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For now we see through a glass, darkly; but then face to face: now I know in part; but then shall I know even as also I am known.

FIRST CORINTHIANS 13:12

#### **PROLOGUE**

# Solitude and Solidarity

When I was admitted to the emergency room at midnight, I used the word *malaise* to describe my condition to the doctor. My head ached, my hands and feet tingled, I was coughing, and I could barely move. Every so often I was seized by tremors. The day that had just begun, December 29th, 2019, could have been my last. I had an abscess the size of a baseball in my liver, and the infection had spilled into my blood. I did not know this at the time, but I knew that something was deeply wrong. *Malaise*, of course, means weakness and weariness, a sense that nothing works and nothing can be done.

Malaise is what we feel when we have a malady. *Malaise* and *malady* are good old words, from French and Latin, used in English for hundreds of years; in American Revolutionary times they meant both illness and tyranny. After the Boston Massacre, a letter from prominent Bostonians called for an end to "the national and colonial malady." The Founding Fathers wrote of malaise and malady when discussing their own health and that of the republic they founded.

This book is about a malady—not my own, though mine helped me to see it, but our common American one: "our public malady," to borrow James Madison's phrase. Our malady is physical illness and the political evil that surrounds it. We are ill in a way that costs us freedom, and unfree in a way that costs us health. Our politics are too much about the curse of pain and too little about the blessings of liberty.

The rage was with me for only a few minutes at a time, bringing warmth as well as light. My body usually felt cold, despite my fever. In my hospital bed on New Year's Eve I wanted the sun to come up, and I wanted it in the room. I wanted it on my skin. After three days of trembling, I needed more than my own warmth, which escaped through the thin sheets that kept twisting around the tubes in my chest and arm. The winter sunrise in New England through a thick window isn't much; I was living in symbols and desires.

I didn't want the torch in my mind to be a lonely light. And it was not. People came to visit me. My wife opened the shade, and the wan New Year entered. When other visitors began to arrive, I guessed how they would react at bedside to a helpless me, but I didn't know. I remembered that some of the old friends visiting me think that patients who are visited get better treatment. They are surely right: health is a matter of being together, in that way and a hundred others.

A visit helps us to be alone. Being together in solidarity permits a return to solitude in tranquility. Just by appearing, my friends set off memories, chains of association back into our past. I remembered a moment when one friend had shared that pragmatic view of why patients should be visited: years before, when it was I who was at her bedside, when it was she who was ill, and pregnant, in the same hospital where I myself now lay. I thought about her children, then about mine. Another mood was coalescing: a gentle empathy.

The rage was pure me, my wish to be a sound not an echo, to compose not decompose. It was not against anything, except the entire universe and its laws of unlife. For a night or two I could shine in my own light.

Yet, slowly and softly, a second mood impinged, one that sustained me in a different way: a feeling that life was only truly life insofar as it was not only about me. Like the rage, this mood visited me when I was alone, when I could do little for myself, when my whole sense of motion came from visions in my mind. In

this mood I felt myself to be in a cluster of something with other people, tumbling through time. When I tried to draw the feeling in my journal, I came up with an uneven, floating conveyance. It looked a bit like a raft.

A raft can be built over time from bits and pieces. I was a part of a raft, and others were, too; we were floating and jostling together in the same water, sometimes effortlessly, sometimes against the rocks. If my plank fell into the deep, the raft might lose its way or capsize. Some planks of the raft were further from mine, and some were closer. I recited to myself the ways my children's lives were bound to my own. What mattered was not that I was distinct, but that I was theirs: their father. Every bit of their existence involved the expectation of my presence. They had never not touched me. Their planks had always been bound to mine.

I imagined what would change without me, beginning with the daily details that mark the mental calendar of a parent: soccer practice, math homework, reading out loud. I recognized with pain that my vision of my son without me, of my daughter without me, were just as real as my previous life with them. I watched their future unfold without me, in my mind's eye, and then I reeled it back.

This floating recognition that my life was not my own, this gentle empathy, escorted me away from death. This sense that life was shared began with my children but extended outwards, an uneven collection of timber making up the raft. I was splashing and tugging forward with everyone I knew and loved, and all would be affected if I fell away now. In this mood I was not raging, but floating along, remembering, contemplating, empathizing.

The rage helped me see myself, helped my body and mind take on distinct form after a shock. The empathy placed me among others. In this mood, it was not so important that I was special. It was important that I was inside other people, in their memories and expectations, a support in the shape of their lives, a buoy during difficult passages. Since my life was not just my own, then my death was not just my own. When I reached that point, I began to rage again. This could not happen.

The empathy, though altogether different from the rage, worked together with it. Each mood revealed a truth, an element of me.

Neither was enough; I needed both. I needed the torch and the raft, the fire and the water, the solitude and the solidarity, to get well, to be free. And what is true for me, I suspect, is true for others.

### INTRODUCTION

## Our Malady

Had I died, my death would have been all too typical, a passing into sad statistics. Far too many Americans needlessly departed life in the early months of 2020. Far too many Americans are too close to death every month, every moment. Although we have been promised ever longer lives, life expectancy in our country has flatlined, with no meaningful change in half a decade. In some recent years the life expectancy of Americans has declined.<sup>1</sup>

The beginning of life in this country is frightening and uncertain. Care of expectant mothers is wildly uneven and grossly inadequate. Black women often die in childbirth, and so do their babies. The mortality rate of babies borne by African American women is higher than in Albania, Kazakhstan, China, and about seventy other countries. America as a whole does worse than Belarus, the most Soviet of the post-Soviet states; and Bosnia, an awkward creation of the Yugoslav civil wars—not to mention forty other countries. Young adulthood has lost its charm. Unless something changes, millennials will live shorter lives while spending more money on health care than Gen-X parents or boomer grandparents. The prime of life is not what it once was. Middle-aged white men are committing suicide and drugging themselves to death in astonishing numbers. Middle-aged white women in the South are dying before their time.

