

How I Got Here from There

Mona's Story

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1956 was not an epidemic year for Polio. The March of Dimes Foundation funds were plentiful, so I had every physical advantage available, a great relief to me and my family. However, for a 20-year old who had cherished my abilities to 'do it myself' from age two, being consigned to a life-saving iron lung meant that I was in a worse-than-newborn position (babies could at least scream and kick). Did I welcome this as a rest from a new job and the responsibilities of planning my upcoming Christmas wedding; as an exciting mental challenge; as a blessed opportunity for spiritual growth? Those who have had a drastic mobility reduction will guess my emphatically negative response to that. Medical care and attention were lavished on me in a Kansas City hospital. Some of the personnel were compassionate and concerned to include me—doctor let me view the changing of my tracheotomy tube in the lung's mirror—others shrouded everything in mystery for the non-initiate. Treatment the first seven months seemed an interminable round of painful surprises.

Family and friends cheered as I made tortoise-like progress. There were some laughs too. One visitor reported to friends that I was now out of the lung clear down to my neck.

Weaned from the lung, enabled to travel by train with the help of a chest shell, my parents and a faithful nurse, I made the pilgrimage to the fabled Warm Springs, Georgia. The rehabilitation experts there soon had me corseted and traveling by wheel chair complete with arm slings.

After seven months at Warm Springs, there had been dramatic changes in my appearance and abilities. I had gained back 20 of the 45 lbs lost to polio, could breathe without assistance (and frog-breathe for coughing) and was skilled with my custom-made appliances. Local Georgia shop geniuses and my occupational therapists had fashioned clever devices for feeders and hand splints—one jokingly offered to make a corn-on-the-cob-holder—that allowed me to do amazing, robot-like feats. I could now feed myself peas with no spills, write large, loopy notes home, and paint, (a hobby that gave me much pleasure and some income later). When I arrived, I had only been able to scratch my nose.

At that time rehabilitation meant only therapy and technological aids to me—being returned to a useful life by regaining maximum physical ability. Confronted by a psychologist, I politely replied that I was at Warm Springs to work on physical improvement. That when I knew what to expect from my body, then I would determine how to lead my life. I refused to go back to her office. She didn't pursue me.

When Vocational Rehabilitation and Easter Seals approached me at home about work, I told them I wasn't strong enough to work yet, and if I needed help I'd call them.

The view from here of my state of mind then is numbed bewilderment. I could not accept simple religious explanations and advice clichés. What I did adopt from some generous strangers, who seemingly had "conquered polio" with hard work and determination, was a sparkling self-delusion. If the doctors were obeyed, their treatments endured, and the therapy completed, there would be only a slight delay before I could resume my chosen life style. I vaguely realized there might be some curtailment of favorite activities, but to have to live without playing the piano, sewing, cooking, tending babies? Unthinkable deprivation.

Beginning my own reality therapy in the warm Georgia sunshine, I contemplated other polio survivors I knew. Almost everyone there had more working muscles than I, some were leaving after six months of hard work still in wheel chairs and braces. No one had promised me any great recovery.

Other equipment and advantages that boosted me toward recovery were the love and welcome of my dedicated family, who, agonizing with me and grieved over my losses, have shared generously their energy, time and resources. Our family was stable, well-rooted in church in community, so we had ample support and encouragement. Dad was a devoted provider, and a quiet but fun-loving and faithful caretaker. Mom was and is a dynamic person who is continuously occupied with laying down her life for her family and her many friends, so consequently has had much volunteer help in return. My only brother was and still is a great friend, a contemporary confidante on whom I could depend for understanding, wise counsel, and good humor. (He now has a delightful family, is director of the Legal Aid Society here, and still helps with my therapy weekly.) Other satellite family were and are generous with loving attention and gifts.

Also, I had a basically strong constitution and mind; a good educational background (I had completed 72 hours of college credit), insatiable curiosity, an almost compulsive bent for reading, studying, and cogitating; and an interest in spiritual matters and social issues. While I missed mobility and self-sufficiency, it was relatively easy to concentrate on a life of the intellect and busy myself with amateur and spectator culture. I enjoyed the new freedom of choosing my own course of study, no papers due or required exams.

As for character, I was equipped with a stubborn willfulness, As going off to college was one of the proudest days of my life, returning home as an immobile dependent was a sad defeat, and in my mind at the time, a very temporary state of affairs.

During those next 16 years with my parents, I worked part time at home (TV monitoring, card and invitation business, painting commissions) entered contests (and won a few), and read voraciously. We enjoyed an active civic and social life. Thanks to family chauffeur services and a VW van—later my brother brought back a new one from Germany for us—got around a lot in those days.

