THE NEXT BREATH

NEW LIFE AFTER NEAR DEATH

Joseph Fisher, Ph.D., M.P.H.
www.the-next-breath.org

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Joe Fisher Books
PO Box 129
Sanibel, FL 33957
www.the-next-breath.org

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Cover design by Christopher Fous
Interior formatting by Veronica Yager

ISBN: 978-09905678-2-0

SYNOPSIS

CHAPTER ONE: A SURVIVOR'S TALE

Describes the immediate medical emergency, the author's reaction to it, and the barriers to seeking treatment and diagnosis.

CHAPTER TWO: HOSPITALIZATION

Discusses the introduction and immersion of a patient into the hospital routine, a chaotic world of diffused responsibility, information overload and the need to evaluate treatment options and ways to obtain the "best" treatment in that context.

CHAPTER THREE: THE NEW NORMAL— PTSD AND BEYOND

Considers the physical and psychological adaptation to the life threatening experience, symptoms of Post-Traumatic Stress Disorder (PTSD), medical treatment and self-help.

CHAPTER FOUR: VICTIMIZATION—FATE AND FORGIVENESS

Examines the origins of depression following a life threatening event – answering the question *Why Me?*; the need to find a cause, place blame, find fault and bring those responsible to account; and gaining wisdom through self-understanding and freedom from depression through forgiveness.

CHAPTER FIVE: FACING OBLIVION

Discusses the implications of the sudden and stark confrontation with death, mortality and oblivion and considers the questions: *What's God got to do with it? Where will I find peace?*

CHAPTER SIX: WINNOWING—
THE WINDOW OF OPPORTUNITY

Explores the process of simplifying one's life by deciding what is important, a process that includes answering questions such as, *Who do I love? What do I want to do with my remaining time?*

CHAPTER SEVEN: RELAPSE

Describes additional life threatening events experienced by the author – a near fatal Coumadin-related bleed out and consequent deep vein thromboses and pulmonary embolism – and considers these events in the context of modern medical decision-making.

CHAPTER EIGHT: EPILOGUE

Summarizes the insights gained from being brought back from the edge of death and experiencing a new life event.

For:

Dorit – Life Partner – who loved me back to life.

Jake – Sentimental stoic – the bravest person I know.

Jane – Quiet leader – the calm in the storm.

On the death of his child:

Dew evaporates
and all our world is dew…
so dear, so fresh, so fleeting

Kobayashi Issa
(1763 - 1828)

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INTRODUCTION

What is it like to be suddenly, catastrophically on the verge of death? While it is something few of us actually experience, we all probably entertain the thought at some time. But no amount of anticipatory visualization of what one might do under the circumstance can fully prepare a person for that moment. No amount of contemplation of how one will be affected afterward can capture how indelibly it etches the psyche. It is a moment when clarity reigns and nothing will ever be the same.

For me that time came as I was walking on the beach, ironically trying to get in shape for a planned trek to the Himalayas. A chronic and massive deep vein thrombosis (DVT) spawned an equally massive pulmonary embolism (PE) that lodged in my pulmonary arteries in the process totally incapacitating my right lung. In the time it took to take a single step I crossed a threshold passing from apparent excellent health to being mortally wounded — desperately choking, gasping to breathe — my life suspended by a thin thread of chance.

At that moment, one is very much in the moment, trying to find answers to very basic questions: *What went wrong? How bad is it? How can I get help?* Most importantly: *Will I die?* Medical explanations lose all meaning at a time like that. The chance of dying, over 50% in my case as best I can assess my chances in retrospect, is completely irrelevant. For the person in the moment the odds are much simpler. It is either 1 or 0, you either die or you don't.

Getting help "in time" means very little either. One is balanced on the keen edge of fate. Help arrives when it does

and by then a cascade of contingencies has already decided for or against the stricken. The immediate denouement comes when one enters the safe harbor of professional medical care and one surrenders their well-being to its authority. There are few things modern medicine does with regularity that are quite as inspirational as saving the near dead.

Although physical recovery after the crisis can be remarkably rapid, repair of the psyche can take far longer. The stricken person survived a potentially life ending event. They were transported suddenly to the threshold of oblivion, stripped of all defense and artifice and forced to confront nonexistence and mortality without time to prepare.

While dying and near death experiences have been studied for some time, this is a qualitatively different experience as is the psychological recovery process. What has happened is best conceptualized as a ***sudden life event***. The patient is adapting less to the prospect of death than to the prospect of living with a new perception of existence with all the portent and potential that implies.

Near death experiences meanwhile with common reports of out-of-body sensations, bright tunnels, feelings of calm, spectral personages in white garments and so forth may shed light on the process of dying, but not on adjustment to life after a brush with sudden death. Adjustment to a sudden life event is not unlike the process of grieving before death outlined by Elisabeth Kübler-Ross. Both have stages of adaptation as well as commonalities among psychological reactions. But one is forward looking while the other involves coming to terms with the past.

Certainly Post-Traumatic Stress Disorder (PTSD) describes some of what is going on. Preoccupation with the event, repeatedly revisiting it, hyper-vigilance to bodily signs that might presage another event, phobias of the place where it occurred, depressive symptoms such as failure to complete tasks, inability to plan, lack of energy and so forth were feelings I experienced and still do occasionally.

But there is more. Among the most immediate and prominent feeling I can recall is the sense of being singled out

unfairly, of being a victim, and having a need to blame someone for my predicament. Regardless, of the objective basis for the feelings, they are common among survivors, very real and at worst self-defeating, tending to exacerbate the ever-present depression. Only through forgiveness of my caretakers and myself was I able to free myself of the burdens of blaming.

