

Losing Dylan

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I could barely feel him in his last year when Dylan put his arm around my shoulder. *If I have to think about it, the only thing I ever really loved was counting*, he said as he watched the clock on his night stand as if he were listening to it, waiting for it to tell him a secret long kept. *You should leave. It's ten minutes to midnight.*

And he was telling the truth. By the age of three he could count to ten. And when he was eight years old, he knew every possible combination of whole numbers that brought him to that number. The number ten was a universe he completely dominated and easily controlled.

In junior high school he learned fractions and percentages and the decimal system, an entire language and culture based on the number ten. In high school he learned geometry and calculus, reinventing ways to count, rediscovering his journey back home to the same number.

Counting was his passion; it was the only way he knew how to love.

That is why, as he grew older, like ten perfect little Indian boys, his fingers betrayed him and left him devastated. They took the soul he had as a child and cut it into tiny pieces and hid them among fire trucks and Legos. By the time he was 25, his soul was fully haunted, ripened, lined with cobwebs and dead trees and all the things adult souls are made of before they turn into nothing.

Instead of a blinking streetlight he saw darkness.

Instead of the laughter of children he heard echoes.

How ironic to look back and say these things now, but they've always been true.

I've known him since the day he was born. As his cousin, I was there when his parents brought him home from the hospital; he was like a moth, wrapped in a cloud of yellow fleece.

He's so tiny, I remember thinking, my small, child's hand able to cover his face entirely.

I was with him in grade school, and I've seen him develop over the years, from the brainy student in junior high to the budding genius of a scientist in high school. Other students spent their days going to concerts and movies and hanging out at fast food restaurants until it was time to go home, but Dylan was different.

As a teenager he always kept a journal. It contained the normal (and expected, by this time) mathematical formulas and scientific notations, but it also contained some of the most disturbing poems and drawings I had ever seen. I felt distant, yet at the same time I knew him in a way no one else did.

I suppose, in a way, I despised being his cousin because, deep down, I wanted only to be a part of the ethereal world that eventually embraced him.

It was while he was in high school when he started to delve into that mysterious land of dark shadows and imaginary spirits that seemed to later possess him. Whenever I caught him talking aloud in full conversation, no one else in the room and eyes fixed in a gaze that took him to universes outside his window, I would ask him who he was talking to.

His response was always the same, *The friends you are not allowed to see, so don't bother asking*.

The spells became more frequent, and that was when the doctors examined him for the first time. And though it would be years before an official diagnosis, they warned us that hallucinations were not unusual. *He needs love*, was all they would tell us. *We don't know much*

about what is happening to him, but one thing we know for certain—he needs to learn to love, and he needs to learn to be loved. That will help make him feel whole and complete.

Whole and complete. I think it was then that I felt real love for him for the first time.

The fact that we were both men didn't scare me. The fact we were cousins scared me even less. What frightened me more than anything else was that since the day he was born it was as though Dylan was fading away from us, and no matter how I tried, I could not penetrate him. He was like a room with no door. A wall made of cast iron. A stone.

If there's any crying to be done, I'll be the first to do it, he would later say when we first found out about his diagnosis. *And if anyone was going to feel sorry for me, it would be me and me alone.* He whispered this from beneath the covers of his bed when I slept over, half the person I remember him being, sleeplessness and despair hidden in shades of yellow.

He was 19 when I noticed that his eyes had grown black—they would later say that is the first physical sign with this disease. Throughout our childhood they were always blue, but it was only when we were in college—he, a freshman, I, a senior— when his eyes slowly started to change to a darker shade of green before turning black completely. I tried to ask him about it one day, lying next to him on his bed, holding him as if I were his surrogate mother. I tried to warn him as one might try to stop a train from running. It was that futile.

Dylan, the blue in your eyes is almost gone, I said, running my fingers through his hair the way a mother might do. *Have you ever noticed that?*

Yes, but I can still see, was his only reply.

