

Recovering from a lung transplant: The rock bunny learns gritty gratitude

Reflections of a life-altering experience; from the highs of mountain hikes to the lows of a fatal lung disease. A lung transplant transformed my outlook on life, leading to newfound optimism and a deep sense of gratitude.

Stewart W. Herman



Have you ever wondered what a lung transplant is like? I never did because I enjoyed excellent health for almost 70 years, thanks to a lifestyle of no smoking, very little alcohol, no recreational drugs, no chronic disease and no obesity on my health card—and lots of hiking and other exercise. Until my lungs crashed, I was a veritable rock bunny, seeking mountains to climb, high places to traverse, and enjoying views in every direction. My will to live found expression in forward motion, which provided the indispensable reassurance that I was truly alive.

Not surprisingly, then, I was deeply troubled when my physical ceiling for walking dropped from 17,000 feet in 2012 to sea level by 2020. By then I was dying of idiopathic pulmonary fibrosis, an incurable disease. This sudden revelation of my onrushing mortality caused a moment of panic, but oddly enough, not for long. I felt a bizarre reassurance, even a certain gloating. Unlike most humans I was privileged with a peek into the future. I now knew not only how but when I would die! But this blasphemous comfort proved transitory, as I soon slipped into a state of melancholy. It was going to be a long and gritty road for me to awaken to an appropriate sense of gratitude for my new life of struggle. The point of this article is to explain that struggle in medical detail as well, for those who also may have failing lungs.

My only hope was to receive someone else's lungs. My elder daughter found a hospital out west, and my wife and daughters and I transplanted ourselves there. To my surprise, the November 28, 2020, procedure had the air of a concierge-organized visit. It

began with an intricate choreography. One surgeon flew far away on a chopper to inspect the donor's body, contact the family, and bring the lungs back in an oxygenated box to the hospital rooftop. Three surgeons participated in the operation itself—one at my head, one on each side. The procedure lasted only three hours. It began with “popping the hood”, as the doctors called the opening of the ribcage. A “clamshell” incision was made from one armpit to the other, just below my pectoral muscles. My breastbone was sawed through sufficiently for my ribs to be propped up high and wide. The old lungs were removed in such a way that kept air circulating into my body and minimized the transfusion of blood. Two anonymous lungs were inserted, one at a time. Then the hood was stapled shut. Done!

But not done. The post-op pain stretched over a month, with ups and downs. Oxycontin made the pain almost bearable in the incredibly noisy ICU. This epidural vacation was discontinued on the fifth day after the operation, as four drainage tubes were yanked from my ribcage. I was terrified of the pain to come, for hospital practice was to provide only hydrocodone and Tylenol. Utterly drained from having been reduced to a medically manipulated body, I badly needed to regain contact with my spirit. I put on Bach's *St. Matthew Passion*. Unexpectedly—note here that I am not a publicly emotional guy—I wept until my bedclothes were soaking. Bach was returning my soul to my body, lofting me into that grand jet stream of saints—past present and future. His heart-stretching polyphony reminded that I have my own finite timespan of self-awareness in this grand aerial river, but that I would never be separated from the giver of life. That was my Revelation. It is renewed, with tears, every time I listen to the opening chorus of the *St. Matthew's Passion*.

Initial recovery: over-optimism

On the tenth day after the transplant I was discharged, but the pain remained intolerable, and I was readmitted two days after discharge. The hospital staff acknowledged that they had let me go too early. Hydrocodone and Tylenol were still largely ineffective, permitting me to sleep only in fits and snatches for the next few weeks. Still, I discontinued opiate-laced pain meds as soon as I could on the stern advice of one doctor who warned me against getting too ‘comfortable’ with them. It was an unnerving time. I was troubled by relentlessly repetitive and obsessive dreams. And I was struggling daily with the multiple overlapping and intersecting unknowns of my ignorance



regarding what was happening to me. I lost much of my pre-op memory (which I am still reconstructing), due to the anesthetics and sedatives I received during procedure.

