



*This book excerpt is the first chapter of the book *Living Life in the Lymelight* by Rachel Long, ghostwritten by Wendy Strain, now available on Amazon. As of 2020, Rachel was in the process of writing her second book with Write Services.*

## Daddy, I'm Dying

The feeling had been lingering for several days, but I didn't know what it was.

It was almost like waking from a blissful dream, everything golden and fuzzy at the edges, a *Through the Looking Glass* kind of feeling. When Joe came in for my regular tutoring. I remember focusing on his dark Justin Bieber hair falling in his eyes as he explained something from a white space on his lap that I didn't recognize as a book. A glint from his braces sent me skidding back into a light place where I floated for a while.

I came back when I felt cold. It was the beginning of November on the east coast so cold was no big surprise. Cold while lying in a heated house under two blankets was hard for my family to understand, but Joe got it. He must have seen me shiver.

"No sense wasting your energy shivering," he muttered as he spread yet another throw blanket over me. "Are you hungry?"

He was only supposed to be a tutor while I was on homebound instruction, but he was so caring and sweet, there were days when I thought I might like to have him be something more than just a friend. I could tell he'd been eating corn chips sometime earlier today and sure enough, he pulled a bag out of his backpack. We shared a smile over the fact that it wasn't open, meaning he'd brought it just for me.

But I shook my head no when he went to open it. It surprised me a little that I really wasn't hungry. I'd been eating everything I could get my hands on for a while, but just kept losing weight. My body was so slim now it could almost get lost in the couch cushions as my sister nervously joked, but food was the last thing on my mind right now. It seemed I was all filled up with that mysterious feeling that was starting to take over my entire life.

I couldn't figure out how I could possibly be physically full with a feeling, so I had to explore that idea for a while. I could hear Joe talking from the other side of the room, but I wasn't sure if he was talking to me, my mother, or the wall. I had to figure out this question of the feeling. It was as if my stomach were on strike, my entire digestive system just no longer present. Whatever had been there was simply replaced by pain, but even that was starting to fade, leaving behind ... nothing.

That made sense. If there was nothing there, there was no need to feed it. But wasn't that supposed to be me? If that was supposed to be me and I wasn't there, what did that leave here and where was I? A creeping realization started to come over me about what this feeling might be and why it was so persistent. I still hadn't come to a definition yet but I could feel it coming. There was a sense of dread that blocked the words from coming clear in my head.

Then Joe was pressing up close to me, like my own private watchdog, as a group of men filed into the room. Wearing a variety of khakis, blacks, and grays, they exchanged meaningless greetings in low, careful voices. Then they each bent down to shake my hand, murmuring

something that might have been their names. Joe shyly shook each of their hands as well. Some of the men looked familiar, but their faces blurred from one to the other they were moving so quickly. Or maybe I was moving too slowly. But I wasn't moving. But I didn't feel like I was anchored here. That was how the feeling worked. I was living in a different time and space, overlapping their time and space for the moment, but it wasn't the same anymore so it wasn't synched just right. I almost giggled at them as I realized I was living outside the lines.

The Pastor from our church came into focus.

"Rachel, your father told us about your health struggles," Pastor Hezlep tactfully mentioned.

My health struggles. I was nothing but skin and bones, my hair was falling out and I was as gray as ET. I was too weak to lift my own head, much less get off the couch. I could tell from the look in the men's eyes around me I was pretty scary to look at. Joe and my dad never let on, but sometimes I could see it in my sister's eyes and hear it in Mum's voice.

"These men are all members of the church board," Pastor Hezlep continued.

"Or past members," interrupted a walrus near my feet. On second look, I realized he was actually a large man with a full grey beard wearing a grey suit, but my mind had morphed into a Disney moment, where all the people became animals. I felt the walrus was more entertaining.

