

## **The Long Trek Upstairs** by Jason Ohler (2014)

Once again, life is taking my breath away. But this time it's not because I'm bedazzled by a supernatural sunset, or overpowered by a stranger's random act of kindness rising above the noise of an ordinary day.

This time life is taking my breath away quite literally, and getting idiopathic pulmonary fibrosis (IPF) to do the dirty work. IPF scars over the lungs, steadily reducing their ability to provide oxygen. Little is known about what causes it, and a cure is nowhere in sight. I have become a balloon with a slow leak. Each day I measure my life in terms of the mundane activities I can no longer do as well as I could the week before. Like walking upstairs.

There are seventeen steps from the first floor to the second, including the landing. A journey all the way to the second floor always seems daunting. But upstairs are my large computer screen, my books, my world. I have to go.

With one hand I grip my laptop. With the other I carry my oxygen concentrator, about the size of a lunch box but much heavier. It sprouts a seven-foot long cannula, a flexible clear tube that feeds me oxygen through my nostrils. I set the dial on four, which is as high as it goes, and begin walking slowly.

Buddy, our 90-pound yellow lab, rests on the landing, waiting for a reason to bark. I step over him onto the fourth step and sit on step five. I set my laptop and concentrator next to me, and I rest so that I can "O-up"—my term for replenishing my oxygen level—before I stand and resume my journey. These days I often find myself waiting for my breath to reinhabit my frame so that I'm able to do whatever is next. Because I am temporarily stuck between two points, I sit with myself, and my mind roams the world of my condition.

"I'm so sorry, Buddy," I say as I run my hand slowly over his head and down his back. I apologize to him daily for no longer taking him on our power walks.

Less than a year ago, we walked an hour or more every day, pounding through the rolling pathways of our neighborhood. We celebrated each new morning this way, two small creatures moving through a vast desert landscape that stretches to mountains many miles away in all directions. Since our walks have stopped, and exercise in general has become too challenging for me, I've lost 25 pounds that I couldn't spare, largely through the loss of muscle mass, otherwise through the loss of appetite. I've gone from fit to fragile in 10 months. Buddy, on the other hand, is gaining weight he doesn't need.

"Sorry, Buddy, I wish I could explain this to you." But I can't even explain it to the humans in my life. As I pet him, the moment slows down, opening into a deep canyon in which sensation and perception fuse. Such moments are common occurrences lately, perhaps an unconscious strategy to slow time in order to preserve what little of it I may have left. I hear Buddy's breathing mix with the buzz and pulsing murmurs of my oxygen concentrator, animal playing counterpoint to

machine. It fills my soundscape so thoroughly that my thoughts ride upon it the way they might upon good music. “So sorry, Buddy.”

As I sit, I prepare to resume my trek by setting my concentrator and laptop up ahead of me four steps. I can manage the trip upstairs much more easily if I move my machines before I move myself.

My second self, a punctilious sort who tries to anticipate everything I do so there is no wasted movement in my life, is disappointed, thinking, “I should have set these ahead of me before I sat down. Now I’ll have to wait to O-up again.” He’s right. I have broken the rhythm for walking upstairs that we established through much trial and error: walk up a few steps, set my machines up ahead of me a few more steps, then sit and rest. Nowadays every activity, no matter how minor, is a mini-drama that has to be staged and scripted. Normal activity has become a kind of chess game I play with gravity and what used to be the effortless, automatic details of movement.

I grab the small, plastic oximeter that always hangs around my neck and clip it onto a finger to check my oxygen level, something I do obsessively these days. A reading of 97 to 99 is normal, but I haven’t seen that level in many months except when I’m sleeping or sitting quietly at sea level with my oxygen turned all the way up. To be able to walk upstairs and drop only 1 point is also normal; I drop at least 10. Below 89, I don’t have enough oxygen to feed my brain, organs and the rest of my body adequately. I watch as the level climbs from 85 to 89 to 94. Ninety-four is a gift. Good enough to start moving again.