Yet my optimism blossomed. Two days after the transplant I began shuffling with a walker through the hospital wards. I quickly worked up to a mile—17 laps on the polished floors. Three weeks after the operation I ditched the walker. Once the hood slammed shut on my new lungs, I assumed I could revert to my walking ways and become once again the person I had been—with fresh young lungs, no less! My optimistic recovery moved along an upward trajectory for half a year. I sought out local trails and hills and got to the point where I could walk 5 miles or climb 1000 feet at a time. But then my forward motion mysteriously lost steam. Over the next six months, my lung function declined to the point I was in worse shape than before arriving at the operating table a year earlier, and it took another half year to regain the strength I had enjoyed on this brief hilltop of optimism.

Real recovery: scare after scare

I had launched my recovery with an utterly unrealistic expectation of rapid progress, driven by my strong hunger for normalcy. My ignorance was not merely due to the blindness of my optimism. I was being given only a very general and sometimes confusing dribble of information about possible complications, particularly the side effects from the strong drugs that were required for the rest of my life.

Now from the perspective of three years out, I see my recovery as a series of scares and adaptations. Medical issues emerged, often unexpectedly, prompting my frantic attempts to understand what was going on. By “scare” I mean a medical setback that seemed to put me on a steep slope down to debility and death. Each scare generated moments of angst and terror, but then faded into my psychic backstage as it was addressed. Each required adaptive coping, which for me required laborious learning. I will present these scares in more or less chronological order based on daily entries in my diary, and medical reports I harvested from the hospital websites.

The first scare occurred right after the transplant operation. One night in the ICU I was convinced I heard staff discussing the fact that I had become a chronic diabetic. That inadvertent disclosure soon proved to be true, thanks to the doses of the steroid Prednisone that I would be taking for the rest of my life. This first panic slowly eased. It took a year to gain control over the diabetes. I learned to replace needle sticks into my fingers with a “Dex-Comm” monitoring bug on my belly. I learned to calculate doses by strict measurement of food intake, to routinize my diet, and to develop habits of when to eat. I gradually learned to smooth out the surges and crashes in blood sugar. So diabetes has receded from a terror to a fact of life, loaded with unavoidable annoyances: no more alcohol, no snacks, no more desserts, no outings without taking my needles along, and so forth.

A second scare resolved itself more quickly. After the transplant, I was presented with a lengthy list of anti-rejection drugs, antibiotics, and supplements to mitigate the side effects of the drugs—more than dozen kinds in all, whose purposes took months for me to understand. The staff terrified me with warnings of dire, even deadly, consequences if I failed to adhere to the inflexible schedule for taking them. I coped by developing morning and evening routines, and soon got to the point where I rarely forget to take them, and indeed can swallow a half dozen pills in one gulp.

A third scare emerged from my preexisting condition of GERD—gastroesophageal reflux disease. GERD happens when stomach acid surges up the esophagus. The lung team had warned me that I might suffer “aspiration”, where the rising stomach acid reaches my throat and then descends through my windpipe into my lungs, triggering inflammation and possibly rejection of my lungs. Under strong pressure by the team, I consented to an injection of botox into the muscles that control the flow of liquid and food into the stomach, and a slit in overtight muscles at the head of the intestines. When that effort failed, I consented to a “Nissen fundoplication” operation to shrink the, which was intended to increase the effectiveness of the ‘sphincter’ that regulates the flow of food and liquid into the stomach.

Unfortunately, the operation served to spin off more scares. Overall, I was beginning to learn that there is a serious price to pay for the miracle of not dying, but nothing diminished my fighting spirit. I had not been informed about possible negative consequences, and they turned out to be numerous and severe. In a fourth scare, I learned that the surgery on my esophagus effectively replaced acid reflux with “esophageal reflux”: the urps and upchucks resulting from liquids and foods bottled up in my esophagus. As I struggled to take in nutrition (without a sense of taste let alone smell) I had contend with the fact that my esophageal muscle was unable to relax at the bottom. Two further procedures “dilated” my esophagus at the entry point into the stomach, and yet a third had to be performed months later. But the problem eased only gradually and incompletely.