Threatening our existence as they do, sudden life threatening events bring us abruptly into direct confrontation with the self-annihilating truth of our own mortality and the shared mystery of all existence—what happens after. Under the circumstances even the most agnostic among us, a group in which I number myself, often recognize the supernatural as the most plausible reason they still live. Whether one gives credence to this type of causality or not, a person is more apt to entertain spiritual explanations for their continued existence for having balanced on the cusp of the alternative.

Looking back with the clarity of what might have been, few matters appear as important as they did at the time. The recognition of the inherent silliness, for lack of a better term, of where I once chose to expend my energies combined with the knowledge of how tenuous existence is, set off a period of intense introspection, a wholesale search to answer the question: Who and what is important to me? The attempt to identify what matters, to winnow the possibilities to the essentials can be transformative as life veers in new directions.

Above all else running headlong into the wall of one's own mortality and escaping to continue living can be the impetus for a profoundly moving period of self-examination and change. I have never loved my wife and family with such intensity as after. Despite my best efforts to man up and suppress my emotions, I wept out of gratitude as I tried to thank those who loved me, not only for the obligatory care and comfort they provide as necessary and nourishing as it was, but because they loved and accepted me as I was and wept along with me.

Personal vulnerability, both physical and emotional, dominated in the period immediately following the accident. All my defenses, the carefully constructed bulwarks against

unfiltered and embarrassing emotions were stripped from me. Patterns of interactions and the web of relationships that define everyday life were cut loose from their anchors. This window of opportunity for change was to be fleeting and short-lived. But while it lasted it proved to be a chance to take a Mulligan on life. One of the rare times we have the insight and need not just to rewind the tape and pick up where we left off but to push the reset button and start life anew.

What follows then is a description of one person's near fatal medical emergencies and life rebuilding recovery. It is an idiosyncratic journey and I do not pretend the psychological after effects I report occur in a set order of stages or for that matter will be universally observed by everyone who has a similar crisis. Nor do I suggest my medical emergency, a pulmonary embolism, and recovery from it can be equated exactly with other sudden mortality-facing experiences such as combat or heart attacks. Each of these has its own unique situational features that give it a character all its own.

At the core, I believe (and numerous blog posts would seem to support my view) this process of healing and adaptation is common to all who have confronted death in an unexpected moment regardless of the proximate cause. I suspect my fellow survivors may not have every reaction I did or give them the same significance I do. Nor will they use the same language to describe what they went through. Nevertheless, I think they will recognize my journey as a road they traveled too. They will have their own stories and anecdotes to mark the milestones along the way and express the life-affirming process they have undergone and the context within which it took place.

A final note. Everything described in this book, no matter how coincidental or seemingly apocryphal, did in fact happen. There is indeed a Dr. Badov and he was assigned to my care at one point. A stranger did confront me on a deserted beach with a question for the ages. My former wife did emerge from three decades of silence to tell me she was dying just as I was contemplating my own mortality. I have tried to recount each of these instances and the other events, thoughts, feeling and emotions that accompanied or were caused by my narrow

escape from death as accurately as I can recall them. The fact that the unusual often occurred with apparent literary serendipity to flesh out the story just proves, I suppose, that you can never hope to make up the best stuff.

Joe Fisher, 2015

CHAPTER ONE
A SURVIVOR'S TALE

"Life is what happens to you while you're busy making other plans."

—*John Lennon*
(1940 – 1980)

It was the first day of spring and I felt great. For months I had been bothered by persistent pain in my left leg. It was red, hot to the touch, sore and slightly swollen, all indications of restricted blood flow. I had been plagued too for weeks with a general malaise. I just didn't feel well, although I could point to no one specific reason or constellation of symptoms that would explain this unease. It seemed to manifest itself most often as night sweats, waking me in the first black hours of the day to find my pillow and bedclothes drenched in perspiration.

But today I felt great. The day before I swam a mile and was experiencing no ill effects. Most importantly there was no pain in my lower leg. So today it was time to start training for my next trek. This was to be my third trip to the Himalayas, a planned three-week, cross-country odyssey from Kathmandu in Nepal to remote western Tibet. The goal was to be at Mt. Kailash, a peak reputed to be the home of Vishnu and sacred to one quarter of the world's population, in time for the Saga Dawa festival in early May. There I would join other pilgrims in a ritual circumnavigation of the mountain at altitudes of 18,500 ft., a journey said to cleanse one of a lifetime of sin upon

completion. I toyed with the notion of doing two laps just to be sure.

Here it was already mid-March and I needed to get in some semblance of fitness if I were to have a chance of making the circuit. Lose 20 pounds, well maybe more, and since my excursions to the Himalayas did not involve climbing high peaks, but rather hiking long distances at high altitudes, it meant toughening my feet and legs in preparation. So I began my pre-trek regimen of dieting and long walks along the beach near my home on Sanibel Island, Florida. As helpful as walking at sea level was it could not possibly prepare me adequately for three weeks of walking in the rarified air above 14,000 feet. But I had to start somewhere.

The Crisis

So off I went to the beach and started to hike along the shore. It was a glorious morning, warm and brilliant. The not yet fully ascendant sun bathed the beach in a candescent glow and reflected off the dappled water to create dancing flashes of light. I was pain free, so out of the ordinary I took notice. It would be an exceptional day, I was sure.

Then a quarter of a mile from the beach access, less than ten minutes into the hike I was starting to hit stride when I took a single step and in that span I went from being healthy, vigorous and in good shape, to a person on the edge of death whose odds of surviving the next five minutes might be no better than two to one against. In that one stride my life changed irrevocably.

