

**Should have
been dead**



SREČKO DODIČ

Should have been dead

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Prologue



I was born a mostly normal baby, or so everyone thought. For the first year of my life, there was no sign of what was coming. But then, everything started to change. I grew fatter, couldn't walk, and struggled to breathe. Concern turned to fear, and I was rushed to the doctor. They said it was nothing more than a vitamin C deficiency, but deep down, my parents knew that wasn't right.

At 18 months old—just a year and a half into my life—I was taken to Ljubljana for answers. What they found wasn't just shocking; it was devastating. I wasn't just sick. I was battling four of the rarest and most dangerous diseases known to medicine. Diseases so cruel that they came with an expiration date: A year and a half. That's how long they said I had.

But I'm still here.

This story is about what happened after that diagnosis. It's about defying medicine, outlasting predictions, and living a life that wasn't supposed to be mine. It's about survival—not as a triumph, but as a raw, unrelenting reality. Because while

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I should have been dead, I'm not. And that has made all the difference.

The doctors identified the diseases, though I can't recall all their names now. Two of them, however, left an indelible mark: Abernethy syndrome and pulmonary hypertension. Their complexity was as daunting as their names, each carrying a prognosis that weighed heavily on my future.

Intro



The news of my impending death at such a young age sent shock waves through my family. At home, everyone was devastated, but my father refused to accept it. He couldn't—and wouldn't—believe that saving me was impossible, no matter how many doctors told him otherwise.

He threw himself into researching my condition. Night after night, he scoured the internet, poring over medical articles, expert opinions, and patient forums. Sometimes, he didn't even sleep. Among the endless information, he discovered a sliver of hope—a liver transplant. When he presented the idea to the doctors, they dismissed it outright. They called him crazy, insisting that such a procedure would be impossible and pointless. Even if it were technically feasible, they said, the outcome would likely be tragic.

But my father didn't give up. He fought for that transplant, and eventually, the doctors came around to the idea. However, the surgery couldn't be performed in Slovenia. The munic-

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ipality began gathering funds for the procedure, and when everything was finally in place, I was taken to Bergamo, Italy, in 2009 for the operation.

My father stayed by my side every step of the way. I even remember sitting in the hospital with him, watching cartoons on a DVD player while we waited. The transplant was a success, but the days that followed were tense. The doctors warned that my body might reject the new organ. Despite their fears, just a few days after the surgery, I was riding a bicycle—with infusion and all—through the hospital hallways. I played in the children’s playroom, pushing cars and trains along the tracks.

I even had visitors—a basketball team came to see me and signed two basketballs for me to keep. Their visit felt like a small moment of normalcy in an otherwise extraordinary and frightening chapter of my life.

Chapter 1 : *Everything Begins, Yet Nothing Starts*



How do you begin writing a story like this?

That's the question I'm asking myself as I sit here, trying to put these words down. My life has been anything but normal, yet to me, it's simply the way things are. Maybe you're wondering: *What's life like for a kid like me?*

In kindergarten, I didn't have many friends. I was mostly out of it, my memories from that time are hazy. I was just a little kid, unaware of how different my life was. Things didn't get easier as I got older. After the transplant, my immune system was so fragile that a small infection could have been fatal. I didn't even start school at the usual age of six.

Let's start from the beginning.

I grew up in a small village, the kind of place where life felt simpler. Our local school was tiny—just two classrooms that served kids up to fifth grade. Most of the students and teachers

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came from the surrounding area, making it feel more like an extended family than a school.

I loved that little school. Classes were often combined because there were so few of us, sometimes just two kids per grade. I remember how we'd build Lego towers in the back of the room, spin our Beyblades, trade Bakugan, and duel with Yu-Gi-Oh cards. It was the golden age of toys, and life felt carefree.

But in the third grade, everything changed. The school closed, and we had to transfer to a bigger one in the municipality. At first, I was excited. A new school! More kids! More opportunities to make friends! But that excitement didn't last.

From the beginning, I felt out of place. The other kids didn't exactly welcome me with open arms. The boys ignored me, and the girls were openly rude. I did have one friend—a buddy, really—but he never stood up for me. I had to fend for myself, and that wasn't easy.

I tried to fit in. I teased the girls to get attention, thinking it might make me seem cool. I even started stealing things like their diaries, hoping it would make me stand out. I thought it would earn me respect, but instead, it only made me the punchline of everyone's jokes.

Looking back, I realize how much I wanted to belong, how desperate I was to be seen. But in trying to fit in, I only made myself feel more alone.