While I was regaining some of my capacity to eat, a fifth scare resulted. I was losing weight. My weight dropped from 140 lbs to 120 lbs (35 lbs lower than my weight pre-transplant of 157 lbs), to the point that a feeding tube loomed on the horizon. In effect, I was starving. I became increasingly lethargic, weak and dizzy. My weakened pancreas shrank by half. Not only was it failing to provide the needed insulin, but my digestive system was losing the capacity to absorb nutrients. The transplant already had effectively reduced my sleep cycle to a series of one-hour naps. Further, steroidal medicine left me with spells of shakiness. Losing weight now meant losing strength. These converging problems not only reduced my capacity to heal from the transplant, but to ward off other secondary threats. Since then, improvement has been slow and bumpy. Months of supplemental carbs and protein enabled me to regain some weight and strength—but only until the next crisis. I have never regained my pre-transplant weight.

Other challenges became evident. In a sixth scare, signs of “acute” rejection appeared in July 2021. My anti-rejection drugs were to keep my immune system from mobilizing its defenses against the imported lungs. The sudden onset of inflammation or rejection—the clues were ambiguous—were cause for alarm. The lung team subjected me to a three-day bombardment of Prednisone, to no effect. I asked the surgeon if any further surgical intervention would help; he said no. To my grateful relief the symptoms of acute rejection faded away, just as mysteriously as they had appeared months earlier.

In a seventh scare, also in July 2021, the lung team discovered that my lungs were undergoing “pneumothorax” (separating from the surrounding ribcage), effectively opening up a space where fluid was collecting. This “pleural effusion” was causing my left lung to be compressed. Almost two cups of the bloody juice were drained through a tube in my side, but the fluid immediately began building back up again. Three months later, another quart and a half was drained. An infection had developed as *C. diff.* bacteria found their way—likely through medical contamination—into the cavity between lungs and rib walls. Further, the antibiotic used to suppress the *C. diff.* enabled a secondary infection to develop. Weeks of antibiotic infusion and pills followed. Fortunately all these measures were effective—for a few months, until the next *C. diff.* attack.

By the fall of 2021, I had reached the lowest point, or so I thought. I was starving to the point of needing a feeding tube; dehydrating to the point of suffering significant kidney damage (“third stage” or moderate kidney disease); and experiencing side effects which morphed into further scares. The lung team out West was largely at a loss to help; they were too narrowly focused on numbers to address all that was needed for recovery. They were not making the referrals that could identify and address the complex side effects which threatened to undo the transplant. I was slowly beginning to understand the limitation of a medical approach which was organized nominally as a “team” but did little to engage other narrow but needed specialties into a holistic approach that could discern clearly what move my recovery along. Also, the staff out West were alienated by my effort to cope with my anxiety by understanding what was happening to me. I was trying to dampen my anxiety by understanding enough of my condition to respond intelligently and survive. The post op care fell far short of what could sustain the forward momentum imparted by the transplant procedure itself.

Disillusioned by poor post-op care out West and anxious to return home, I transferred my recovery care to a clinic and hospital system in Minnesota. The needed referrals began immediately and ultimately branched out into multiple specialties. Such wider consultation was needed because I was faced with the eighth and worst scare of my entire recovery so far: “chronic” rejection, where the body slowly but surely rids itself of the new lungs. The signal was provided by my lung volume, which had been declining steadily for six months and dropped to two liters by January 2022. Two liters was less capacity than

I had when my old lungs were removed a year earlier. Unlike its acute cousin, chronic rejection cannot be halted, and so portends unavoidable death.

A glimmer of hope appeared when a pulmonologist during an emergency hospitalization reviewed my CT scans and X-rays and stunned my wife and me with the news that there was actually nothing wrong with my lungs per se. This unexpected news only deepened the continuing mystery which no medical person could explain: why could I not breathe more deeply? A dietician consoled me with the thought that my body was taking all the energy I could absorb from food and putting it into healing. But that still didn't explain why my perfectly healthy lungs were unable to take in more air. Constantly dizzy, I shuffled about as if a zombie, unrefreshed by miserably broken sleep. My melancholy returned in a form of fatalism about my pending mortality.