Our system of commercial medicine, dominated by private insurance, regional groups of private hospitals, and other powerful interests, looks more and more like a numbers racket. We would like to think we have health care that incidentally involves some

wealth transfer; what we actually have is wealth transfer that incidentally involves some health care. If birth is not safe, and is less safe for some than for others, then something is wrong. If more money is extracted from young adults for health care, but they are less well than older generations, something is wrong. If the people who used to believe in the country are killing themselves, something is wrong. The purpose of medicine is not to squeeze maximum profits from sick bodies during short lives, but to enable health and freedom during long ones.

Our malady is particular to America. We die younger than people in twenty-three European countries; we die younger than people in Asia (Japan, South Korea, Hong Kong, Singapore, Israel, Lebanon); we die younger than people in our own hemisphere (Barbados, Costa Rica, Chile); we die younger than people in other countries with histories of British settlement (Canada, Australia, New Zealand). Other places keep passing us in the longevity charts. In 1980, when I was ten, Americans lived on average about a year less than inhabitants of countries of comparable wealth. By 2020, when I was fifty, the difference in life expectancy had grown to four years. It is not that other countries have more knowledge or better doctors. It is that they have better systems.

The gap between the United States and other countries grew in 2020, since no democracy mishandled the coronavirus pandemic as we have done. People in Japan and Germany, in South Korea and Austria, and indeed in all rich democracies, were at less risk than we were, because their governments treated them better, and because they had better access to information and care. It was already far too easy to die in this country before the novel coronavirus arrived in the United States. Our botching of a pandemic is the latest symptom of our malady, of a politics that deals out pain and death rather than security and health, profit for a few rather than prosperity for the many.

The new threat ought to have been taken seriously from the time of my hospitalization, which is when it was documented. In January 2020 we should have acquired a test for the novel coronavirus, tracked the new disease down, and limited its reach. This could easily have been done. Far poorer countries did it. Americans infected with the coronavirus should all have had

#### LESSON 1.

## Health care is a human right.

I was in Germany when I got sick. Late at night in Munich on December 3rd, I was admitted to a hospital with abdominal pain, and then released the next morning. In Connecticut on December 15th, I was admitted to the hospital for an appendectomy and released after less than twenty-four hours. In Florida on vacation on December 23rd, I was admitted to the hospital for tingling and numbness in my hands and feet, but released the following day. Then I began to feel worse, with a headache and growing fatigue.

On December 27th, we decided to return to New Haven. I had not been satisfied with treatment in Florida, and I wanted to be home. But it was my wife, Marci, who had to make the decisions and do the work. On the morning of the twenty-eighth, she packed everything up and got our two kids ready to go. I was a burden. I had to lie down to rest after brushing my teeth and after putting on each article of clothing. Marci arranged for wheelchairs at the airports and got us where we needed to be.

At the Fort Myers airport I sat in a wheelchair with the children on a curb while she returned the rental car. As she remembers the journey, "You were fading from life on the flight." At the Hartford airport she wheeled me from the plane straight to a friend's car, and then stayed with the kids to wait for the luggage. Our friend had not known what was happening; she took a look at me in the wheelchair, said "What have they done?" in Polish, and got me into the front seat. I lay down flat as she sped to New Haven, because my head hurt less that way.

I struggled to get admitted to the emergency room in New Haven. I had to use a wheelchair to get from the parking lot to the lobby of the emergency department. Another friend, a doctor, was waiting for me there. Although I did not understand this then, I had a massive infection in my liver, which was leaking into my bloodstream. I was in a condition known as sepsis; death was close. The nurses guarding the entrance to the emergency room did not seem to take me seriously, perhaps because I did not complain, perhaps because the friend who advocated for me, though a physician, was a black woman. She had called ahead to say that I needed immediate treatment. That had no effect.

After the better part of an hour sprawled between a wheelchair and a table in the lobby, I finally got into the emergency department. Nothing much happened then, so I reflected on what I had seen as I stumbled from the lobby to an emergency room bed. I have been in many emergency rooms in six countries, so I have a feel for them. Like most American emergency departments, this one was overflowing, with beds lining the hallways. In Florida six days before, the overcrowding had been even more severe. I felt lucky in New Haven that night to get a small area to myself: not a room, but a sort of alcove separated by a yellow curtain from the dozens of other beds outside.

After a while, the curtain started to bother me. Getting attention in emergency rooms is a matter of figuring out who staff are and catching someone's eye. I couldn't see people passing when the curtain was closed, and so it was hard to decipher the uniform colors and the name badges and ask for help. The first doctor who opened the curtain decided that I was tired, or perhaps had the flu, and gave me fluids. My disconcerted friend tried to suggest that my condition was something more serious. "This is someone who was running races," she said. "And now he cannot stand up." My friend told the resident that this was my second emergency room visit within a few days, so extra attention was warranted. The resident left unconvinced, and with the curtain partway open behind her. I caught a glimpse then of the two nurses who had admitted me, and heard what they said as they passed: "Who was she?" "She said she was a doctor." They were talking about my friend. They laughed. I couldn't write this down then, but did later:

#### VINTAGE

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