And I remember that moment as if it were just yesterday. Going back to my dorm room that evening after he fell asleep I asked the sky, *Why does every second feel like the last, as if the*

*moment I leave his side the next bomb will fall, or the sky will turn to ash and bury us alive?
Why are my thoughts always like captive birds, my words like sad prison songs?*

These were the questions of a prisoner losing his cell mate, my cell just a thought and a room away. And as I walked inside my world as if nothing else existed in it, secretly he walked around with me, haunting those walls, reminding me that my life sentence had already begun, that life both stops and carries on, that the minutes pass by without parole, without any relief other than his smile and his words as they fell like flower petals from his lips.

The diagnosis finally came one year later, and when it did, neither of us could believe it. *Invisibility?* We asked the doctors incredulously.

It's hard to believe, and to this day doctors cannot completely explain it, but since the day of his birth Dylan has suffered from an illness without a name. Simply put, he is becoming involuntarily invisible, slowly but steadily with each passing year.

To understand this phenomenon, it helps to understand the basic principles of physics. Objects are seen when light reflects off their surfaces. In its simplest form, invisibility occurs when objects no longer reflect light. This stage is called transparency. But before an object can become transparent, it must first go through a stage of translucence, where light is allowed to pass through it, but does so diffusely, so it cannot be clearly seen through.

Dylan once told me, *Think of tinted glass that then loses its color and becomes a frosted window pane. Over time, it becomes clear, like glass. Only when the light has completely consumed the glass is the glass no longer seen.*

In Dylan's case, his disease caused his body—from his cells to his muscles and even his bones—to pass through a stage where he had become translucent. His image was still there, though it was vague and cloudy.

Am I beginning to lose you? I asked, not fully aware of what to expect.

Lose me? He asked as if the question did not warrant merit.

I had to remind myself that he won't be dead, that wavelengths of light would begin to shift at a frequency outside the normal optical spectrum. Then, he won't be seen or heard of ever again.

What I learned over the years is that when the body becomes invisible, it does not do so overnight, and it does not occur finger by finger, limb by limb. Instead, this is the way it happens:

In an attempt to separate itself from the body, the mind hallucinates, as if it knows the body will soon disappear, so it spends its time finding a new home for itself. Color is the first thing to go away. The eyes turn a pitch black color, giving credence to the belief that black is the absence of color, and not the combination of all colors. The same is true with hair, just before it falls out. The blood then becomes clear, as if it were only plasma, and thins itself as it runs its course through the body. The loss of pigment in the skin then follows, and the body becomes pallid, and must be protected from the sun.

Only when all color has gone does the light begin its slow ascent.

Then slowly—so slowly that it almost goes unnoticed—the body simply begins to fade all at once as light passes through it more intensely with each passing day, as if the body were a

chalk mark left in the rain. As it does, the body becomes lighter in weight, its outlines more blurred and difficult to see, until it presents itself like a mist just before saying goodbye.

I say this because the very last thing to go is the voice.

At times this sounds unbelievable, but at other times it makes so much sense, like when I am on a plane, and it passes through clouds and causes turbulence. Clouds remind me of Dylan because they, too, are somewhere between empty space and physical matter, almost unseen by the human eye, but very much in existence. Enough to shake a plane. Enough to shake my entire body.

Is it the mindlessness of childhood that opens up the world? Because today nothing happens in a gas station. This he said as we stopped to get gas before heading on a weekend camping trip to Connecticut. It was when he said things like this when my world would suddenly stop, and I'm reminded that our time together is sacred, and each moment—each carefully sewn moment—must be held in my hand and cherished like a fine, silk tapestry.

Today nothing happens in a gas station. I wanted to bottle that moment and preserve it forever. He loved to count, but I loved him most when his mind worked words this way. His illness was something I had grown used to, but over time loving him meant loving only a fragment of him, never loving the entire person completely. And though I desperately wanted him to get better, it was his mind I was most afraid of losing. So as his body slowly left him his mind never did, and I came to love that mind because it was the only part of him left to love; it was the only part of him that mattered.

I no longer thought of him as my cousin, but as a soul mate. A partner in life, however brief that life may be. Of course I told no one because no one would understand, but I came to love him as a lover.