I was immediately aware that something had gone terribly wrong. But it was the second step that confirmed something catastrophic had occurred. From my sternum to my spine, under my arm to the end of my ribcage the entire right side of my body was constricted as if clamped in place. It was as if a malevolent giant had placed the heel of one hand on my breastbone and the other on my backbone, linked fingers under my armpit and held fast.

My chest would not move, it would not inflate. It was not so much painful as it was a constriction. I could not take in air. Somehow I felt the condition was transitory and would abate with the next intake, but it did not. I was gasping for breath, air coming into my starved lungs as raspy gulps.

I took halting steps away from the water, moving toward the dunes not more than 10 yards away. My heart was racing, my pulse palpitating and irregular. Despite the ambient temperature above 90 degrees I was instantly cold and clammy. And oh, the anxiety. I needed to run, to flee, but unable to do so and not knowing where to go in any case.

In the dunes, half hidden among the sea oats and saw grass I spied a beach chair stashed there for future use. Its allure was overpowering, beckoning me with the promise of relief. For a moment I wanted nothing more than to sit, to rest and wait for my body to return to normal. Somehow though I knew intuitively and without a scintilla of doubt that if sat I would never rise again.

I grabbed my cell phone, my lifeline, and called my wife as much to end my isolation as to get help. Between huge gulps for air I was able to blurt out "I can't breathe. I don't know what's wrong. I just can't breathe." My gasping was so extreme, my sister, who was traveling with my wife at the time, could hear it across the car even though the receiver was pressed against my wife's ear. She asked me where I was and promised to come immediately to pick me up.

I paced in small circles waiting, heart racing, anxious and oxygen starved. Although I was vaguely aware I was on the verge of death there was no real terror associated with that possibility. I was much too preoccupied with the immediate here and now of the event. My mental state was characterized by hypersensitivity to my body, ever vigilant for signs that would signal what would transpire next. I had no time to worry about death and nonexistence or the finality of separation from loved ones that implied. All that would come but much later.

As minutes passed my heartbeat slowed and the anxiety slackened enough for me to take stock of my condition. There were only two explanations for what was happening. I was

either having a heart attack or I just had a pulmonary embolism, a blood clot that forms in an extremity, pieces of which can break off, travel through the heart to the lungs cutting off its blood supply. Anxiety, heart palpitations, breathing difficulties, feeling cold and clammy are symptoms of each, I knew.

Controlling my anxiety marginally, I performed a quick self-triage. The constriction was on my right side only. There was little real pain, just the suffocating constriction. By comparison, my left side was completely uninvolved, a fact I would later find out saved my life. More importantly, I had none of the crushing pain in the middle of my chest, like an elephant sitting on it as it is often described by heart attack survivors. There were no shooting pains in my left arm. Other symptoms, erratic heartbeat, difficulty breathing did not differentiate. I just had a pulmonary embolism (PE) I concluded.

On a personal level I was not unfamiliar with PEs. My mother had, in fact, died of a massive one some years before. She had been stricken and stood over a bathroom sink gazing incredulous at herself in the mirror before slumping to the floor, her pallor turning ever more gray, until she perished from asphyxiation. Or so it was recounted by my sister who was with her at the time of her death; ironically the same sister who was in the car when my wife received my first desperate call.

The story of my mother's death impressed me indelibly. The suddenness of her demise frightened me the most. The finality of it. So quick that no help could be summoned and reach her no matter how consequential it might have proven to be. No time to say goodbye, to have last words with loved ones. After her death PEs were a morbid phobia of mine and I was hyper-vigilant for signs that could indicate I might have one. And yet here I was reliving my mother's dying moments.

But as the minutes passed, it became increasingly clear I would not succumb immediately. My breathing, albeit labored, became less desperate as my now rested body required less oxygen. My heartbeat slowed and became regular as my anxiety diminished. The immediate crisis was over. Maybe it

wasn't so bad after all. With that thought stupidity took over. At that moment I was quite literally one half inch from dying where I stood, the size of a second embolism that would have stopped my heart. Yet, even though I was certain of what had just happened and I suspected the gravity of my situation my reaction was equal parts denial, procrastination and magical thinking.

The next precious minutes were spent arguing with myself about what to do. My mother died of a pulmonary embolism in less than 15 minutes. I was still alive and ambulatory, so I would not succumb I reasoned. Perhaps I overreacted. Maybe it wasn't as serious as I thought. Feeling somewhat abashed that I might have overplayed the incident I called my wife to let her know the crisis was over and that I would walk home. I also took the opportunity to point out that breathing was still a challenge so she would not interpret my first call as a hypochrondriacal figment of an overactive imagination.

I did not so much walk home as proceed with a shuffling trudge. I lacked the energy to lift my foot in order to take a step. Instead I dragged my feet along the shell road raising a small cloud of silicon dust around my shoes. All the while I struggled to breathe by drawing air through my clenched teeth. The constriction in my side was painful now. Breathing through the pain, my lips drew back over my teeth in a sardonic grin as I braced against the tightness.

Plodding along I retraced my route from the beach to my house two blocks away. Lingering in the back of my mind was the pregnant question: What should I do now that the crisis was past? Should I go immediately to the hospital? Should I wait at home to determine the trajectory of the problem, whether it would improve or worsen?

It was Saturday. Spending hours in an emergency room waiting to be seen, only to find it was not as serious as I supposed was a prospect I was not willing to entertain. The contrary possibility, that I needed immediate hospitalization for a life threatening condition, did not rise to the level of consideration. The threat simply did not seem real or immediate enough, since by virtue of my mother's example I

deemed myself in no danger of imminent death. I decided to wait until Monday when I could see my personal physician and let him decide the appropriate course of action.

