

# Preface

This book offers some of the fruits of my labors in medicine and healthcare advocacy. If you count the years I volunteered as a candy striper under the stern tutelage of the nursing nuns at St. Joseph Hospital in Joliet, Illinois, I've worked in healthcare almost fifty-five years. Dozens of clinical settings and assignments, countless patient encounters, years of advocacy in courtrooms and statehouses, decades of observation and experience—those are the seeds of the fruits borne by these pages.

As a young nurse, intensive care and emergency rooms were my specialty. I loved the blend of high technology and bedside care. I came to believe that comforting attentiveness, clean sheets and a backrub contributed as much to the recovery of frightened and frail patients as all the machinery and medicines did. Still, I was comfortable with the darker side of intensive care, too, inserting large-bore needles into fragile veins, passing tubes down noses and throats to suction or feed, sedating bodies that bolted against the ventilator forcing air into their lungs, tying arms and feet to bedframes when delirious or angry patients thrashed and pulled at their lines. These things were routine and I never questioned them.

So, I can pinpoint exactly when the seed of understanding and passion for a “strong finish” began to germinate. It was with one patient, one night in 1972, as I was on duty in the coronary care unit of Group Health Hospital in Seattle.

Ed had end-stage heart failure. His heart was so weak he was unable to live outside the hospital more than a few weeks before

he would decompensate, collect fluid in his lungs, and need to return to our unit for stabilization. Over the months I grew close to Ed and his wife, who often stayed and rubbed Ed's feet until he fell asleep at night. By chance, Ed and I had been photographed together for an article in the Group Health Magazine highlighting the new, state-of-the-art CCU. A copy sat on his bedside table.

One night, Ed slept quietly while I sat at the bank of monitors that formed the nurses' station in the center of the unit. I was watching the sleep of the eight patients on the unit and watching their heart rhythms on the monitors. The electrical activity of Ed's heart became increasingly erratic, so I started into his room to adjust the medication dripping into his vein. I expected to be able to correct this without even waking him up.

Suddenly his heartbeat broke down completely and Ed was in a fatal arrhythmia—ventricular fibrillation. Without hesitation, I did what I was trained to do. I grabbed the defibrillation paddles that hung on the wall, lubricated them quickly, pressed them firmly to Ed's chest and pushed the button. They delivered an electric shock that rocked him in the bed, restored the heart to a normal rhythm and woke Ed up with a cry. He was stunned and angry. "Why did you do that, Barbara?" he shouted. "How dare you? Don't you ever do that to me again!"

I felt terrible, as though I had assaulted him and invaded the sanctity of his body. I apologized and cried. He calmed down and forgave me. The next day Ed left our unit, transferred to a part of the hospital where rescue protocols were not the rule.

Ed taught me that heroics and technological interventions at the end of life are not always what a person wants. But this perspective came as something of a jolt. High-technology medicine was just getting going, with seeming miraculous treatments invented every day. Pacemakers were relatively new on the scene and heart transplants were just becoming feasible. Ventricular assistance devices, implanted defibrillators, a host of complicated tools to monitor heart and lung function and hundreds of procedures and pharmaceutical breakthroughs were rapidly coming online.

## PREFACE

In the early 1970s, palliative care was unknown and hospice was in its infancy. When a hospital patient died, it was usually after a long period of “code” activity. The curtains were pulled around the bed, family was excluded, and a bevy of doctors, nurses and trainees cut, poked, pounded, shocked, intubated, passed tubes, connected machines and delivered medication every way possible, including through long needles directly into the heart. Sometimes a doctor would even cut open the chest and massage the heart directly. When all this failed to revive the patient, which was almost always, we broke the sad news to the family and reassured them that “we did everything possible” to save their loved one. Those words were considered to be the kindest, most comforting message at a time of heartbreak and loss.

Twenty years later, high hopes that medical technology would always extend life had begun to fade. Awareness had dawned that a long, drawn out “full code” was just brutal torture of a dying body, and it often left the family traumatized. Now full codes were applied more judiciously, and often more abbreviated if the effort failed to produce results within the first few minutes. Our words of comfort when a person died were just as likely to be “he passed very peacefully.” A vision of peace at the end of life had become as treasured as technological wizardry.

But it was not until May 20, 1994, that I heard the words of comfort that seemed to usher in an age when people can find solace in knowing a beloved has completed life on their own terms. That was the day after Jacqueline Kennedy Onassis died of non-Hodgkin’s lymphoma. Her son, John F. Kennedy, Jr., emerged from her apartment that morning and comforted the crowd that stood grieving on 5th Avenue. He said, “My mother died surrounded by her friends and her family and her books. She did it in her own way and on her own terms. And we all feel lucky for that.”

By the time I heard John Jr. utter those words, the seeds for this book had bloomed into a growing advocacy for just that sort of take-charge attitude in life and death. Jacqueline Kennedy Onassis, seeing death approach, had retreated from the revered towers

of the New York Hospital and gone home. She had called those she loved to be with her as she passed quietly, privately from this world. She died with the same grace and dignity with which she lived.

As with any movement, people become motivated when awareness of an injustice breaks into consciousness. The awareness comes as a stunning “Aha!” moment, when you notice suffering and inequality, as if for the first time. You feel energized to find something that averts the suffering, and cures the injustice.

I have often felt that perhaps I worked so hard for public policy to empower people in their healthcare and relieve end-of-life suffering as a kind of redemption for the unnecessary suffering I visited on dying people in my ICU days.

Everyone should have the opportunity to die as Jackie Kennedy did. Everyone should receive candid information and medicine’s respectful deference to their beliefs and values. This book aims to deliver that opportunity, through an empowered attitude and the sharing of tools for a more productive doctor-patient relationship. I hope its pages help people with every decision they face about tests or treatments as illness advances and death approaches. I hope it helps people be strong in their understanding and resolve as they apply the final touches to their well-lived lives.

This book is not about medical aid in dying (the option for a terminally ill person to take medication and die peacefully in one’s sleep). But as the seeds of change and advocacy have grown over the decades, it so happened that only legal authorization of medical aid in dying has served to break through habits and assumptions perpetuating medical overtreatment and overbearance.

Advance directive laws swept the nation in the 1990s but they were completely ineffective in this regard. The medical establishment, from emergency technicians in ambulances to doctors in hospitals, have ignored advance directives with impunity. Healthcare providers all up and down the line have continued to deliver unnecessary, painful and unwanted treatments to people who had expressed a wish to avoid them when death was imminent. If

## PREFACE

medical aid in dying seems prominent in my narrative, it is only because it has been the most powerful change agent, and a symbol of the agency and autonomy this book aims for.

Finishing strong will be different for different people. Some will examine their options carefully and decide to dedicate their final months to experimental and taxing treatment. Others may decide to spend precious energy focusing on passing life lessons and values on to their heirs. But for those who choose to “Finish Strong,” the common thread will be a certain strength in knowing that treatment decisions were well-considered, and they honored the values and beliefs that gave meaning to the life that is ending.

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