My most active life, however, was in an imaginary future. Visions of my own apartment, travel, a meaningful career, marriage, were running like a magnified background movie in my brain, (the only truly private place an immobile, physically-impaired person can have). While some of that mental activity was an unhealthy biding of my time in fantasy land, much of it was a necessary process of scanning possibilities, of envisioning a fuller life.

In the early 60's, I found an excellent little rehab publication, the Toomey J. Gazette, whose funky name appealed to my self-image as a refined hippy. I pored over its tiny-print pages and met other polio survivors performing feats such as running a business from their full-time home in an iron lung. These stories of real people succeeding at real tasks both humbled me and brought new hope. I felt excitement, bitter envy, shame, admiration, despair, dissatisfaction, determination.

Until then, I had ignored my physical differences and associated mostly with the A.B.'s (able bodied people) of my past, who had known me as I was. I shunned the disabled whom I didn't know, refusing to believe I had much in common with them—I was unique and preferred to remain that way.

Therefore, tuning in and appropriating my own reality was definitely the most difficult chore of getting on with my life. Enduring tortuous stretching exercises and tedious reprogramming of scattered muscle strands was elementary compared to bearing the torments of knowing how to do many things well, wanting and willing to do them, but being stuck with a nerve network that didn't receive the messages.

Taking cues from everyone around me, I felt that I had to be unfailingly cheerful and brave. But, periodically, subterranean pits of despair would bubble up noxious clouds to obscure my vision. Now, I shudder to think that I was sometimes ungrateful for receiving the basic care I desperately needed and was so kindly given by my family. At the time it seemed I had no viable choice but to return to a kind of babyhood. Probably as a result of great stress, and of having to relinquish full control of my body and life, I became more narcissistic and introverted—dark moods, haughty attitudes and passive/aggressive behavior, accompanied vain attempts to be OK in my own and others viewpoint.

Also, knowing that my illness interfered with my family's lives produced bothersome guilt. (Paul Tournier speaks of this in "Guilt and Grace," a book I highly recommend). But I, the tough Halliburton, for many years disdained what I mistakenly labeled self-pity and so deprived myself of the health-promoting process of grieving. That path of grief necessarily runs through the dark forest of denial, the gloomy glens of anger and depression in order to arrive at acceptance of reality, a refreshing place full of light and clean air. Thank God that we are now aware of this and can encourage newly injured pilgrims to make the journey soon and swiftly.

Eventually, a dear friend helped me to begin looking the Truth full in the face, and trying to focus on it. We had long and wonderful talks. I gained back the confident joy of knowing I was a desirable, lovable woman (a belief I had surrendered with my engagement ring eleven years before). What we didn't have was a workable life plan acceptable to both of us. Sad and discouraged, he left without saying good-bye. I sang sorrowful songs and mourned for a long season.

That mental-emotional stimulation combined with disappointment catapulted me into a new seriousness. I began a search for meaning and purpose for my life, and became increasingly confused and depressed.

At the Christmas holiday time I had a severe respiratory ailment (Even though my vital capacity had increased, I still functioned on about 1/3 normal). My brain was revved up from fever and I began to read every book we had about God.

God saved my life! I'll explain briefly why I believe that. At this point, having seen many truths previously ignored, I was desperately longing to believe the Forever and Ever reality that Jesus described. I desired the Kingship and counsel of this great Father/Saviour/Standby God. But, my cynical mind was demanding some positive proof. Just then, a choking cough started in my chest, but nothing sounded, or came up. My airway was clogged. I was in terrible danger. I addressed the King of the universe in blunt terms: "God, if you're real, you'd better help me right now or I'm going to die." The room was very bright and quiet, as I tentatively took a breath through my nose to test if wind would go through. All was clear! After several deep breaths without a rattle or wheeze I said to myself, "It is true!" and said to Him: "Thank you very much, Sir!"

Everything looked and sounded different to me from that time on—someone had tuned in my reality, turned up the brightness and contrast, and muted the static interference. I became a radical Believer, who had taken the Lord's solemn covenant offer seriously ("I will be your God, and you will be my people,") and had signed the blank-page discipleship contract.

Here was quite enough identity and self esteem to last a lifetime. Jesus came to earth to be a servant, and I could be one too, in my own unique way—I was open to whatever he had for me to do. I was hungry for understanding. Advice from the "Manufacturer's Handbook" was quite different from the world's "How-to-succeed" books. His standards were significantly higher and more demanding: "Do justly, love mercy, and walk humbly with your God. Love your enemies, do good to them, and pray for them. Be holy as I am holy." Because "Reverence for the Lord is the beginning of wisdom," I had much to learn and unlearn.