Doubts still lingered, however, about the course of action I had chosen. My sister lobbied hard for me to seek attention. She told my wife in confidence, "I have seen this before. He needs to go to the hospital immediately." But I obstinately held to the belief that I could delay. If I were to change my mind I would need incontrovertible evidence that I needed to seek medical care before I would go. To prove to myself this was not the case I devised tests, physical challenges designed to provoke a worsening of my condition, deliberately tempting fate to prove to myself I was all right. One such occurred immediately upon arriving home when I decided to sweep out the garage, despite the exertion and dust raised exacerbating my breathing.

I have often marveled in retrospect about my foolhardy stubbornness. Was it an integral part of my personality, the need to take care of myself, to make my own decisions, to require proof? Or was my reaction in some way a consequence of the event and its psychological sequalae? Was denial a more universal response than mine alone, springing perhaps from a common desire to diminish the gravity of one's condition? Did most people procrastinate before seeking help? Did they create implausible reasons to persuade themselves that they did not need treatment?

In my case certainly the potential for embarrassment played a role. I had a reputation, perhaps well-earned, among my family as being something of a hypochondriac. To go to the hospital in an ambulance outside of normal hours only to find out that nothing was too seriously wrong had personal and psychic costs for me. It is difficult with hindsight to understand how the fear of making a fool of myself could trump the fear of suddenly dying from a preventable cause, but it did. By that point though, I was already visualizing the future after diagnosis not evaluating the present danger. This behavior became all the more baffling when I learned that even another

small embolism could have ended my life during these days of delay.

Seeking Treatment

Whatever the reason for my behavior, the next two days were spent living in the delusion of my own making. The medical signs were obvious. Walking up a flight of stairs caused me to double over at the waist gasping for breath as badly as I had on the beach. I dreaded climbing the second flight of stairs to go to bed each night and the gasping and emptiness in my chest that waited at the top.

I dreaded too the black loneliness of night that waited there when I was alone with my thoughts and fears. Lying still while I repeatedly scanned my body for sensory signs that I was all right or not. Rolling over in my mind the events of the day, the decisions made or not made and the possibility that I chose in error. Wondering about the small divergences in life's path and their consequences that I could never hope to foresee at the time. Always searching for the answer: would I live until morning?

I tried to keep up a semblance of normalcy through the weekend. It proved to be impossible. I was worn out, weak and preoccupied with my fears and questions. The very act of breathing became an arduous relay. Forcing my ribs to expand to fill my damaged lung yet never feeling as if enough was air taken in. Deeply inhaling but always coming up short. Trying to pull harder but never getting more. The process had to be repeated every few seconds. It was tedious, exhausting and without relief.

Monday finally came. I was able to see my primary care physician in the afternoon. As I sat panting in the examination room, he checked my respiration and measured the oxygen saturation in my blood. Air was moving in and out of my lungs unobstructed, while my blood oxygen level stood at 97%, both quite normal. Whatever was causing my respiratory distress it was not preventing life-sustaining oxygenation of tissues and

organs throughout my body. Discounting my obvious respiratory distress in the face of the results, the doctor saw no reason for me to go to the hospital immediately. I enjoyed a brief moment of smug self-satisfaction when he seemed to confirm that I had made the right decision not to rush to the emergency room over the weekend.

Instead, he ordered an ultrasound test of my legs two days hence to rule out the presence of blood clots in my lower extremities. These clots or deep vein thromboses (DVTs) are the chief source of pulmonary emboli if that were the cause of my symptoms. On the way out of his office the nurse supervisor wished me luck, a sentiment I found odd until eventually I learned that luck had everything to do with my survival.

Ultrasounds are benign diagnostic tests, noninvasive ones since they require no penetration of the body. Instead ultrasound waves emitted by a wand bounce off the underlying structures and are read as they return, showing the contours of what lies beneath, in effect sonar for examining the underlying body topography.

Ultrasound scans are particularly useful in visualizing soft tissues such as veins and hence are an excellent tool for discovering the presence of a blood clot. In this case, the wand is passed along the vein in question. At intervals it is pressed down by the technician. If the vein compresses, that is, one wall of the vein can be forced to touch the opposite side, it is clear of any obstruction. If on the other hand it does not compress, a blood clot is indicated.

I arrived at the testing facility almost exactly four days after the original accident full of expectation for a final determination of what had happened. No stranger to ultrasounds I was calm and at ease. Given my family history of PE's I had occasion to have several over the preceding years. I lay relaxed while the technician efficiently scanned my right leg. Moving to the left leg she repeated the procedure.

Upon completion she said demurely, "Would you mind taking a seat in the waiting room while I call your physician?" But while this should have sounded ominous were I not in such

deep denial, it brought on a sense of relief instead since I would soon have a definitive answer as to what, if anything, ailed me. A few minutes later she poked her head out of the examination room. "Your doctor would like you to go to the emergency room right away," she said.

The ultrasound report, obtained much later, details the extent of the thromboses and hence the cause for alarm.

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Noninvasive Vascular Report

Indications:

Dyspnea (shortness of breath) and edema (swelling)

History:

Patient states onset of shortness of breath x 4 days (4 days ago). Left leg swelling. Patient denies right leg symptoms.

Venous exam 12/2009 revealed negative for DVT and venous insufficiency.

Findings:

Rt. Lower Venous: Chronic wall changes of right peripheral vein. The remaining visualized veins appear patent at this time.

Lt. Lower Venous: Positive for acute deep vein thrombosis of the distal femoral/proximal popliteal vein (abductor level), popliteal and posterior tibial veins. The peroneal veins were not identified. The remaining veins appear patent.

Conclusions:

Positive for acute deep vein thrombosis of the left lower extremity.

Comments:

Verbal preliminary report given by the sonographer.