And I remember the first time we made love. Nothing scared me like his body that night. His hair had already fallen out, and his eyes were black eyes and soft skin white. Afraid of himself, he asked me to hold him. And when I did, he said, *I feel like a clam shell bending in half, testing my strength as I test my hinge. I feel 'undone'.*

And I remembered the words of his doctors, *Only through love would he feel complete.* So that night, under the canopy of the New England sky, we made love, each completing the other.

Eventually, it would not be enough.

It was late November. Nearly four weeks passed after that incident and he avoided me at all costs. At Thanksgiving the only real words he said were related to food.

Dylan seems to be angry with you for some reason. His mother said to me when Dylan got up to go to the bathroom. *Is there something going on between you two?*

Nothing that should make him angry, was my reply. And that was exactly how I felt.

That night I wrote him a letter. Like a seed that needs nine days to grow, my thoughts began to take root on the tenth day. This is what I wrote: *It wasn't epilepsy, because epilepsy was never like this. Granted, your body jerked in convulsions as if you had an electrical storm raging inside you, and your eyes rolled into their sockets like two cameras eager to take a snapshot of you from the inside, the way I see you. But all that stopped the moment I removed my lips from your shoulder and kissed it and cupped it in the palm of my hand as it quivered like a lost bird and whispered in your ear, 'Everything will be alright.'*

The first rule with epileptics is to keep the mouth open. Watch the tongue to make sure the victim does not swallow it accidentally. But it was my tongue he swallowed. My mouth he pried open to retrieve the sweet, magical elixir reserved only for him.

I wrote this only once I was completely consumed by him. Never had such an experience moved me. The electricity of his body scared me at first, as if he lost control of his reflexes.

But what I was trying to tell him was that he did not lose control; instead he gave it to me, trusting me with it like his most intimate lover. The effect was still the same, but the passion made all the difference. It was not the loss of control, as with epilepsy, but something more, like love—a love too little, too late.

He later called to tell me the letter disturbed him because I compared our lovemaking to a disease.

I spent the next few months trying to determine what had the greatest effect on me, making love to the softness of his skin as his body fluttered beneath mine, or kissing away the tears that leaked from his eyes as he told me he wanted desperately to love me, but didn't know how. *I feel half empty*, he said, but what does this mean when it comes from someone who is half visible?

Making love to him felt comfortable and natural, as if we were completely alone in our own private Eden. It felt that new. Maybe he wanted me to say, *I love you*, but I could not. Not because I did not feel love, but because saying so would be like trying to squeeze a lifetime of emotion into three tiny words—a cruel and unjust minimization. Instead I let my body speak for itself. My fingertips. My lips.

Do you know what is happening to us? I asked between kisses.

What? He asked.

We are communicating on a level far beyond the physical. I said this because the physical, we had come to learn, no longer mattered.

Why are we doing that? Dylan asked, the confusion only gripping him slightly.

Because I am trying to save you.

And he smiled for the first time since his diagnosis, and said, *I'm fading, yet with you I feel as impervious as scarlet.*

These were the last words he said. And as he said them, I reminded him that he was named after one of the greatest poets our world has ever known. One who wrote, *Do not go gentle into that good night. Rage, rage against the dying of the light.*

It has been nearly six months since he faded away; apparently, my love was not enough to keep him with me. It is now twilight, and the only light is the moon as its fingers slide through the window shades and point to the cobwebs on the ceiling and to the chair in the corner and to the mirror that sends them dancing on all four walls in a frenzied cabaret.

These are the things that reflect light; not people.

Within the family we refer to the incident as the *loss of Dylan*, but I think that sounds as if we misplaced him. As if it were completely appropriate to say, *He was here a minute ago, and now he's gone.*

After all, this couldn't be less true, but how do you grieve the loss of someone who has not really died?

How do you make love to a shadow?

But we didn't really lose him at all. The doctors remind us that Dylan has moved into another dimension, one that allows him to see and hear us, although we are not allowed to see and hear him. This is worse than losing him because there is still room for words in this place, so I must work overtime to not tell him the things I want to say:

That I see him in the eyes of complete strangers.

That I hear his voice when no one else is around.

That I am jealous of the loneliness that surrounds him.

And that in his last few weeks I wanted nothing more than to be the empty chair by his bedside, the echo of his voice in the hallway.

Instead I remain as silent as the light waves between us.