

A Child Shall Lead: *A Love of Life*

Matthew 1:18-25

Whenever children portray the Nativity on Christmas Eve, I find myself entranced by their charm and purity of heart in conveying the story of Jesus' birth. The parts are played, of course, reflecting each child's own personality and color, and not so much with an idea of what the original characters may or may not have been like on that eventful night so long ago. So, in their own way, children tell us how Jesus was born in a manger with angels, shepherds, and magi in attendance. Then, we all sing a carol or two and go home. From a child's point of view, that's pretty much it. They tell a story and display a love for baby Jesus untarnished by life's complications and drama.

As grownups, though, our perspective is somewhat different; we realize life is rarely so carefree and straight-forward. Angels, typically, don't make an appearance in our lives (so we think) and we certainly don't experience sages traveling from afar to bring us treasures (although I still hold out hope for Publishers Clearing House to recognize and affirm the eternal significance of us sharing the same initials!).

Aside from the childlike charm, in our adult world the Christmas story usually becomes real and authentic when we consider its historical context and human complexities. Those are elements of the story which resonate with the dramas of life as we experience it. For instance, we might be intrigued by what Mary or Joseph each were thinking once they discovered she was suddenly pregnant (something that would certainly generate some family drama!). Or, we might ponder the rather unappealing circumstances of the story's setting, where the health of the

mother would have been at risk traveling nearly a hundred miles across the countryside before birthing her babe surrounded by the stench of manure and in the filth of a feeding trough. The Nativity's charm portraying Mary and Joseph as specially blessed and that all was right with the world appears absurd; had we been there, it would have felt like an unfolding nightmare—in other words, not the kind of “beautiful” story you'd want to find yourself playing a role.

Yet, in both raw reality and mythical perfection, in the minds of both adult and child, it's a story about life and love—how both are experienced and shared. Life is viewed differently in a child's mind than in that of an adult. For that reason, most adults would like to keep an understanding of love in two distinct worlds—one that is G-rated for children, and the other, rated M, for mature audiences only. As parents, we fiercely guard the proverbial gates of Eden protecting our children's innocence for as long as we can—at least before they reach the age of responsibility and reckon with the fruit of their actions and the knowledge of both good and evil. Prior to that, we do our best to ensure our children experience life with happy endings, in its beautiful fairy-tale mystique, before they reach the time when they realize life is far more harsh and complicated and the stories they learned as a child begin to lose their credibility. Perhaps that's why, as adults, we prefer to protect children from losing their innocence, even if they are faced with real world challenges. We want them to be carefree, when what they are capable of being is *wise*—sometimes even wiser than adults.

Wisdom, as you know, is something one hopefully gains through life experience. It is knowing the difference between what brings about good and that which results in worse circumstances, or even evil. It's gauging

beforehand the consequences of one's words and actions. It's maintaining a healthy perspective in life, especially through tough times. As much as we expect wisdom to be earned over many years, sometimes it comes in unexpected ways in our young.

Such is the story of Mattie Stepanek, who lived his life of childhood innocence within unimaginable hardships—one who, in his outlook and perspective, conveyed remarkable wisdom for his tender age—a wisdom that continues to impact lives.

If you know about Mattie, you will note that he never considered himself a victim of misfortune, as much as one might assume. His life was defined by a rare form of muscular dystrophy (technically, a form of Mitochondrial Myopathy—a terribly debilitating disease), but his life story could not have been told apart from it, because he would not have been born or be who he came to be without it. This was his reality from infancy. Mattie's mother unknowingly carried the genes and gave birth to four children before the condition was defined and Mattie and his siblings showed symptoms of it. It's an unimaginable hardship in a family, but one that allowed Mattie as a young child to recognize how much life itself is a gift under any circumstance and context.

Mattie was born on 17 July 1990, the youngest of four siblings—two who died in infancy. His parents divorced soon after Mattie was born due to an abusive relationship, leaving his mother, Jeni, to take care of the two surviving children in their Upper Marlboro, Maryland home. This would be the beginning of her challenges. Within a year or so, Jeni was diagnosed with an adult onset form of this neuromuscular disease—meaning all members of this household were suffering in kind.

Mattie, though, was amazing even from a young age. Though spending most of his early years in and out of the Pediatric Care Unit, his intelligence and spiritual maturity were remarkable. Baptized as an infant in their local Catholic Church, by age eight he was confirmed. The next year, he became a lector in worship, reading the Scriptures during weekday and Sunday masses. The following year, he was teaching CCD classes to second graders and at 11-years-old, he taught CCD for his own peers. At that age, his spiritual maturity was extraordinary well beyond his years.

Though wheelchair-bound, disability did not limit Mattie. On many levels, he was a child prodigy which became apparent once he left the public school system and was homeschooled. By ten, he was completing a high school curriculum and auditing college courses. Mattie read hundreds of books each year on a number of subjects—from children’s classics to *New York Times*’ bestsellers to historical biographies. He kept a journal of his observations about life and wrote creatively, both poetry and prose. Mattie wasn’t merely a bookworm; he loved sports and creative playing, and somehow even managed to earn a First Degree Black Belt in martial arts.