Patient sent to ER

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While the right leg did evidence venous deficiencies there was no evidence of clots, i.e., the veins were "patent". By comparison, the left leg had extensive DVT's. Of most concern were the clots in the popliteal vein which runs behind the knee and up the thigh. Clots above the knee are especially prone to throw off pieces and spawn pulmonary emboli. The clots in the lower leg and calf, the tibial and peroneal veins respectively, while troublesome are less likely to have pieces separate.

The ultrasound did not conclusively show that I had experienced a PE, but it did provide a high degree of suspicion that one had occurred. Even if not, blood clots in the leg of the extent and magnitude observed are health risks in their own right and demand immediate medical attention.

Upon hearing my doctor's directive to go immediately to the ER all my illusions of good health and unassisted recovery were shattered. The defenses I so carefully constructed collapsed. A crystalline reality shown through – I was in grave danger. The possibility of dying was suddenly very real again. I felt the overwhelming need to communicate with loved ones, to say goodbye, to leave an expression of what they meant to me and what I hoped for them should I not be there to watch their lives unfold or communicate with them again. So I hastily sent text messages to my wife and two young adult children.

This action gave me some respite against the rush of time. Although I derived some comfort from the realization that I would soon be safe, under care and in a setting where treatment resources could be marshaled if needed, a tyranny of

urgency took over. The person who had responded to a major medical crisis with aggressive nonchalance and perilous procrastination, now fretted that another devastating event would occur before reaching the emergency room, a trip of no more than five minutes. All the worry about suspicious symptoms that had been denied, diminished or blocked from consciousness before flared anew in response to the confirmation they were indeed real.

Fortunately the ER was immediately across the street. I drove there and walked into the waiting room. Then began a drama that can only be created by the way modern medical care is delivered in America. I had just passed into the Medico-Pharma Twilight Zone. Only the sonorous voiceover of Rod Serling was missing.

I went to the receptionist, told her who I was, where I had come from and assured her my physician called ahead to vouch for the fact that I needed immediate care. I was referred instead to the billing area where I was required to provide evidence of my financial bona fides. Having completed that task I returned to the receptionist and informed her that no administrative barrier remained to prevent me from seeing a physician. Unimpressed she told me to take a seat until I was called.

Two hours went by. The waiting room emptied, filled and emptied again. Finally, my sense of fair play got the better of me. My turn should have come up long before. So I returned to the receptionist ready to demand to see a physician and unwilling to take no for an answer this time. The hypocrisy of petulantly demanding treatment after having avoided it for days never occurred to me. This was a matter of principle after all. I plead my case pointing out that the need for emergency care was a directive of my primary care physician who obviously believed I was in mortal danger. She was nonplussed and cooled me out by saying I would be next.

I returned to my chair in the waiting room. Fifteen minutes later I was finally called and ushered in to see a triage nurse. Total elapsed time since arrival: 2 hours and 45 minutes. This being a weekday morning with a full complement of physicians

and nurses on duty, I could only imagine what the wait would have been had I come in on the weekend.

Through the halting breaths I gave the triage nurse a history of the accident, physician visit and ultrasound results. To my astonishment the nurse ignored the information given and asked, "How did you get here?"

"I drove," I replied.

"Did someone drive you?"

"No, I drove myself."

"Why did you drive yourself?"

"Because I was told by my doctor to come to the ER immediately," I said, assuming this was obvious.

"No," she scolded. "Why didn't you call an ambulance?"

I was incredulous. "Because I was just across the street," I exclaimed.

Having reached the end of the interrogation she launched into a lecture. "There are some people who come to the ER in an ambulance who shouldn't," she opined. "There are some people who do not come by ambulance but should," she continued and concluded. "You are one of those".

I agreed she had a point even though it seemed quite irrelevant since I was there and ready for treatment. Besides I was only a quarter of a mile away, I pointed out one more time. She was unmoved. It was also clear she had no intention of letting me proceed until I at last repented. Recognizing I was without leverage in this debate, I fervently said I would never again, if faced with the same situation, drive myself to the emergency room. This promise of respect for protocol seemed to placate her but not enough to prevent her from sending me back to the waiting room, perhaps to contemplate my misbehavior. Ten more minutes passed before I was called to see a physician.

In retrospect I often wondered about this exchange. Was it a juvenile exercise of power by an authority-obsessed gatekeeper? Was it a testament to the monumental inefficiency of the typical emergency room and the callous disregard of the staff? Or was it something structural in the way emergency rooms are organized and deliver care? Perhaps an ambulance

is a symbolic indicator that the occupant needs immediate treatment, the golden passkey that can cut through any bureaucratic barriers. After all the ambulance delivers patients to a separate entrance, disgorging passengers directly into the ER, bypassing the process of payment proof and treatment prioritization.

An ambulance has symbolic significance for the patient as well. It is an admission that they feel their condition is an emergency and requires care as quickly as it can be delivered. In my pre-diagnosis mental state, I was not prepared to make that concession. But I was capable of learning. Whatever the role and meaning of an ambulance in determining the need for care, when presented with the same choice, ride or drive, again a few months later, I chose to ride.

Diagnosis: Pulmonary Embolism

Once ushered inside, the emergency room was a model of efficiency. Within minutes, I gave a history, vital signs were taken, and I was transported to radiology to get a CT scan of my lungs. Shortly after the ER physician came in to deliver the verdict. My condition was in fact caused by a very large blood clot, a massive pulmonary embolism, that blocked all the arteries to my right lung.

A clot is often confused with or considered to be synonymous with a scab but the two differ in several important ways. A scab is a hard crust that seals a wound, re-establishing body integrity and protecting it from external hazards. A clot by comparison stops blood flow at the site of a wound. It can be a necessary precursor to the formation of a scab since scabs cannot form in the presence of flowing blood. However a clot, known medically as a thrombosis, bears little physical resemblance to a scab. It is instead a gelatinous mass that is soft, flexible and malleable. Its flexibility allows it to conform to the contours of the space around the wound while its size and heft make it difficult to displace by the backpressure of flowing blood.