Then the problem took an unexpected turn, thanks to a ninth scare. In February 2022, pain enveloped my torso, and rapidly intensified. What was left of my sleep was destroyed. Fortunately, this pain proved to be the moment of darkness just before dawn. A visit to the ER triggered a series of referrals, eventually to a kind of therapy not available in hospital or clinic. "Deep-tissue massage" is a method of releasing muscular tension responsible for the "trigger points" of excruciating pain. Semi-weekly sessions gradually loosened the muscles of my torso which had been compromised by the scars left over from the transplant operation—and, I might add, decades of poor posture and sloppy breathing. This frankly painful kind of massage is definitely not for relaxation. But it imparted optimism as my lungs expanded once again. The massage therapist further recommended "network spinal analysis." I tried this gentle form of chiropractic, which taught me to breathe in a way that would loosen the muscles inside my torso which were also tortured by months of pent-up stress induced by the transplant.

From "interventional" medicine to the self-healing of the body

In early 2022 I was starting my recovery from the transplant all over again, in effect. The learning curve was broad and steep. The transplant operation had awakened me to the miraculous power of what I call "interventional" medicine. It imparted an unrealistic expectation of rapid progress, anchored by my strong hunger for normalcy. My ignorance was not merely due to natural urgings. Now, with a year and a half of struggle under my belt, I came to believe that the burden of healing had passed to my body and its own processes, independent of my conscious oversight. My expectations about recovery changed dramatically. It dawned on me that my body was engaged in sustaining itself, and that my job was mainly to keep it stoked with fuel and patiently wait for it to pursue its own priorities in healing.

This revelation was not wishful thinking. I had been noticing all along from lab analysis that most of my various bodily chemicals and processes remained stable despite all the scares. So I became more interested in the kinds of medicines and therapies which

provided gentle nudges rather than sharp corrections or surgery. Once the scarred and stressed muscles of my torso were identified as the problem, the pace of healing picked up. By summer 2022, I increased my lung volume from two to three liters. This surge in available oxygen encouraged a benign upward spiral in strength, endurance, and clear-headedness, in direct contrast to the downward spiral I had experienced in 2021. I increased my walks from one, to two, to three miles, and pulled my dusty bicycle out of the garage for the first time in two years. And I planned a long walk along an Italian pilgrim trail.

Alas, this upward spike in healing was not nearly the end of the story. By the third year after my transplant, the scares were becoming somewhat less scary but no less disheartening, as the prospect of recovering my rock-bunny energy slipped further and further away. I learned belatedly that a transplant accelerates the aging process, and so does the steroid Prednisone. I could not absorb as much nutrition as before, thanks to an underperforming pancreas. Sustaining proper levels of white blood cells has proven a major ongoing challenge. One of my neck vertebrae collapsed, portending future fractures from osteoporosis. Neuropathy set in on my legs and feet. An “obstruction” of some sort was impeding the flow of nutrition into my digestive system, foreshadowing the need for another round of surgery.

The scares still happen—and some come back. A year after the first pleural effusion, I had another, again complicated by a *C. diff.* infection. A long parade of antibiotics and probiotics were needed to drive the *C. diff.* from my system and restore the flora in my gut. It took months to get it under control. This constituted a tenth scare because it opened up the prospect of endless recurrences of infection due to my weak defenses. An eleventh scare occurred as my blood pressure rose into a dangerous region. My mother had a stroke that took out her left side due to high blood pressure, and I wondered if I was similarly vulnerable to a stroke. Efforts to control it with Losartan and Amlodipine failed. A twelfth scare occurred as my heart suffered “failure”—proving incapable of pumping enough blood, as well as demonstrating its “chronoscopic incompetence” by not accelerating sufficiently during exercise. These two deficiencies raised the prospect of a heart attack.

But it was the thirteenth scare which perhaps has had the most impact. My left lung collapsed in August, 2023, thanks to the pressure of yet another pleural effusion. The healing challenge was to bind the lung to the rib cage, so as to prevent more fluid from coming in. I spent two weeks in the hospital as staff went through a series of steps to reinflate and reattach my lung to the rib cage. These efforts (known medically as thoracentesis, pigtail insertion, Lidex and pleurodesis) failed, leaving me condemned to being drained, like an oilpan, every time the fluid builds up again. My non-medical response has been to strive mightily to expand my ribcage so that my lungs might fully expand again, but the net effect of these hospital procedures was to trap my reduced lungs within a

hardened wall of pleura (the thin tissue that envelops the lungs), preventing them from ever expanding again, according to my pulmonologist. Rock bunny takes yet another hit.