Strangely enough, I then met a group of physically impaired people; even conversed with them (even liked them) and accepted their invitation to their next club meeting. I prodded them for purpose, challenged them to do more than drink beer, and play games. One guy took the bait, got in touch with the National Paraplegia Foundation (NPF) and some of us became a chapter. After five years our NPF chapter phased into the Whole Person Organization, a dynamic group which acts as advocate for all people with disabilities in Kansas City.

When my dad was terminally ill with cancer in May of 1972, he arranged for us to move from our home of 30 years to a Co-op housing development, which was much easier to care for. This was in June. He died in August.

While Mom and I were recuperating from Dad's ordeal, and our loss of him, we had many friends and neighbors visit. A family friend of 30 years called Mom when he was passing through town. He had lost his wife the year before, and was shocked to hear that Mom had lost her husband.

Dr. 'William A. Aufranc, 'Bill,' was an MD retired from the U. S. Government Public Health Agency, and worked for the Joint Commission of Hospital Accreditation, which moved him around the Midwest.

He spent an evening with us, and kept calling back from Chicago and other places—soon Mom was eagerly anticipating those calls and whistling romantic tunes.

The solid, renewed old friendship escalated into full blown romance, resulting in a marriage proposal. Mom, being an extremely devoted, dedicated, and responsible parent, had a big dilemma about how to care for me when they married. They would have to be traveling for Bill's work and I obviously was not a very portable child.

This was my big opportunity to live out the dream I cherished for years—to establish a household of Christian believers as an experiment designed both to meet residents' needs and to demonstrate the desirability of Christian precepts for healthful, peaceful living.

After much consulting with God, and counting the personal cost as realistically as I could, I gave them my blessing, tried to convince Mom she deserved retirement (after 16 extra years of my babyhood), and determined to stay in Kansas City.

A period of negotiating, expressing anxiety and various other emotions, and listening to others opinions followed. We finally came to an agreement: they would set a wedding date 10 months from then, I would begin working on practical planning for the adventure, I would remain in the Co-op townhouse for a year before moving back into the city to a larger house (which I wanted to do immediately).

In Gini's request for this article, she asked about motivation for independent living. Besides the obvious primitive one of surviving, my primary, propelling force has been the desire to live out my faith, to translate my beliefs into daily living. The success of that 1973 experiment became a necessity for my personal integrity and a point of honor to win for my God. He keeps his promises. He is faithful.

Steeped in scripture for four years, I had gained some understanding of the God who "calls into being what does not exist," who has great compassion for the afflicted and is able and willing to supply everything we need. Also, the truth that "in the beginning was the Word" permeated my thinking. My ability to care for myself was still limited to feeding and grooming. Skills such as writing and telephoning, still required having someone set up equipment. Nevertheless, I still had a problem-solving mind which could use the word to formulate ideas and could convey those ideas and convince others of their worth. And I believed the Word: "Nothing is impossible with God."

When I "think about how You did it," as Gini requested, and remember how I got from there to here, I have no secret formula to divulge, and no prideful delusions about being a self-made, Independent Living Specialist who pulled myself up by my own hand-splint straps. Without God, His words of encouragement, His committed people, and the family and resources I was given, I would be neither alive, nor well, nor living happily in Kansas City.

On Mom's wedding day, in November 1973, the experiment began. A new friend and a woman from the Visiting Nurses Association had agreed to live there to help care for me. Other friends volunteered to give me breakfast in the mornings. That day I had a taste of the kind of ingenuity that would be required of me in years to come. The neighbor lady whom we had trained and hired for personal care, remorsefully informed me she couldn't do it. I begged her not to tell Mom, had a brief panic attack, prayed fervently, phoned my faithful Doctor, John Singleton, for references and support, and then called the Visiting Nurses Association. They had someone competent there Monday morning, and provided good helpers for over a year at income-adjusted rates.

Regarding financial provision, one of the timely events which helped make this adventure possible, was that the law about disability insurance for children of Social Security contributors had just been changed. Previously it was only available for those who had been disabled before age 18. In 1972, those disabled before age 21 qualified to receive benefits plus Medicare insurance. That monthly amount plus Dad's Social Security benefits to Mom, and dividends from some mutual funds she let me use provided a livable income.

Most of those years, my part time help cost 50% of my income (the entire SSD amount), so it was amazing that the other half covered all other expenses. I considered living on what I had an interesting challenge and my stewardship responsibility, so became a frugal bargain hunter.