But clots can move if the pressure is too great and once dislodged they move freely through the body or out of it. Freed of its mooring, a clot is called an embolism. Clots that originate in leg veins, so-called deep vein thrombosis or DVT's, once dislodged will move effortlessly with the blood to the heart, aided by their soft shape-shifting features. A journey that is further enabled by the fact that travel through the veins becomes easier as the clot nears the heart since the veins increase in size and diameter along the way.

Entering the heart, the clot arrives in the collection point, the right atrium chamber where it subsequently flows into the right ventricle. The ventricle in turn pumps the oxygen-depleted blood through the pulmonary arteries to the lungs where it will be reoxygenated. The newly enriched blood is returned to the left side of the heart through the pulmonary veins. It collects again in the atrium, flows to the left ventricle and is dispersed to waiting tissues and organs throughout the body, thereby completing the oxygenating portion of the circulation system.

Mobile clots, emboli, have characteristics that make them pathologically able to disrupt this process with life-ending consequences. Clots travel to and through the heart painlessly without betraying their movement. Lack of sensory nerves in the veins and heart make an embolus undetectable until it reaches a stopping point and disrupts a body function. It is only when the clot goes into the pulmonary artery and can go no further creating a blockage that interferes with blood flow and oxygen exchange that it becomes noticeable therefore.

The pulmonary artery branches into three main divisions, each bringing oxygen- depleted blood to a lobe of the lung, named without creativity, the upper, middle, and lower lobes. Arterial branching continues as the circulatory network approaches the site of oxygen exchange, the air sacs or alveoli. The alveoli are surrounded by a mass of capillaries some that carry oxygen impoverished blood from the heart and others that, after oxygen exchange, will return oxygenated or oxygen rich blood to the left side of the heart. PEs disrupt this process

by blocking the pulmonary arteries before the blood can reach the alveoli and can be rejuvenated.

The plastic nature of the clot allows it to branch with the vein and travel as far along the branching process as room allows. Therein lies the fatal potential of the pulmonary embolism. If the clot is relatively small it will travel to the smaller branches of the pulmonary veins, disrupting blood flow and the reoxygenation process only slightly. Clots of this sort may cause little, limited or unrecognizable changes in circulation or respiration. In fact, PE's may be much more common than thought because a substantial number exists below the threshold of serious damage and awareness.

However, as the size of the clot increases, so does the capacity to cause pernicious changes. The clot can block the pulmonary artery to a single lobe of a lung creating noticeable constriction and diminished respiratory capacity. Bigger still and it can affect multiple lobes and in the worst cases, both lungs. If the clots restrict respiration significantly the victim can slowly asphyxiate, dying from a lack of oxygen in a few minutes to a quarter of an hour as my mother did.

Ultimately though, a pulmonary embolism is a cardiac problem not a pulmonary one. If the clot is sufficiently large it will stop the flow of blood entirely in which case death is nearly instantaneous. The heart cannot pump blood beyond the clot, it stops beating, and the victim loses consciousness and dies.

If the patient survives the lungs are often damaged sometimes beyond repair. Below the clot, away from the heart, the alveoli collapse due to lack of oxygen caused by restricted respiratory capacity, a process known as atelectasis. Atelectasis can cause permanent changes over time if the cause is chronic e.g. from Chronic Obstructive Pulmonary Disease (COPD). But in the case of an acute cause such as a pulmonary embolism the alveoli will most often reinflate when normal airflow is restored.

With respect to cardiac changes, blood can be restricted to parts of the lung itself causing an infraction or death of the tissue nourished by the affected arteries. This is analogous to a

myocardial infarction or heart attack where portions of the heart muscle die due to a clot in the coronary arteries causing a stoppage of blood flow to a section of the heart. The pulmonary embolism can cause a similar localized death, infarction, of lung tissue. Unlike atelectasis however damage from an infraction is permanent.

A better sense of the process and the damage caused is shown by it the following selected excerpts from the CT scan results that confirmed the presence of a massive PE when I was stricken on the beach.

———

Examination: CTA Chest

Clinical History:

Possible Pulmonary Embolus

Results:

There is a large embolus in the right main pulmonary artery that extends into the right upper lobe, right middle lobe and right lower lobe. There is some contrast that flows around the margin of the embolus.

The left-sided pulmonary vessels are patent.

Bone window images demonstrate dependent atelectasis.

There is some scarring in the right apex.

Impression:

1. Large right pulmonary embolus

2. Dependent atelectasis.

———

The effect of the plasticity of the clot can be visualized by the description in the report. The clot involved the entire right lung branching with the pulmonary artery and shutting off blood flow in all three lobes of the right lung. In effect, the right lung ceased to operate. Below the clot the lung had collapsed (dependent atelectasis) and there was evidence of pulmonary infarction (scarring in the right apex-or upper portion of the right lung). Meanwhile the left lung was uninvolved, all "vessels were patent" i.e. free from clots.

This report could be the definitional equivalent of a near miss. After the fact a pulmonologist commented that had the clot been perhaps just a centimeter larger, four-tenths of an inch, I would have died on the beach. The difference between life and death was less than half an inch. It was a sobering thought from which a cascade of emotional and behavioral consequences flowed for the next two years.

The report too provides some suggestions for my good fortune. First, consistent with my symptoms, the left lung was not involved at all explaining the ribcage constriction on the right side only. Second, there are hints that total circulatory function in the right lung was not shut down entirely. The observation that "some contrast that flows around the margins of the embolus" suggests that the clots did not completely occlude the pulmonary arteries but rather allowed some blood to flow around the sides. On such small margins life or death is decided.

