

Say Thanks Before the End of Life

A True Story of a Great Father and a Strong Son



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By Fang Wen

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Foreword

If you were someone with an incurable disease that would soon cut your life short, how would you spend your precious remaining days in this world?

If you were to have a sick child who needed full-time care and might leave you forever at any time, what would you do?

Whatever choice you were to make, people would likely be compassionate and understanding. Most people dying from a degenerative disease prefer to spend their last days peacefully. But a father with his sick son took the time to travel around China to say thanks to everyone who had helped them.

The father quit his job 12 years ago to take care of his son who has CMD (Congenital Muscular Dystrophy). As the boy's condition worsens, and their money drains, the man shores up hope and courage in their lives by fulfilling a wish of the son every year. The one he has just accomplished over the past three years is to bring the boy to every one of the many people in 80-plus cities in China who have helped them, in order to express their gratitude personally.

Only the power of the mind could provide the strength to enable a moribund boy and his distressed father to undertake such a journey, during which every day is a race against death. Living through the darkest and most

bitter periods of life, the pair has repaid people for their kindness with brightness and hope. And here is their explanation.

Son: "Facing the end of my life, I find I have more wishes yet to be realized. My life is brief, so I treasure it more, and owe it greater gratitude...I receive help from others, but I never see them. This thought makes me feel ashamed, and prompts me to say "thank you" to them in person... A miracle is nothing but a work of man. It is unusual only because generally people think that adversity is too strong, and that they are too weak to overcome it."

Father: "A life doesn't have to be long, but it must be meaningful... I love my son very much, and am willing to make his life brilliant at any price... After experiencing so many things, we have come to a point where we are thankful for the care and support of many other people. Gratitude provides us with tremendous strength."

Feeling gratitude is the message the father and son disseminate during their cross-country tricycle trip. They strike the hearts of numerous people *en route* with the son's optimism and adamancy, the father's love and devotion, and the strength of human kindness. As a result more people are inspired to offer a helping hand to those in need, keeping the circle of giving and reciprocating endless.

As the son's life ticks to an end at a relentless unchanged pace, it grows more splendid, distinguishing its host from the average person.

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I. Life's Countdown Started at the Age of 7

Huang Ge and his father Huang Xiaoyong live in a dilapidated bungalow in the Wangyuehu neighborhood, Rongwan Town, Changsha in Hunan Province.

The elder Huang, 48, ran a successful restaurant business before his son, 19, fell ill. He divorced when the boy was one, and from that time on assumed sole custody.

Huang Ge couldn't walk as steadily as other boys of his age when he was a toddler. The father however was not alarmed, presuming that this might be caused by slow growth. He began to worry about his son when the boy still experienced frequent falls at the age of three or four. But medical checks didn't uncover any problem with the boy's skeleton. The father then thought the cause might be a calcium deficiency, and so he intensified nutrition in the boy's

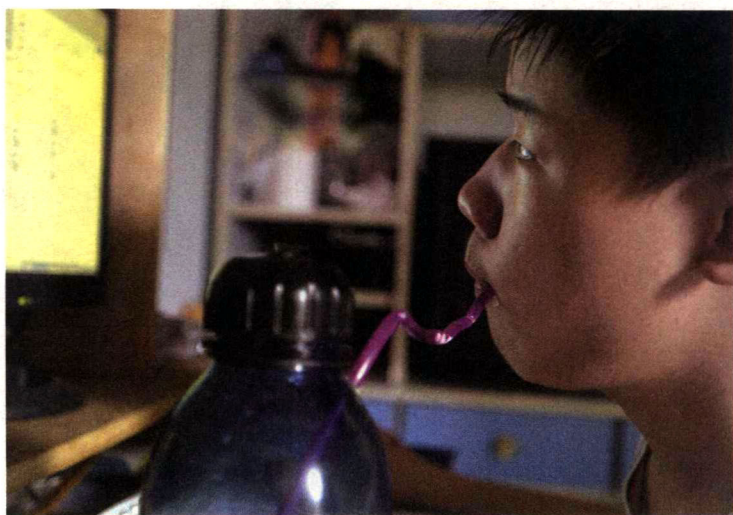
diet. Despite such efforts, the boy's condition deteriorated steadily. After he groaned that he had "no strength in my legs" repeatedly when climbing steps, the father brought him to the hospital for a thorough examination. The results indicated that he had Congenital Muscular Dystrophy, a disease caused by a genetic defect for which a cure has not yet been found. The patients are expected to go through a painful progression of losing control of their muscles, a process which terminates when the heart stops and is followed by death, usually before the age of 18. Huang Ge was 7 that year.



The humble house is the Huangs' pleasant home.

Full-time Dad

The news was a jolt from out of the blue for Huang Xiaoyong, knocking his mind blank for the moment. The man, known for his resilience and optimism to those close to him, didn't give up the hope that someday medical research would yield a cure for the disease, and spare his son from doom. Besides, he believed that his business could fund the boy's treat-



The father has tailor-made a bottle for his son with a straw that extends to the height of the boy's mouth.



It is becoming increasingly difficult for the aging father to carry his son in and out of the wheelchair, but he never complains.

ment until a miracle occurred.

The father hid the truth from his son, and from that time on spent all of his time out of the office with him. Besides daily visits to the hospital, the father took the boy around the city and then throughout the nation to try every method that might help, including acupuncture, massage, *qigong* (*chi kung*) and even prayer in front of the Buddha. The costs accumulated to more than RMB 8,000 a month, but the boy's condition grew worse with each passing day.

