriever named Micah. I wanted Micah to see Mattie and know that he had died rather than abandoned him. But I had only a certain window of time. For Mattie to go straight to the funeral home and not to the morgue, which he wanted to avoid, the hospital said I needed to have the funeral home pick him up within three hours of his passing. He died at 1:35 in the afternoon.

Barely ten minutes had passed when people started coming by. A hospital public relations agent came to me and said, "I'm sorry, but we have every news station on the phone. Word has gotten out. Are you able to issue a statement?" By two o'clock, television stations were interrupting their programs to announce Mattie's death.

Micah didn't make it to the hospital until six that evening; the storm and traffic tangles made getting him there difficult. He jumped up on Mattie's bed, excited, licked him, sniffed him, then lay on the floor and just sighed and moaned. He smelled death, literally, and grieved rather than felt confused or abandoned. He lost twenty pounds in only weeks.

The funeral home attendees came by around seven. Nearly six hours had passed, but the hospital waited rather than calling the morgue. In accordance with Mattie's desire not to have his face covered or be left in the dark, the body bag was zipped only up to his face.

Once at the funeral home, the request to leave on a light all night was honored, and Mattie was put in a room with others who had died so he wouldn't be "alone." Nobody can explain it, but his body was still warm when I left the funeral home that night. He was gone; there was no doubt. It was not as if he had slipped into a deep coma. And the life support had been removed as soon as he passed. But seven hours after the time of death was called, the heat of a live person had not yet left him.

Four days after Mattie died, I arrived at the funeral home to finalize

plans for the wake and funeral. He was lying there exactly as he had been left, wrapped in a blanket, holding his stuffed animal wolf, Grey Hero. Someone had pinned a note to his blanket: "My name is Matthew. I prefer to be called Mattie. Please leave me in a room with other deceased, and keep a light on for me. Please do not do anything. My mother will come and dress me."

Mattie liked dressing sharply when the occasion called for it, having once said, "I always breathe better in a tuxedo." With that in mind, I dressed him that day in a black tuxedo with a silver vest; Grinch boxers; Simpsons cartoon socks; his black light-up sneakers; his watch and glasses; and his trach tube, which he did not want removed. I also gave him a fresh haircut, fashioned with the number 3 trimmers instead of the usual number 2 trimmers because he wouldn't have wanted it to look *too* fresh.

The funeral home was about a twenty-minute drive from the church, Saint Catherine Laboure. I had never been there, but it was the largest church in our county, with a capacity of 1,350 people, and a large crowd was anticipated. Just how large I couldn't have imagined.

Mattie's casket, four and a half feet long and draped with a blue-and-white United Nations flag that had flown during a peacekeeping mission in Kosovo, was carried out of the funeral home by his pallbearers. Three of them were the children of my closest friend, Sandy Newcomb, who came to see Mattie when he was born and was in the hospital room when he died.

The pallbearers brought the casket to a fire truck decorated with swags of black crepe. The International Association of Fire Fighters is a major supporter of MDA, and Mattie had become good friends with a number of firefighters around the U.S. and Canada. The fire truck was their way of honoring Mattie's wish not to be taken in a hearse.

Out at the curb, the six family pallbearers handed over the casket to six firefighter pallbearers, whose specific job it was to lift the casket onto the truck. Two firefighters with whom Mattie had become particularly close friends, Bert Mentrassi from Greenburgh, New York, and Jim Jackson from Mississauga, Ontario (affectionately known as "Bubba" and "J.J."), rode on the ledge at the back of the truck. Mattie was being honored with the funeral of a fallen firefighter.

I wasn't prepared for the ride to the church from the funeral home. I had considered that, because Mattie had become a person of note, the church might be full. But major roads were closed to traffic. A police motorcade in front of us blocked access. Television newscast helicopters were flying above, along with other aircraft; the airspace above the church was being closely guarded because former President Carter was expected to attend.

Sandy drove my van, which followed behind the fire truck carrying Mattie's casket. From the radio we heard, "Mattie's funeral procession is starting now. They're making their way out of the funeral home." It is a surreal experience, listening to your life in real time while living through your raw grief. At the same time, I was so proud for the attention being paid to my little boy.

That attention turned out to be an even greater outpouring than I had anticipated. I had wanted to stare at the casket in front of me. But my eyes kept being pulled to the sidewalks. People were stopping, making the Sign of the Cross, bowing their heads, taking pictures as the fire truck went by. They put their hands on their hearts. As we came closer and closer to the church, signs were held up: "We love you, Mattie!" "You won't be forgotten!" "Our little peacemaker."