Armed with a definitive diagnosis the ER staff swung into action. An IV was put in my arm and an anticoagulant (Lovenox – low molecular weight heparin) was injected into my lower abdomen to prevent any further formation of blood clots and pulmonary emboli. Having performed its function to diagnose and stabilize, the ER staff made arrangements to pass responsibility for my continued care to the adjoining hospital where I was transported and admitted.

At that point I relaxed, almost deflated as all the muscles released and I seemed to sink into the mattress. Only then did I realize how rigidly I had been holding myself. But I knew. At last, I knew. My beachfront diagnosis was confirmed I was not exaggerating. I needed to be there. The problem had a name and now it could be treated. I was on the road to recovery and I had nothing more to worry about. Or so I thought.

Epilogue

Some months after the attack I decided to begin a memoir of my experience. I thought it might be informative to get the reactions of other people who were present or were directly affected by the events. So I asked those with first-hand knowledge, my wife, daughter and sister to write a short description of how they were affected – their observations, thoughts, fears during those fateful four days. The only person who complied with this request was my sister Ellen. It was perhaps too raw and frightening for the others.

As mentioned previously, my sister was visiting the day I had the PE and she remained throughout the crisis before I was hospitalized and treatment began. She was also present at my mother's death from a pulmonary embolism two decades earlier. As a consequence, Ellen had a unique perspective from which to observe and to provide an eyewitness account of my wife and my response to the crisis and the events that transpired while matters were very much in doubt.

Her description (following) in many ways confirms my own recollections[1] while providing greater depth that could only come from an interested and familiar outsider.

> The clerk was slowly sliding my few purchases through the scanning device. Bailey's on Sanibel Island, is an institution. I was there with my sister-in-law, Dorit,

[1] Discrepancies in my and my sister's recall of events are discussed in Chapter 1 Notes.

picking up a few items that I wanted to contribute to the household during my visit. I felt as sleepy and relaxed as the clerk until I was suddenly – and dramatically – lifted out of my trance by Dorit.

"Put them all down, NOW!" she was yelling as she grabbed my arm and moved me toward the door. "We have to go!"

I looked at the clerk. He was a young guy and he was clearly as confused by this demanding behavior as I was.

Embarrassed and apologetic, I mumbled "sorry" and followed Dorit out to the car. She was clearly agitated as she explained to me that Joe (her husband and my younger brother) had called her from the beach. He couldn't breathe and might be having a heart attack.

I thought to myself... boy is she being a little dramatic... She could have waited a few more minutes for me to check out... This couldn't be so serious that it would warrant a return trip across island to retrieve the needed groceries that we had so abruptly left with the clerk.

As these thoughts flew through my consciousness in short fragments, Dorit talked about what Joe had said and she was clearly worried. Joe had called Dorit, told her (in short, labored gasps) that he couldn't breathe, his pulse was racing and that he might be having a heart attack.

I reassessed my position and decided that this was serious. There was definitely reason for concern.

Our car trip from Bailey's across the island to their home seemed to take forever. It was April and although visitors were beginning to return north, it was still a bumper-to-bumper car ride on a two lane road slowly moving toward Joe who was in trouble.

I began thinking, we should have called an ambulance. Certainly they could have made more progress in less time than we were. I started to really worry. I felt really anxious. What if he was dying?

Joe is my "little brother". He is a tall, strong man who works out regularly. While I don't think he's in perfect health, he seems in good shape for sixty-three. Of course, like the rest of us (myself and our other two sisters) he is always trying to lose those extra couple of pounds.

He was on the beach walking on that particular morning, training for a planned trek to Nepal. He is adventurous and had been around the world on many challenging "vacations". He and Dorit and their oldest child, Jacob, had recently completed a climb of Mt. Kilimanjaro.

Dorit and I talked continually, weighing the odds that this was something catastrophic. Because I wasn't willing to consider that, I reassured her that this was probably nothing really serious and we would find Joe in fine shape.

I felt confident because Joe can be a health "worrier". He was probably just exaggerating. I talked myself into a nice serene calm. Dorit wasn't buying it entirely.

Finally we got there. Joe was standing at the end of the beach access road, very near their home. He was indeed out of breath and he looked scared. His eyes were wide and pleading. He was sweating. He was holding his arm and taking his pulse.

Wow, I had not expected this. I was suddenly scared. We tried to get him in the car for the short drive to the house. He refused. Dorit asked about going to the hospital. Should she drive? Should she call an ambulance? Joe was not going.

He reported that he was breathing easier (than at onset) and that his pulse had slowed. He felt sure that the crisis had passed and that he would be fine. I was not so sure. If he was fine, how labored had his breath been fifteen minutes before? I really felt that he should be checked.

We got home and somehow Joe got up the flight of stairs to the main level of the house. This was Friday afternoon. Joe's breathing was still labored and any exertion at all caused real deep draws for breath. It was scary to sit by and watch but even more so, to listen.

Joe seemed scared. He checked his pulse regularly. He discussed his symptoms. Yet he flatly refused to "bother" any medical personnel until regular hours on Monday. He had called his doctor and had made an appointment on Monday. There was a long weekend ahead of us.

Joe was very quiet. He seemed absorbed in his survival. He was better (not breathing as heavily) when he was seated and inactive. As the weekend days passed by, Joe's symptoms didn't dissipate.

Dorit became immune and was almost dismissive of his complaints and comments. She mentioned to me that he "got worse" when he approached the stairs, intimating that he was adding drama to his situation. I understood her feelings, but I didn't agree with her. He couldn't breathe and this wasn't an act. However neither she nor Joe were doing anything until Monday and I had learned long ago not to argue with one stubborn person, let alone two.