Pastor Hezlep had continued talking, but I missed much of what he said. Besides the man who looked like the walrus in *Alice in Wonderland*, there was a fox (*Robin Hood*), a penguin (*Mary Poppins*), a duck (*Donald!*), a hound dog (*Lady and the Tramp*), and a cat (*Oliver*). It seemed I had many of my favorite Disney films represented in these church elders. Maybe they could channel some of that magic and help me spring off the couch with the energy I used to have; as a teenager, the energy I should have had.

With my father, the Pastor and Joe, who stood by my side through all the introductions, that made nine people who could stand up and one skeleton on the couch in our cozy little sunroom turned sickroom. Almost standing room only.

I might have drifted again, because the figures around me suddenly morphed back into serious men who were now surrounding my couch and linking hands.

It was comforting to have them praying over me, the sounds of their voices raising and lowering, the vibrations from the sound waves felt physical, bouncing against me, pushing past me. I lost myself again in trying to follow the patterns they formed, reveling in the way they tickled as they passed. I realized I wasn't actually feeling much of my physical body anymore other than the light, fluttery feeling in my chest. It felt like I inhabited a small glowing ball bobbing on the couch about where my neck was, big enough to include my head and chest but not tall enough to raise above the couch and too heavy to float away but not heavy enough to press on the cushion. I wondered when I moved into this kind of body. I wondered if it was part of the mysterious feeling.

The voices stopped. The men looked more serious than ever. The Pastor said another short prayer and I could feel my full body again, like a paper doll, but it was there. The men filed out, each one stopping first to shake my hand and murmur some more words of encouragement, then shaking Joe's hand.

"Keep fighting."

“Stay strong.”

“You can beat this with God’s help.”

“Have faith.”

It was sweet of them to say, but the words didn’t feel right. I’d been fighting, I’d stayed strong. When people thought I was making it up, I kept trying. When I saw Mum and Daddy struggling, I tried to not be sick. I avoided everything, I tried everything. I prayed, I read my Bible, I tried to have faith. But I was so tired. According to Joe, I couldn’t even stay focused for half an hour anymore. I used to be afraid of what would happen if I just stopped. But the truth was in their eyes. I wasn’t beating this no matter how much faith I tried to have. I wanted to cry by the time the last of my cartoon friends left. There’d been no sparkly lights, no fairy dust. So much for Disney magic.

The Pastor was last. He knelt down next to the couch facing me.

“Rachel, I know your road has been dark and frightening. I know you’ve been trying to stay strong and I know it’s hard. You have a full life ahead of you, though. You have a family that loves you. You need to have faith that you will survive and that you have a purpose. Hold onto that purpose.”

Then he got up and my father escorted him out of the room. Oddly enough, the Pastor seemed to have keyed in directly to my thoughts. I wondered about the connection. Was there some place in that floaty, white space I found myself in more and more often that he was able to understand? Maybe there was something more to what he said than I’d thought. It was worth considering, but first I had to figure out what to do about that feeling, the one that was so persistent and so distracting.

I felt as if another room closed down somewhere. I saw it in my mind and almost felt it in my body as the lights went off, computer hummed down to silence, shoes tapped through the empty space and faded away. I was confused because we didn’t have a space like that in our home. Everything but the kitchen on the other side of the house was carpeted and the kitchen was too tiny to have inspired this impression. The only room I knew of like the one that just shut down in my mind was the computer lab at the school I hadn’t been to yet this year.

Daddy was watching TV. Maybe it was on a show he was watching. Not sure when Joe left. I could see my dad sitting in his favorite chair in this room, my own private garden when he wasn’t in it. It was covered in a rose-colored floral fabric with a cream background. Sometimes I thought I could see faces looking out of it. I felt bad that he was trying to spend time with me and I was somewhere else, but I couldn’t seem to focus anymore. That feeling kept pulling me away.