Also, through the years, family and friends have given clothing, food, services, (a cousin kept my old VW bus running well for 14 years), spendable gifts, and treats. People who have lived with me have contributed to house payments, utilities, and food as they were able, or exchanged services for housing. I have rarely felt needy, have always tithed and usually had something left for a "kind act to others."

Securing basic daily care has always been a bigger problem than funding. In that first year, there were times when I didn't know where my next bed pan was coming from (one morning a stranger, a neighbor's mother, appeared in a snow storm to give me breakfast), but God always proved Himself faithful to provide, so while it was sometimes hard on the nerves, that year was good for my faith.

The next big step was home ownership. To condense my fourteen years' housing history, I'll only explain that I have bought two houses, sold one (at a fantastic profit), rented a town house, and helped friends buy a home where I lived with them. Of all these ways of solving the roof-over-the-head problem, I prefer the security, the freedom to alter my environment, and the good feeling of investment that are benefits of owning a home. I have many pleasant memories of each place, knowing it was right for the time.

Much credit goes to my supportive family and friends for making these moves possible. Mom has helped with down payments, a loan to fit my budget, moving and settling in. My brother has given practical and legal advice, moving help and lots of fix-up service on the first house. Countless other friends have made themselves available for helping to find a house and adapt it, for packing, toting, and muscling my possessions around town-- quite a feat with a 750 lb iron lung and a 450 lb. bed—and, for the most part, have done it cheerfully, without grumbling.

Many people have lived with me through the years—I count 35—staying anywhere from two months to six years. A faithful sister in the Lord, Jane Buckley (see Insights), holds the longevity record. Most of my housemates have been younger women from church—most have been responsible and enjoyable. A few were problem people, entrusted to our care by our pastors. That was gratifying, but difficult, too. Sometimes I had that dorm-mother feeling. Visitors and associates marveled that four or five women could live together in peace and harmony.

Because of the continual change, I learned that "life is dynamic, not static," that I should expect and could adjust to people moving in and out. Gradually, I became more flexible. The discovery that it usually took two weeks to feel at home with a newcomer eased my worry about feeling disoriented or insecure during that adjustment time.

A succession of other part-time helpers (too many to count), both paid and volunteer, aged eleven through eighty, have kept me fed, clean, and clothed. Some have been willing to be my hands and feet for extra projects too. I especially like training and working with junior high aged girls, as I did the years when my parents covered all the personal care—only now it's usually the basics we do (cleaning, laundry, food prep), instead of the luxuries of tending roses and clipping articles.

During the winter of 1975-1976, several respiratory infections weakened me. I developed pulmonary hypertension, was hospitalized twice (for the first time in 20 years), and was dismayed to hear that I would now have to sleep in an iron lung again—that yellow submarine which I had slept happily without for 20 years, was back to complicate my life.

In '81, a mysterious illness, eventually diagnosed as a kidney abscess, required surgery, a month's hospital stay, and a long period of recuperation. Bouts with respiratory and urinary tract infections have been temporarily inconvenient and debilitating, but the tough ol' bod keeps serving me well for the shape it's in.

Other aspects of my physical condition have improved—strengthening and coordination of remaining muscle strands have allowed me to develop other methods of doing daily things, so I could shelve feeders, handsplints, and gadgets.

Since 1980, my trusty Abec electric wheel chair has opened a new era of mobility—with "Beckley's" cooperation, I have participated in two weddings (besides my own), attended a Post Polio Convention, taken several trips, explored many miles of neighborhood and nature trails, and gleefully "danced."

From the first of what I call my Interdependent Living Experiment, I have been very involved in our church activities. Always having found it hard to have to receive so much service, much of it voluntary which I could never repay, it felt good to be able to serve others. At various times and places, I have operated a job placement service, taught five-year-old Sunday school, made my home available to lonely people needing fellowship, volunteered for the 'Abounding Love—Ministry to Handicapped' program, and with the aid of my housemates, provided many dinners for the ever-starving bachelors.

In 1981, I was envisioning, however, an even more intense life of service in Israel—expanding our hospitality ministry into a Christian kibbutz. The realization that health problems would make life there too difficult for me, brought deep disappointment, consternation, and questioning. I still hadn't won the \$10 million dollar sweepstakes that would allow me to be a great philanthropist. Statistics said an unmarried woman of 48 probably would never marry. Where shall I go from here? What should I do with the rest of my life?

Meanwhile, another important person came on the scene—Mark Randolph. A new comer to KC, Mark had attended some of our bachelor dinners and eventually was added to the draft list of "lifters." He was an unusually polite, intelligent guy with great insight and a bizarre sense of humor (like mine). While visiting, he once lamented he had no friends he could really talk to, so I offered to be his official friend. It was to be a strictly platonic, working relationship for practicing communication skills and encouraging each other to be the people we wanted to be—no "dating" or "romantic involvement," I declared.