To be fair, I don't understand enough of these scares and resulting changes to distinguish the consequences of the lung transplant from the "accumulation of diminishments", as theologian Joseph Sittler dolorously termed the aging process. I certainly have lost any certitude about how I will die. But I have learned some gratitude, the hard way, which for me finds expression in my Lutheran faith. The sheer accumulation of interconnected medical issues makes me wonder whether the end to my forward motion may resemble the fate of the proverbial one-hoss shay more than some single organic breakdown.¹

Recovery in light of Lutheran convictions

For almost three decades as a teacher, I encouraged students to think of vocation, grace, works-righteousness, inward-curving selfishness, paradox, and other convictions from the Lutheran tradition as nodes around which to weave their self-understandings. My lung disease and transplant have put these convictions to the test in a way that has strengthened my faith, which principally takes the form of gratitude.

First is the venerable notion of living out a vocation. My looming mortality raised the question: why should I struggle so persistently to stay alive? Here I heard a very clear call—not a gossamer voice from the heavens above, but the concrete concern of my loved ones, friends and my congregation. They did not want me to die, simply put. My pastor sought to understand my evolving condition as well as provide support. Congregational members expressed warm concern, especially those in the medical field. My siblings chimed in. For further encouragement, I had only to think of my mother, who struggled for twenty years with the debilitating after-effects of a stroke. I dared not give up. I heard the clarion call: Struggle! Heal! Recover! I had no doubt I was hearing a genuine call to stay alive.

I heard the call to survive most pointedly from my wife and daughters, and with a particularly jarring impact. I had no prior inkling of how strong a protective impulse my post-op vulnerability would elicit from them. A tension developed between my urge to return to my old way of living and their determination to protect me, especially from myself—a determination for which I was insufficiently grateful. I did not face this tension with grace, and they were bruised as a result. I learned the hard way that I needed to retreat into silence for a day or more, saying nothing while I "deep-listened" to them for what I clearly was not understanding. New medical symptoms only increased the strain on our communication.

¹ Oliver Wendell Holmes. "The Deacon's Masterpiece or, the Wonderful 'One-hoss Shay': A Logical Story." (<http://holyjoe.org/poetry/holmes1.htm>, accessed October 4, 2022).

Regaining my capacity to breathe was my vocation, but it raised a question of justice. Given the wretched swathe that COVID was cutting through the American population, how could I justify the taxpayer resources required for my care in the hospital and clinic? More bluntly put, what value did I have that justified the massive subsidies covering my medical expenses, when other patients were struggling to cope with inadequate insurance? What made me worthy of staff time needed by other, needier patients? This doubt played out as a doleful theme particularly during the height of the pandemic.

Eventually, I found comfort in a question—not an answer—posed long ago by the ethicist James M. Gustafson. He asked why intrinsic value was generally privileged over instrumental value. Are we to be valued simply for existing, or because of what value we can generate in our lives? I resonated with this philosophical question because I badly wanted to be useful to Creation, this world I live in and cherish, rather than merely ornamental. My unsteady recovery has ramped up the pressure to be productive. I didn't have physical strength, but there was a solar power system to be built at my church in Minneapolis. I was intent on publishing my father's letters from Nazi Berlin in the 1930s. And there was our net-zero house to be maintained. So I buried myself in these projects as a way of living out the grace of my extended life. Enforced pandemic isolation without forward progress in these tasks would have left me convinced that I was nothing but a useless, moribund social parasite on this good earth. These projects gave me reasons for living of an instrumental sort, which also likely had a good psycho-somatic influence upon my healing. Not exactly justice, but at least they softened the question of injustice.