Now there was a fluttery sensation deep in my chest. I’d heard about butterflies in the stomach before going on stage for a performance and had felt first-hand that wonderful sensation you get as a ballerina on stage dancing in the beauty of the moment. But this was more like bats in the ribcage and I considered how beautiful it would be to dance among the clouds of heaven, not limited by the pain and weakness I’d been struggling with so much. It felt as if there was something living inside of me that just had to get out. For a moment, I felt panic. A scene from an old movie flashed in my mind of a tiny alien bursting out from some girl’s chest but I knew this was something different. This was something that was connected to that feeling I’d been having. The mysterious sensation came and went, never staying long enough for me to figure out just what it was, but never going away. That was what was so strange about what I was feeling, it

kept changing, sometimes physical, sometimes emotional, sometimes mental, but I always knew it was connected to the same thing. I just couldn't figure out what that thing was.

As my father knelt next to me that night, praying for my health, it suddenly dawned on me. The feathery light feeling, the reluctantly giddy sensation that was both floating and clinging, it was the feeling of death. As the soothing tones of Daddy's low voice washed over me, I felt a strange awakening to the idea that I was preparing for eternal sleep, my organs shutting themselves down like rooms at the school, my brain finally understanding what it was all about.

By the time these thoughts finally translated themselves into words my mind could comprehend, my father had finished his nightly prayer and had already begun walking across the living room toward the actual bedrooms of the house where my mother and sister were getting ready for bed.

"Daddy," I called after him. I didn't want him to find me in the morning not knowing that I'd been ready, so ready, to leave this life behind.

My heart was barely beating now, so it took massive effort for me to suck in another breath to give my voice enough power for the second call.

"Daddy."

He was almost across the room by now, but he heard me this time and came back.

"Did you call me?"

I waited until he'd reached all the way to the sofa that was now my bed before I tried to talk with him again. If he didn't hear me the first time, I wasn't sure I had the energy left to repeat it. I wanted to touch him, to let him know through my skin what I wasn't sure I'd be able to say with my lips.

After all the pain and misery, the mystery of what was wrong with me, receiving practically no actual help from the medical community and now living in what used to be the family's screened in sun porch coincidentally converted to a cozy add-on room the year before I got sick, I was tired of the struggle.

He saw my hand fluttering around, failing to obey my commands, so he knelt down again and took it in his own. He was so warm, I could almost feel the pulse of his blood pumping through his veins and half-wished I could crawl inside that warmth and stay there. The light in the base of my brain grew brighter and I remembered the warmth I was heading for.

I opened my eyes again and he was still there, still holding my hand, still kneeling by my side, still waiting for me to tell him what was on my mind.

But I couldn't. Even if I knew how to put everything that was going on in my head into words, I couldn't possibly express it all to him in the space I had left. I couldn't look into those dark eyes filled with tears and sorrow, the salt and pepper scruff that had accumulated on his chin through the course of the day outlining the sad lines of his face as he watched his daughter, me, melt away in front of his eyes, and tell him about the ecstatic joy I could feel in the lightness that was seeping into me. At the same time, I wanted to comfort him that there was extreme gladness in what was happening, I needed to express the soul-crushing sadness I felt at leaving him, leaving everything I've known, and never having the chance to live any of my dreams. How could I express to him how much I appreciated everything he'd given me, all the love he'd shown me, how much of himself he'd freely shared with me?

I couldn't say it all, but I had to say something. I had to let him know his efforts had worked. I was at peace. So, I said it not with a sob or a plea, but as the statement of fact that it was, a truth as neutral and beautiful and painful and peaceful as a clear mountain lake.

"Daddy, I'm dying."

My Daddy pulled my hand to his lips, leaned his head upon mine, and wept for us both. I didn't even have the energy to cry. I couldn't tell if the tear that slid down my cheek was mine or his. It seemed even my eyes were disappearing now.

"You can't leave us now," I heard a broken voice from above. "We need you too much. Not just your family who loves you, but all the people you're meant to help. I know there's a reason for what you're going through. Please, Rachel, you have to hold on a little longer. Don't leave us yet, Rache. Please don't leave us yet."

I wished I could hold on a little longer.

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The next thing I knew, I was smelling waffles.