These aren't easy memories to revisit. They don't bring comfort, only a bittersweet ache. Trying so desperately to fit in while carrying so much on my shoulders at home—it was overwhelming. I missed a lot of school, too. I wasn't even a teenager, yet it felt like I had to grow up overnight.

Chapter 1: Everything Begins, Yet Nothing Starts

My life revolved around pills, constant check-ups, and long hospital stays. Some visits lasted days, others weeks, and sometimes even a month. My dad wasn't around as much during those times—he was always working, making sure I was insured and that we had what we needed. I've never blamed him for that. He did what he had to do.

Being alone wasn't always bad. I had hospital roommates, some younger, some older. You see so much in a place like that. The hospital became its own little world, filled with stories that could break your heart or restore your faith.

One story stayed with me. I met a boy and his mother, who was there with my grandmother. The boy's mother didn't have much money. I remember watching her pour a single drop of water onto a napkin to wet her son's lips when he was thirsty because that's all she had. She often went without food, giving her meals to him instead. My grandmother couldn't stand to see that. She went shopping and brought back bags of food, water, and fruit juice—enough for both of them. Their gratitude was overwhelming; they couldn't stop thanking us.

Moments like that left an impression on me. Even through all the pain and isolation, sometimes I felt better off in the hospital. I knew everyone there, and they knew me. It wasn't just a place for healing; in many ways, it became a second home.

Chapter 2 : Between Life and Death



So Much to Tell... But Not Many Words

That's how it felt. When you're used to being quiet, not telling anyone anything, the weight of it all can be hard to express. The hospital had become my second home.

The year was 2011, and by far, it was the saddest year of my life. My grandpa grew seriously ill. It was clear he didn't have much time, though we didn't know how soon it would be. At the same time, my grandma fell and broke her hip while going to the bakery. And then, I found out I had cancer.

Grandma wasn't home much after that. She was in a rehabilitation center, and so I stayed with Grandpa. I loved spending time with him, even when Grandma was around. We watched MotoGP together, ate pasta with tuna—his favorite, and mine too, though I never told him that. We ate it almost every day. Grandpa was a well-known accordion player, but by then, he didn't play much anymore.

A while later, Grandma came home from rehabilitation, and just when I thought things couldn't get worse, life hit us again.

Chapter 2 : Between Life and Death

Grandpa passed away. He could have been saved, but the nurses made a mistake, and within two days, he was gone. I still miss him.

Grief hung over us for months. Then, just as I was beginning to process it, I became seriously ill. Everything I ate, I threw up instantly. I couldn't drink. I couldn't eat. I was sick day and night. Grandma took me to the doctor, and the diagnosis was grim—early stages of two cancers in my small intestine. The doctors said they needed to operate immediately, or I'd have only a week to live without treatment.

Surgery was the first step. They removed 20 millimeters of my small intestine. At the same time, I was going through heavy chemotherapy. My hair didn't fall out, thanks to the strong medication I'd been on for my liver and lungs.

Looking back, it was a time to remember—if you can call it that. I fought through two cancers at once. How did it feel? Honestly, I just prayed to keep living. I knew that somehow, this story would be something worth sharing. Even though I'd never wished for death, I just wanted to keep going. And I did.

There were moments when I was so weak, it felt like I was crossing over to the other side. I even had dreams about it. But no matter how close I got to the edge, I never gave up.

Chapter 3 : Scars of Growth



School Was Starting to Get Serious

School was starting to feel more serious as I got older. After everything I'd been through, some people saw me as a hero for surviving so much. But in reality, life didn't feel heroic. By 2012, I was in the 5th grade out of 9, and things began to get messy.

That year, I signed up for a cooking class, which I absolutely loved. At home, I wasn't allowed to experiment with food, so this was a new and exciting outlet for me. The class had a playful rivalry—boys versus girls. Somehow, the girls always won, though I think our teacher, who was vegan and seemed a bit biased, may have tipped the scales in their favor.

I also joined the singing class. It was mostly girls—16 of them—and just me and one other boy. I loved the group performances, but when my voice started to change in the 6th grade, I stopped.

Despite these activities, school was tough. I started acting out, particularly toward the girls, likely seeking attention. The boys

Chapter 3 : Scars of Growth

didn't take kindly to this, especially as everyone was becoming obsessed with love and relationships. They turned on me, and their words cut deep.

"Kill yourself."

"You should've been dead already."