When we turned down the road that led to the church, we saw hundreds of people lined up—Harley-Davidson riders, another big MDA sponsor, in denim and leather; firefighters in dress blues; Muslim women in head scarves; nuns in traditional habits; men in both African dashikis and business suits; the governor of Maryland; country singing star Billy Gilman; homeless people; a U.S. senator; television celebrities; Mattie's former schoolmates; clergy. . . . In that moment, it felt like Mattie really had succeeded in bringing the world together in peace. He would have been thrilled. It was a central tenet of Mattie's message of hope that "we have to make peace a habit"—actually live it day to day in our own choices as well as bring it out to the larger world as a reality—share it "even with people with whom we disagree" or feel angry about or wronged by.

The line of people at the church doors wended down the sidewalk and out of sight around the far side of the building. Two and three thick,

they slowly made their way forward. Those who couldn't fit inside stood on grassy hills and other areas nearby.

I sat in the van for fifteen minutes before getting out. During Mattie's final few years, when he existed in the celebrity spotlight, I had become accustomed to television cameras and interviews and chatting with people I didn't know who wanted to tell me that Mattie had somehow touched their lives, and it all made me feel wonderful. But I was going to be following my son's casket into the church. I couldn't face people even to receive expressions of sympathy, and certainly not reporters' questions that day. I knew that if I started talking, I might start crying and that "the mother's grief" would become news. I didn't want the focus shifted from Mattie. I left the van in dark sunglasses so as not to betray any emotion. Fortunately, not a single reporter came up to me the entire day, nor to any famous person there.

I and several others close to Mattie, including Sandy and her mother, were wearing purple. A song he had written that was going to be sung during the funeral service talked about purple being one of the colors of hope, and we wanted to wrap ourselves in Mattie's vision of what hope looked like.

Inside the church, three people gave pre-funeral Mass tributes. One was Jann Carl, a correspondent for *Entertainment Tonight* and also a cohost for the annual *Jerry Lewis Labor Day Telethon*. She read a poem written for Mattie by Jerry Lewis, who couldn't be there because he was quite ill at the time. She talked about "that sparkle" in Mattie's eye, "that innocent yet mischievous grin . . . the way he would push his glasses back to the bridge of his nose." She also said that Mattie "left us a blueprint . . . step-by-step instructions, to not only mend our broken Heart-songs, but to make the world a better place"; that he taught people to play, which "brought back a touch of innocence in all of us. And from that innocence, hope. And from hope, the elusive peace."

Another speaker was Dr. Murray Pollack, director of the Pediatric Intensive Care Unit at Children's National Medical Center, who reminded those in attendance of Mattie's "wit and his wisdom" and reiterated Mattie's advice to "play after every storm." Dr. Pollack said, "Medical

failure with Mattie was inevitable . . . yet his spirit and enthusiasm made it oh-so-easy to try. He was a world-class prankster. He really did put apple juice in the urine cup. . . . He really did watch *Ferris Bueller's Day Off* just to get some inspiration. He really did make liberal use of his fart machine. . . . He had adult thoughts—he brought people together—but he was a child. . . . And that was, in large part, his magic.”

Oprah Winfrey, who had become a close friend and confidant to Mattie, spoke also. She told the crowd how she “fell in love with him” from the very first moment she met Mattie, and called him “my guy” during phone calls and e-mails. “It’s not often that we find people in our lives who create magic,” she said. “I found him to be magical. I could not believe so much wisdom, so much power, so much grace, so much strength and love could come from one young boy. . . .

“With Mattie,” Oprah said, “the light of his life shined so brightly that every one of us who knew him, who were honored and had the grace to meet him, will feel the glow for the rest of our lives.

“I loved his desire to be known for his work,” she commented, “and not just to be famous.” She cited an e-mail exchange from a few years earlier in which Mattie talked about some kids he knew who said to him that because he became famous, he should “*always be happy and never sad.*” But Mattie added:

I don’t think they understand what it’s like to know you have to live your life so fast . . . my life here won’t last. . . . I get scared about the pain of dying and about what I will miss because I love living so, so, so much. . . . I want to leave so many gifts for people to have when I’m not here anymore. . . . I want people to remember me some day and say, “Oh, yes! Mattie! He was a poet, a peace-maker, and a philosopher who played.”

Oprah also talked about how Mattie loved sunrises, about how he had seen magnificent sunrises during beach vacations in North Carolina. She told him that most people wouldn’t bother to wake for a sunrise because

they like to *sleep* on vacation. That didn't wash for Mattie. In living fast, he wasn't rushing so much as relishing, getting as much out of every moment as he could.

He wrote her that he "*can't understand why everybody wasn't out on the pier at sunrise . . . can't figure out why people would want to miss*" such a miracle. . . .



Jeni and Mattie, Outer Banks, North Carolina, July 1992