I stand up slowly, crouched over at first, then I straighten right away, my second self reminding me not to hunch over—the taller I stand, the easier it is for oxygen to fill my lungs. I move steadily, reaching the step where my machines are waiting. Then, in an unconscious moment while my mind is elsewhere, my cannula becomes tangled up with my right foot. I shake my leg vigorously before freeing myself, then grab my machines and quickly set them four stairs ahead. I drop onto the step, tired and winded. Too much motion, too quickly. The second self needs more practice. My breathing is challenged and audible—fast, deep, guttural. For some reason, this episode is particularly difficult, and panic emerges from deep within my body.

To counteract the panic, I practice calmness, the most unnatural response to being short of breath. I have had to teach myself to be aware of every muscle, to sense strain on a cellular level. I have never been a detail person, so this has required extensive reprogramming. Simply yawning or curling one leg under another as I sit robs me of a little bit of oxygen, and every bit is important.

My default position is feet flat, legs bent at ninety degrees, hands resting lightly on my legs, much like I had to sit at the start of class every morning in third grade. Eventually my panic slips into what I suppose is a kind of Zen serenity. It’s something I have always wanted to experience that has come to me in response to a disease that arrived like an unexpected comet from deep space, exploding normal life into bits. With calm comes oxygen.

More waiting. And more thinking.

Often about Saint Terri, my wife, and how she has glided into the new life I have thrust upon us, embracing it almost without noticing. My mind forms a collage of her many kindnesses. She is my beautiful steady rock, who bears my illness with a commitment that I am sure must be rare. She's my Sherpa, since I can't carry much anymore. Traveling is particularly hard, as I need to bring two oxygen concentrators and an army of heavy batteries and chargers, as well as an abundance of pills and inhalers that are now staples of my diet. She's my advocate, working her way resolutely through the bureaucracy of airline restrictions each time we travel. She uses the same patient determination to do battle with healthcare companies and to organize my encounters with the many doctors who form a kind of outer family in our lives these days.

The expansion of deliberate patience into once habitually hurried areas of life has been hard for me, but not for her. When we travel, we show up at the airport very early, wait for the wheelchair she ordered, wait for a TSA agent to scan me while I sit in my chair, wait as agents swab my oxygen concentrators for hints of malicious chemicals. At home, I was used to walking briskly, unconsciously, from one room to another. Now I live my life in slow motion. My gait is gradual and measured. The urge to hurry, to test my condition, has dissolved after many failures. I think to myself, "I have always wanted to be more graceful. Here is my opportunity." Yet it's hard for me to get past the frustration.

But not for her. Fast, slow, it doesn't matter. "It's what it is," she responds when I ask her how she deals with all of this, showing a commitment to the present that I have yet to master. Mid-thought I walk up four stairs. I move my laptop and concentrator ahead of me, resting them at the top of the stairs, and then sit.

Terri does all of this despite the fact that it is my fault that we are rapidly losing any fun that might counterbalance the limitations of our new life. I have lost my taste for wine and most food, making dining out not worth the bother. I can no longer honor serendipity by going for a bike ride because the sunshine beckons, or by visiting our neighbors next door just because we miss their company. The guilt I feel is overwhelming, a perspective she thinks is dumb. "You'd do this for me. You didn't ask for this disease. I love you. Now just cut it out." I redirect my thoughts, reminding myself of the three rules about living with her that have emerged from my experience with IPF.

First, don't apologize for what I can no longer do. Instead, thank her for everything she does. *Everything*. For keeping me alive, for getting me a glass of water, for all that she does behind the scenes that I can't see. I thank her not only to acknowledge the life I owe her, but also to keep honing my newly developed abilities of being hyper-conscious of her needs.

Second, cultivate independence as much as possible. When life with IPF was emerging, it became a series of horrifying surprises, like walking through a house of

mirrors at the carnival. Taking a shower induced panic because the water, the steam, the closed shower door made it hard to breathe. Simply pulling on my socks or retrieving a pen I had dropped was a disorienting struggle. Terri has stuck close and helped me with everything. But I am determined not to adopt helplessness as my new lifestyle—I owe it to her not to demand more than I absolutely need.

Third, encourage her to leave the house, to spend time away from me with her friends and her family. I'm not really much fun anymore, and she really needs to have some fun these days.