They mocked me for my surgeries, joking that I'd had so many that my penis must have fallen off. It didn't stop there. They followed me to the toilets, taking pictures and videos, laughing as they said I should use the women's restroom instead.

It was a brutal year, but I held on, waiting for the summer holidays.

That summer, things felt different. My grandma had a friend, a partner, who moved in with us, and we traveled together to his family's place in another part of Slovenia. It was a quiet, rural area near Austria, surrounded by vineyards, cornfields, and wheat. It felt like a different world.

One day, while exploring, my brother and I found a friendly German Shepherd at a neighboring house. The dog seemed eager to play, so I picked up a stick and started a game of fetch. At one point, we ended up tugging the stick in opposite directions. The dog was smarter than me—he let go, and the stick smacked against my foot. In an instant, he grabbed it back, biting my leg in the process.

Blood poured from the wound. I screamed and ran back to our summer house, terrified. My grandma quickly tied the wound to stop the bleeding. It was bad—so bad that you could see the bone. Adrenaline blurred my vision, but I could feel the severity of it.

The first emergency center we went to was too small to treat me properly, especially with my condition. My skin doesn't heal well, making stitching a challenge. We had to drive to

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a bigger hospital, where they attempted to stitch the wound. When that failed, we went to an even larger hospital that had the expertise to deal with my unique medical needs. Thankfully, the dog didn't have rabies.

I spent the entire summer—and much of the fall—with my leg in an orthopedic cast. By the end of it all, I had a massive scar. But for me, that scar wasn't just a reminder of the accident—it was proof that I'd made it through another trial.

Chapter 4 : *When the World Stood Still*



“The Day My World Stopped”

As we move into my later school years, not much seemed to change on the surface. I was still going for regular medical checkups, still being laughed at, and still trying to focus on my education. The days blurred together, and before I knew it, 7th and 8th grade had come and gone in a flash.

By the end of 9th grade, though, everything changed. My world began to crumble.

The coronavirus pandemic had reached Slovenia. Masks turned classmates into strangers, and life felt surreal. Oddly, during that time, I started forgiving those who had wronged me. I even began talking to a few girls, but I wasn't truly their friend—just someone they gained a little respect for. Some of them still say hello when they see me, and I think the weight of

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everything I'd been through finally sunk in for them.

I started writing—songs, poetry, anything to channel the storm inside me. My dad encouraged me, sometimes correcting my lyrics or giving me ideas. I poured my heart into 40 songs that winter. There was a girl I liked at the time, though I'm not sure if it was love or just the need for validation. I gave her the songs as a gift, hoping they'd mean something.

She barely glanced at them before tearing them in half, laughing and calling me a simp. She threw my work in the trash, dismissing not just my feelings but the hours I'd spent with my dad creating them. It didn't hurt as much as I expected—not because I didn't care about her, but because I cared so deeply about what those songs represented. Losing them felt like losing a part of myself and my connection to my father.

A few months later, life delivered a blow I could never have prepared for.

It was April 9th. I had been waking up in the middle of the night for years to take my medication without an alarm, but that night, I didn't wake up. Three missed alarms rang out as my dad lay on the couch, his heart quietly stopping sometime during the night.

When we found him in the morning, his body was cold. He lay with his arms outstretched, his mouth open, his eyes still staring into the room. He looked like Jesus on the cross, peaceful in a way I couldn't comprehend. We panicked, desperate to wake him, but it was too late. All we could do was close his eyes.

That day, my heart shattered.

Schoolmates sent their condolences, likely prompted by our teacher. Some were sincere, but others made cruel jokes later on. I got into fights—fistfights—because I couldn't let those insults slide. When others partied at the end of the school year

Chapter 4 : When the World Stood Still

and laughed, I felt like I was drowning in sorrow.

Music became a painful reminder. My dad was an incredible accordionist, and when schoolmates played accordions, I couldn't bear to listen. Yet, despite the grief, I eventually found myself drawn to the instrument. Little did I know that one day, I would play, too.

Thank you, Dad, for everything. For teaching me how to dream, how to fight, and how to keep moving forward—even when the world stops.

Chapter 5 : New Paths, Old Scars



The year that followed felt like skies painted in gray—a time of uncertainty and loss. I had finished primary school, and it was time to start high school. My choice was clear: the high school my dad and I had visited together in February, just months before he passed away. That visit is etched in my memory, down to the very classroom we had toured—a room I now often found myself in.