It is an interesting phenomenon watching long married couples deal with medical problems. I had been married over thirty years and had been quickly willing to dismiss my husband's medical complaints and issues, until convinced otherwise.

Dorit's response seemed to me to be very normal. A long married, long suffering wife who had listened to a litany of complaints from children and spouse for years and was done with a compassionate response. Dorit wasn't cold hearted. She just didn't believe that Joe was quite as sick as he claimed to be.

I continued to be concerned. Joe was in trouble. I didn't like his breathing issues. I understand that I had significant breathing problems as an infant and somewhere deep in my memory, struggling to breathe resonates with my soul. I hated it. I was also present at the time of my mother's death, my father and I holding her as she struggled to breathe, gasping, eyes open and pleading, until the pulmonary embolism strangled her ability to breath and she lost the battle.

It is terrifying. I wanted Joe to get some help. I was anxious. I wanted him in some experienced medical hands, not with Dorit and me. That just wasn't going to happen. We were waiting "it" out!

Monday came. Dorit offered to go to the doctor with Joe. He declined the help/company. He went off alone. Dorit and I went on about our day. When we got home Joe was pleased to report that the doctor was taking a slow approach. The doctor had been made aware of Joe's leg problem (swelling, redness, hot bulge behind his knee) and the breathing crisis that had prompted the office visit. Nevertheless the doctor saw no need to rush. He scheduled an ultrasound for Wednesday.

REALLY? I was stunned. Joe was in crisis. He needed more help and he needed it now!

It wasn't going to happen. Another two days were in front of us and the waiting continued. Joe was stoic. He didn't complain but his breathing didn't improve. He was in distress. Though he accepted and actually seemed to

appreciate his doctor's slow and cautious plan, I knew he was worried. Dorit stayed steady but somewhat removed. She had been reassured by the doctor's visit and was less concerned than she had been through the weekend.

I was glad to be with my family but there were constant silent questions which dominated all of our thoughts. What was happening to Joe? Was he going to be all right? Would he die?

Wednesday arrived, the day for the ultrasound and my return flight home. Once again, Joe declined Dorit's company for this medical test. Dorit was driving me to the airport when the phone rang. Joe said simply that the ultrasound had revealed a very large deep vein thrombosis behind his knee. He was being sent immediately to the hospital.

Though bad news, I was relieved that he was finally going to have the medical attention that he required!

Hearing how I presented my illness and reacted to it as seen through another's eyes I realize how self-defeating my behavior was. I had done nothing to help myself and instead played a game of pure chance with my life. But I also see we were all part of a process. Denial and diminishing the severity of the event and its aftermath was common to all of us.

ACKNOWLEDGEMENTS

While writing this book I was fortunate to have the support and assistance of many people. My three sisters helped enormously. Barrie for reading the manuscript as it was developing and providing comments and suggestions for improvement. Ellen for contributing her impressions and recollections of the days of crisis. Joanne for inadvertently providing the springboard for an interesting discussion on the power of prayer.

Others were equally instrumental shaping what became The Next Breath. Hank Weed, my friend of nearly three decades, reviewed the document in its formative stages and provided much needed input and support. My first wife, who prefers to remain anonymous, provided a valuable counter perspective that helped me to better understand my recovery journey. My best wishes for her continued ability to beat the odds.

As she has for many years, Cara Davis helped with research and production. Sandy Doubles and Debbie Norris also helped put the book together. My friend and creative resource extraordinaire Christopher Fous was the inspiration behind the book jacket and website:

www.the-next-breath.org

Despite how it might sound at the times in the pages of this book, I did receive quality care throughout this ordeal even though at the time I was often unable to recognize it as such. Thanks to Drs. Daniel Dosoretz, Stephen Hannan, Ashish Adi and Scott Dunbar for helping me through the crisis and Drs. Calvin Wei and Elizabeth Guardiani when I relapsed. Dr. Paul

Mantel and Dina Porter LPN have stood by me faithfully for my continued care when lesser caregivers would have abandoned me. I will be forever grateful to them.

Two additional people deserve special thanks. Linda Conklin lent a nonjudgmental ear when I needed one and offered insights and encouragement. Irv Feferman was my sympathetic and knowledgeable life line when I was floundering. Irv was kind enough to read the manuscript afterward as well.

Of course, if there are any errors in the text as there might well be with such a technical subject, I am solely responsible. The same can be said for any unevenness in presentation where I have given a topic less emphasis than it deserves or have omitted important stakeholders or organizations.

Mostly though, I want to thank my immediate family for making this work possible. Writing a book is an act of faith. You have to believe someone will want to hear what you have to say. Doubts abound. It is also a long and laborious process that takes away from other things. For the sacrifices they made and their undying love and support I thank my children Jake and Jane, always my closest friends, and my partner and wife of 35 years, Dorit, the love of my life and dedicate this book to them.

ABOUT THE AUTHOR

After a successful career in market research and public health policy consulting Joe Fisher now writes full time from his home base in Sanibel Island, Fl. His earlier work has received praise from *Publishers Weekly*, *The Miami Herald* and the *New England Journal of Medicine* among others.

With a doctorate in Sociology (Tufts University) and a Master of Public Health degree (Harvard University) Joe is well qualified to speak to the consequences of life-threatening medical emergencies from both a professional and personal perspective.

OTHER BOOKS BY THE AUTHOR

Killer Among Us: Public Reactions to Serial Murder

Advertising, Alcohol Consumption and Abuse: A Worldwide Survey

Advertising, Alcohol Consumption and Mortality: An Empirical Investigation