I start walking again. As I near the top of the stairs I wonder if I will sit on the top step or go all the way to the chair another six feet away, parked at a counter in the middle of a large open area. We have placed chairs strategically throughout the house in case I need to sit down unexpectedly.

I'm feeling ornery, so when I reach the second floor I pick up my laptop and concentrator and shuffle towards the chair with steady determination. I set my machines on the counter, feeling a bit faint as I sit down. The oxygen concentrator is on full blast, so the only way to O-up any further is to relax, to reach for Zen serenity without actually reaching for it— that seems to be the Zen way. My mantra lately seems to be "Okay," which I whisper several times as I settle into the chair and relax, feet flat, knees bent, hands resting lightly on the counter.

I love this spot. The open area is spacious, surrounded by three bedrooms, a bathroom and my office. When all the doors are open, as they are today, the view through the windows provides a panorama of our neighborhood, and of the valley and mountains that surround it. Above me a skylight frames the sunlight that showers my body.

For some reason, sitting here invites contemplation of a deeper sort. My mind squints and spans out in all directions as I step deep into the river of thought that rushes just below my conscious mind at all times. Sometimes it's filled with my music, played by an orchestra only I can hear. Sometimes it's filled with imagined meetings, half-developed stories and emergent ideas. The recent, relentless reminder of my mortality has filled the river with metaphysical musings. It's an attempt, I suppose, to refine a lifetime's worth of thought about my spiritual identity.

This has been a favorite subject of mine ever since third grade, when my father let me decide on my own whether or not I would continue going to Sunday school at our local Presbyterian church. I remember searching for words that I didn't have in order to explain ideas that intuitively were very clear to me. All I could tell my father was "No thanks, it's not big enough," my way of saying that I didn't believe that our religion, or any religion, was big enough to be everything. I remember knowing deeply that day that the world was always going to be much bigger than I would ever be able to describe.

I'm suddenly aware of the murmuring sounds of my oxygen concentrator humming next to me on the counter. I pause for a moment and close my eyes, thankful that life is as mysterious as it is. Instinctively I check my oximeter. It's at 95. I'm enjoying the calm and am in no hurry to finish the last leg of my journey to my office. So I step back into the river.

Where have I landed after a lifetime of reflection on the transcendent? Somewhere that is very clear to me until I try to explain it to others.

My body doesn't define the outer edge of my identity. Instead, I am a mosaic, made up of bits that are scattered throughout eternity, across the ages, as well as the continents and the galaxies. Bits of me are also interwoven throughout cascading dimensions, some physical some not, many beyond our abilities to conceptualize. Somehow all of my bits are in touch and coordinate their activities across all dimensions. They make up a whole me; they connect me even further to all that is. Somehow this happens sequentially and all at once.

Many of my bits exist in dimensions beyond this one, in which spontaneous creativity is the norm. In these dimensions, cause and effect merge, time dissipates, and space is so unlimited it ceases to exist. Everything is immediately possible.

In contrast, this earthly dimension is slow and viscous, and requires a great deal of energy and effort simply to move or communicate. Here I can do only one thing at a time, a fact that is amplified by a disease that has forced me to live breath by breath. The power of this dimension is that it requires me to weigh options and set priorities, forcing me to define myself by the choices I make. I have invested a small part of me here as an opportunity to find out what I truly value. My life here has been a wild journey, a story about discovering the treasure of my essence. I will miss this body.

I am about ten steps away from my office. My oximeter still registers 95. Because I am on level ground I know I can make it in one try. I rise, grab my machines and move slowly to my desk where I will spend the day immersed in my world of devices plugged into the ever-expanding Internet. I will talk with students and clients, friends and family, with strangers and with machines that have been programmed to recognize me. I will create the next chapter of my story. It will unfold as a synthesis of the goals I consciously pursue and the flashes of inspiration that will send me off on unanticipated adventures.

Every day is a celebration, muted but triumphant. Yet my life is the deep blue color of twilight. A soft steady undertow is pulling me out to sea. The only way to resist is to be, one breath at a time.

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