The boy felt that he was getting weaker. Whenever he asked his father what was wrong with him, the answer was always malnutrition, and he was promised that he would be ok if only he ate more. While himself enduring heart-wrenching pain, the father put a smile on his face in front of his son, and worked out various lies to field the boy's questions.

In the third grade, Huang Ge's mobility reduced to the point that he could no longer move freely. He had to leave school for fear of imposing a burden on his classmates, who were often late for class after carrying him to the bathroom. On October 30, 1998, his tenth birthday, Huang Ge was no longer able to



Papa used all means to make Huang Ge happy.



Huang Ge is taken to a temple in Yiwu, Zhejiang Province, to be treated for his illness.

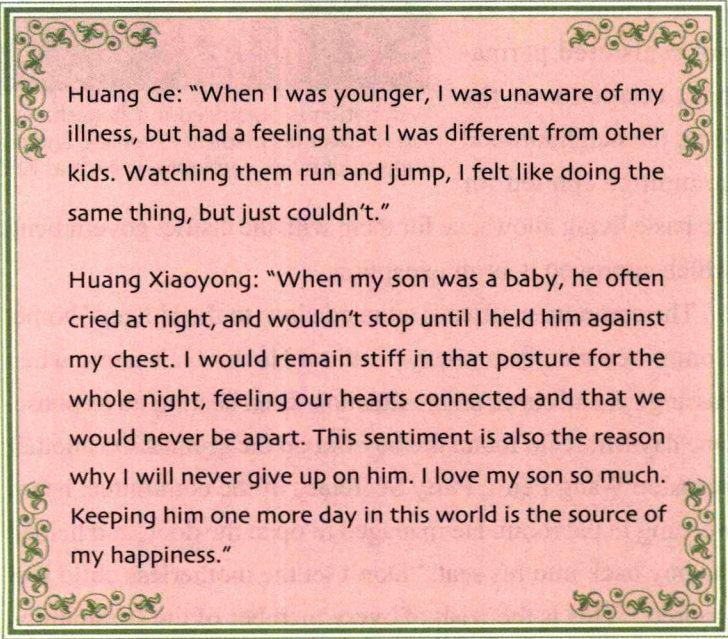
walk, and received a wheelchair as a gift.

The son's deterioration didn't stop there. After turning pages and handling pens became increasingly difficult, the only thing he could do to kill time was to watch TV in his wheelchair, but the remote controller would slip out of his hand from time to time. At first he was taken care of by nannies. When he grew older and his temper grew shorter, it became difficult for a female outsider to accompany him, compelling his father to spend more time at home and inevitably less time on his business.

Finally, Huang Xiaoyong had to sell his restaurant.

With no income and the medical bills piling up, the elder Huang took a job driving a taxi. He worked only half-days, and left the boy to watch TV at home when he was out. One day he returned from work at noon, and was alarmed when he did not hear the usual greeting from his son. When he rushed to the living room, he saw the boy on the floor face down, his neck stuck in a chair, and at his last breath. When the father pulled him up, he tried to utter the word “dad,” but couldn’t make any sound. The father’s tears poured down. He later learned that the boy had fallen from his seat while trying to retrieve the remote controller on the floor. This had happened before, but had never ended so dangerously. After this accident the father never dared to leave his son alone for long.

A man in the best years of his life gave up everything for the sake of his sick son. Nothing but a father’s deep unselfish love could have prompted him to make such an enormous sacrifice.



Huang Ge: “When I was younger, I was unaware of my illness, but had a feeling that I was different from other kids. Watching them run and jump, I felt like doing the same thing, but just couldn’t.”

Huang Xiaoyong: “When my son was a baby, he often cried at night, and wouldn’t stop until I held him against my chest. I would remain stiff in that posture for the whole night, feeling our hearts connected and that we would never be apart. This sentiment is also the reason why I will never give up on him. I love my son so much. Keeping him one more day in this world is the source of my happiness.”

Child of the Whole Neighborhood

Since selling their restaurant, the Huangs have been living in a rented home in Wangyuehu Residential Area. Though they are not registered permanent residents of the area, the neighborhood committee applied for the basic living allowance for them with the district government, which approved it as an exception.

The committee office is situated close to the Huangs' home. Committee members always call out Huang Ge's name when passing by, and check on his situation when hearing no response. One day Mrs. Sun found the boy flat on the ground. On another occasion Wang Peiru, Party Secretary of the committee, heard weeping in the room. He managed to open the door, and helped the boy back into his seat. "Don't let the motherless child feel ignored." This is the wish of every member of the community.



A donation is organized in Changsha for Huang Ge to cover his medical expenses, and draws the support of many corporations such as KFC.

The Huangs' neighbors Mrs. and Mr. Yang shoulder the mission of providing the boy meals when his father is out. On bad weather days, their son and daughter-in-law take over the errand of bringing food to the boy, and watch him finish it. Another neighbor Mrs. Xia handles other chores, such as collecting clothes outdoors before it rains.

Whenever the elder Huang goes out, even for a couple of hours, he always leaves the key with his neighbors, asking them to keep an eye on his son. The neighbors can enter the Huangs' home whenever necessary.

Though the help from neighbors is often with the trivial things of daily life, it is heart-warming and evokes a sense of belonging and security for the father and son.

Huang Ge: "In many cases I couldn't straighten up after bending over to pick something up off the floor. I remained in that position for a long time, and dad didn't show up. Desperate to alleviate the pain, I threw myself against the floor. The force of the impact caused more pain for the moment; however, it freed my legs from the oppression by the upper part of my body. So sometimes I dropped off the seat intentionally."

Huang Xiaoyong: "Without the help of my neighbors, I could not have stepped out of my home. I cannot imagine how our life would have been."