Mattie’s writing career came about when he compiled some of his earliest writings for a book contest in Kindergarten. It contained three chapters of poetry he had written since he was a three-year-old, included along with some of his finger-painting artwork. Here are a couple of selections, written when he was only five:

Making Sense of the Senses

Our eyes are for looking at things,
But they are also for crying
When we are very happy or very sad.
Our ears are for listening,
But so are our hearts.
Our noses are for smelling food,
But also the wind and the grass and,
If we try very hard, butterflies.

Our hands are for feeling,
But also for hugging and touching so gently.
Our mouths and tongues are for tasting,
But also for saying words like,
“I love you,” and
“Thank you, God, for all these things.”

About Angels

Do you know what Angels wear?
They wear
Angel-hair and Angel-wings and
Angel-dresses and Angel-shirts under them and
Angel-underwear and Angel-shoes and Angel-socks and
On their heads
They wear
Angel-hair—
Except if they don't have any hair.
Some children and grown ups
Don't have any hair because they
Have to take medicine that makes it fall out.
And sometimes
The medicine makes them all better.
And sometimes
The medicine doesn't make them all better
And they die.
And they don't have any Angel-hair.
So do you know what God does then?
He gives them
An Angel-wig.
And that's what Angels wear.

Mattie called his poems, *Heartsongs*—based on his belief that every person had a song in their heart which expressed their purpose in life. Such a belief is endearing to say the least; but within his young mind was an emerging wisdom about the meaning and purpose of human existence—relevant even to an adult audience. Over time he authored several companion volumes—many of which made the *New York Times*' bestseller list!

Mattie's books brought attention to his remarkable outlook and wisdom through his love of life, despite his medical condition and

limitations. Larry King interviewed him several times and he appeared on *Good Morning America*, where he was introduced to his hero, former President Jimmy Carter, who wrote many of the Forwards for Mattie's books, including, *Just Peace: A Message of Hope*. President Carter observed: "With wisdom and uncomplicated vision, Mattie reminds us how easy it is to forgive, to find something amazing, even in the most trivial things, and to celebrate the little gifts of life every day." The 29th President would also tell people that he considered Mattie to be the most impressive person he has ever met, even while in the Oval Office!

Oprah Winfrey, too, was taken by Mattie's insights and story, featuring Mattie on a number of occasions on her talk show and book club, which expanded his fame and popularity. Even the Westerly-born, Billy Gilman, runner-up this past week on NBC's show, *The Voice*, recorded an album early in his career (2003) based on Mattie's poetry (*Music Through Heartsongs*).

Mattie Stepanek was, in every sense, a lover of life, ever grateful for each day and for each person he encountered. Oprah calls him a prophet who speaks the truth to everyone. In each of his books, he described himself in this way:

I am Mattie J.T. Stepanek
My body has light skin,
Red blood, blue eyes, and blond hair.
Since I have mitochondrial myopathy,
I even have a trach, a ventilator, and oxygen.
Very poetic, I am, and very smart, too!
I am always brainstorming ideas and stories.
I am a survivor, but someday I will see
My two brothers and one sister in Heaven.
When I grow up, I plan to become
A daddy, a writer, and a public speaker.
And most of all, a peacemaker.
Whoever I am, and whatever happens,
I will always have my body and mind,

Even if it has different abilities
Than other people's bodies and minds.
I will always be happy, because
I will always be me.

To possess an outlook such as this when he and his family had encountered so much sorrow and pain in their family losses and disabling conditions, it helps mute some of the easy complaints many of us have about our own hardships through life. Mattie offers the wisdom of a child who suffered much in the innocence of childhood, whose courage and hope continues to inspire adults around the world. Indeed, a child shall lead.

As a parent, one often hopes that a child escapes tragedy and suffering of any type, particularly, the limitations imposed by disability. Children are often shielded from facing sorrow, disappointment, or anything that might traumatize them. The intent is to defend their innocence, to have them experience a perfect life in a perfect world for as long as they can, as much as it's within our power to provide that. But in doing so, we may do them, and us as well, a disservice.

Children are often quite capable of handling the challenges of the real world and finding a perspective and strength that copes with whatever life throws at them. As Mattie's story and his Heartsongs attest, sometimes, they will be the ones to show us how to handle life, how to identify what and who is most important, and how to trust God and others to help us through.

We sense this at Christmas. In the story of the Nativity, we find a child's world and an adult one come together portraying the presence of the incarnate God—the Christ Child. Those worlds are not as separate as we think. In the birth of a child, we often discover the face of God and grasp

for a moment's time, the precious gift of life. Mattie did, as evident in his poem, "Touch of Heaven," written when he was nine.

What is it like to have a baby
Fall asleep while holding your finger?
It is a soft, precious touch.
It is so relaxing, yet exciting.
It is a feeling of trust and importance.
It is so soothing, it makes me want to
Fall asleep.
It is a sign of peace and love.
What is it like to have a baby
Fall asleep while holding your finger?
It is a great gift from Heaven.

This is our world—innocent, yet real, wonderful and filled with wonder—the human story as it is in all our children, who on this Christmas Eve, will lead us back to God and toward the essential love of life found in this blessed story and in everyone's Heartsong.

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