That first year of high school was a blur. The pandemic was still in full swing, and classes were conducted via Zoom. Like many other students, I found it hard to focus. Instead, I sought distraction in video games. My dad and I had shared a love for *Need for Speed* games, often racing against each other's times. I still remember the ghosts of his races left in the game. Unfortunately, the PlayStation 3 had succumbed to the infamous yellow light of death before he passed, taking with it a piece of our shared world.

I struggled academically that year and ultimately didn't pass. It was a tough pill to swallow, but the following year brought

Chapter 5 : New Paths, Old Scars

new opportunities. Classes resumed in person, and with a new group of schoolmates, everything felt different. I was older by two years, which automatically earned me a certain level of respect. The dynamic was refreshing, and for the first time in a long while, I felt like I belonged. I've made friends there, ones who genuinely seem to care.

Rarely do I speak with the so-called buddies from primary school. I had hoped some of them would remain close, but time has a way of revealing true colors. My 19th birthday was a turning point. I invited friends from high school and a few from primary school. While we were having fun playing accordions and joking around, the primary school group kept pestering me for alcohol. I don't drink—not a single drop, not even 0.0% beer. It's expensive, pointless, and often leads to more problems than it's worth.

After an argument about it, I left their group on social media to cool off. Later, I checked my messages from that week and discovered they had been talking about me behind my back. Hurt and disappointed, I blocked them everywhere. I didn't give them an explanation—just a few final words to let them know how much they'd let me down. Now, I only exchange polite greetings if I see them, but I've made it clear we could never be friends again. My dad always taught me to be kind, but he also taught me to stand up for myself.

Since then, I've spent more time with my high school friends. We've shared good moments, like trips to burger places and long conversations that made me grateful for their company. They still drink occasionally, but never around me—a sign of respect that I deeply appreciate.

I've completed the first three years of high school and am proud to say I'm now a certified computer guy. It wasn't easy,

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and the next steps in my education promise to be even harder. Still, I'm ready to face the challenges ahead with the same determination that's carried me this far.

Chapter 6: A Love Worth Waiting Far



The year 2024 came around, and I thought it would be just like any other year. But it seems God had been listening to my thoughts. I had been yearning for my other half, and in March 2024, my prayers were answered. It marked the beginning of a beautiful chapter in my life—I met a girl, a very special girl.

She's just like me in so many ways and brings such immense joy to my life that it makes all the suffering I've endured feel worth it. We met online, and I have no shame in that. We're a long-distance couple, and soon we'll be celebrating ten months together. From the very beginning, we clicked in an instant. She's so beautiful that words alone can't do her justice. Being with her feels like we've known each other forever.

Within a week of our relationship, we both knew we could trust each other completely, and I'm incredibly proud of that. I'm proud to call her mine. As the months have gone by, my

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love for her has only grown deeper. I adore her and look up to her. She's so amazing, even if she doesn't fully realize it. She sometimes sees herself as not much, yet to me, she means everything. Her beauty surpasses even the northern lights.

For my birthday, she gave me a gift that I will always cherish—a bundle of love that included a special Christmas surprise inside. Before her, I never truly experienced the magic of Christmas. Sometimes, my dad would run out of money, and social services would provide a small gift. After I turned 12, even that stopped because I was considered too old. But she changed that. She gave me a collection of snacks, her hoodie, and a Nintendo Switch for Christmas. It means the world to me.

She has brought light into my life, and I'm proud to call her my future wife.

Epilogue



A Journey Worth Living

As I reflect on the chapters of my life, I realize that every moment—every triumph, every tear, every battle—has led me to this point. Life is not just a series of events; it's a mosaic of experiences that shape us, challenge us, and ultimately define who we are.

I've faced darkness that seemed insurmountable and walked paths that many thought I wouldn't survive. Yet, here I am, stronger, wiser, and filled with a deep sense of gratitude. Gratitude for the love I've found, the lessons I've learned, and the life I've been blessed to live.

This story is not just about me—it's about the people who have walked beside me, even in spirit. It's about the power of hope, the importance of kindness, and the enduring strength of the human heart.

To anyone who has ever felt lost, broken, or forgotten, let my journey remind you that your story is not over. Every setback is a setup for a comeback, and every scar is proof of your survival.

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Keep pushing forward. Believe in the light, even when it's hard to see.

And as for me, my journey continues. There will be more battles, more triumphs, and more stories to tell. But for now, I'll cherish the present, hold tight to those I love, and live each day with purpose and joy.

Because if there's one thing I've learned, it's this: life, no matter how difficult, is always worth living.