At this point, Lutheran theologians might suspect me of works-righteousness, that bugbear of pointless striving for heaven that haunts Lutheran theology. But my projects had nothing to do with salvation, justification or sanctification. As H. Richard Niebuhr argued once in a philosophical vein, all value is always measured relative to some center ("The Center of Value").² I measure my specifically instrumental value relative to earthly need and the partial vindication of my earthly life which might result. I also have intrinsic value measured relative to friends and family. But all these connections are to be distinguished sharply from my intrinsic and instrumental value for God, for these dimensions of value lie wholly beyond my claim or control. Even as I feared death from lung disease, I never worried about my ultimate disposition, since it was utterly in the hands of a graciously judging God. Grace was taken care of; my job was to help preserve Creation.

Beyond vocation, justice, and works-righteousness, my struggle to remain alive put an arresting new spin on selfishness—the Lutheran conviction that we humans are curved in upon ourselves by our inescapable self-centeredness. My extended recovery reoriented my thinking from my healthy earlier days. For almost seventy years, I had been convinced

² H. Richard Niebuhr. "The Center of Value". in *Radical Monotheism and Western Culture* (New York: Harper & Bros, 1960), 100-113.

of my endless health while bounding over mountains. Now, the kaleidoscope of problems I faced hardened me into a projectile bent on a narrow and frankly self-absorbed trajectory. The demise of my old lungs and the implant of the new ones focused me on my mortality, which is about as deep a pit of self-concern as I had ever fallen into.

It took a long time and some jarring ego bruises to call me out of this pit of mortal fear. The prospect of a “new normalcy” beckoned, but to gain it I needed to put some distance between me and my medical struggle. I began to realize that my healing required distance from my woes, and that is another dimension of gratitude. I took my name off the prayer list at church. I learned to bite my tongue about bringing up my recovery in conversation. I stopped using my condition as an excuse to avoid challenges, particularly of the physical sort. This distancing remains very much a work in progress. I do not want to be seen as a survivor, but rather as an continuation of my old self. I am learning how powerful that ache is, to return to normal. But the doleful Lutheran view of our inevitable inward curving reminds me that the struggle to lean outward will never be won.

Finally, the Lutheran taste for paradox has helped with me that perennial dark question: how should I face my death, whenever it comes? Where is there room for gratitude, given that inevitable ending? Of course, I am called to consent to God’s will as death looms, but I am also called to resist mortal challenges to my health. How can I do both? A paradox arises when two convictions are opposed to each other yet must both be true. In my Lutheran view, these two imperatives are redeemed from outright contradiction by being anchored in an underlying commonality—much like fractions based upon a common denominator. Both resistance and consent are underlain by a love that will not let go. Each must be pursued in light of the other, much like while driving with one’s foot working brake and accelerator in a coordinated dance to avoid collision. So I am haunted and comforted by a line from Dylan Thomas—“Do not go gentle into that good night”. My resistance to bodily decay continues in the faith that consent is warranted at the same time. In short, I am grateful for the challenge to struggle, and confident that the outcome will be good, even when resistance finally fails, as it must.

Conclusion

I have described here my ongoing and shaky recovery from fatal lung disease. The medical consequences continue to unspool in scary and depressing ways, and the learning curve of resistance has been extraordinarily steep and difficult. The aim of this article is to make this journey easier for others. Of course, no two journeys are alike, and this article is not meant to be a guide so much as a catalog of possible consequences and side-effects, veneered with reflections about the consequences for my inner self. By this point (the journey is hardly over, after all!) I have been sobered by the many scares. I never will be the ‘rock bunny’ I used to be, bounding along mountain trails and seeking high vistas. The major scares may be past, but the prospects for returning to full strength and energy while

in my mid-70s are dim at best. The scares continue and likely at some point will put me on a steep slope down from debility to death.

On a happier note, this sobering experience has embedded me more firmly in my earthly home. I don't long for heaven. I still have a vocation. In pursuing it I remain blessed by the continuing humbling experience of being sustained by loved ones, friends, my congregation and the pieces of a wider community. And my will to live? The pressure is off. Even if I can no longer hike and run, I am called now to move outward, rather than simply forward. There is ample work to do in all directions. And that is ok. The hiking can wait. After all, Joseph Sittler once said that to live forever is to reside eternally in the memory of God. Who knows? That ethereal place might furnish interesting terrain for endless wandering exploration.

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