After some hesitation, he decided that was what he needed and set Tuesday night (his old Boy Scout meeting night) for our regular get-together. We learned much about ourselves and each other that summer. But soon I began to have stronger positive feelings for him than I wanted—and vice versa.

There were many differences besides the gulf between my severe disability and his robust strength: age—he was almost 30, I was 46; aptitudes and interests—I was artistic and musical, he was scientific and analytical (a computer application engineer); I was a peacenik, he liked wargames. Nevertheless, I had strengths and understanding that benefited him, he had great compassion and the gift of encouragement that built me up. We were comfortable with each other, felt accepted and appreciated, so we began "dating" and spent more and more time together. Finally we admitted to ourselves and each other that we were IN LOVE. Oh, No! - what to do about it?

Mark and I both wrestled with our conflicts over this relationship for four years, growing ever closer and more trusting. I strongly believed the Lord had initiated it, but, I also knew that God gives men free will to opt out of tough situations. So I alternately despaired of Mark's ever being "ready" to commit to a frightening permanent alliance (he had had many damaging romances and divorce was not an option for either of us) and hoped that we could eventually overcome our objections and combine our strengths to create an unusual, strong couple. Our pastor from India defined marriage as "two rivers meeting, flowing together to become one mighty river."

For several years I had believed I had the gift of marriage and God's go-ahead—at least a flashing yellow light. Even though my natural, skeptical mind couldn't see how that could ever come about, I, like Abraham, "when hope was gone, hoped on in faith," and continued to prepare myself for the role of helpmate. In March, 1985, when I moved into our current home, I needed help with lifting and paying utilities until I could find a married

couple to live upstairs. Mark's living arrangement with three other guys was breaking up, the new house was five minutes walk from his job, so we agreed it would be logical for him to move in with me for now. Even though I wanted to be with him, I was apprehensive that he would settle comfortably into this pseudo-marriage, postponing a covenant relationship indefinitely. Anyway, I enjoyed having him around more and needed his help, so I relaxed and stopped worrying about it.

If he ever asked me to marry him, I knew he would surprise me. And he did. Wonder of wonders, the morning of my 50th birthday, August 26, 1986, he startled me awake with The Big Question. He actually said the "M" word—and I, with only a moment's hesitation, said the "Y" word.

We were married the day after Christmas, December 26, 1986 (he needed a day easy to remember), in a small family ceremony at my brother's home. In May 1987, we repeated our vows at our church before our families and friends. Some generous, talented friends, Mom, and I put together an elegant wedding celebration feast for two hundred (a treat for that multitude of friends who had contributed to my survival for the previous 14 years). Mark's uncle even hired a bagpiper for the reception. All agreed it was a memorable occasion.

As our pastor counseled us before marriage, he gave us much encouragement, pointing out that we had many advantages. We knew each other well, had already worked out many relational problems, and, "Unlike most couples, you know exactly what your handicaps are."

Though I can't say our marriage has been constant bliss—I have had to endure and work through some old but now new grief and frustration over not being able to serve my husband with my own hands—and there never seem to be as many able hands available to help as I would like; Mark has had to come to terms with sharing his time, energy, and income with a needy person (we lost my SSD income and Medicare when we married);—I can say we are successfully adapting. I feel more complete and joyful than I ever have (even B.P.)and we're both still happy to be together after all these years.

Life now is full and busy. New areas of service are opening all the time. We've taken a small group leadership class at church in order to form a group. A new interdenominational organization named Broken Wing Ministry, is being formed and I hope to begin a personal care referral service as a part of that. We hope to complete my dream of visiting Israel someday. We could even have children, adopted or our own, if we wished.

And, what can you, esteemed reader, gain from this long saga of tragedy to triumph? There may be similarities in our stories, but probably there are vast differences also. Each of us comes to his point of disability with an unrepeatable set of circumstances. Only God and you know exactly what is best for you, what you are willing to give and risk to reach your goals, and how to retain your integrity and sanity in the process. I don't consider myself wise enough to say "you should ..." to anyone. But, as a scarred veteran of domestic wars, who is sometimes battle-weary but still responding to reveille everyday, I do feel qualified to offer encouragement and some tips. It may seem overwhelming to choose your own lifestyle and to implement your choices, but it is definitely worth the effort—you are worth the effort. If you seek God, know yourself, and love Truth, you will grow and prosper—the growth and prosperity may not be to your specifications and timetable, but

"The vision has its own appointed hour,
it ripens, it will flower;
if it be long, then wait,
for it is sure, and it will not be late"

THE END

(for now)