

# Reflections on September Eleventh, Coping With the Late Effects of Polio and the Vital Importance of a Good Blueberry Pie

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In some ways, George Bush has helped me outline this speech. Since September 11th, I have been feeling and observing how he has led our country in dealing with the horrors of world terrorism. But what does blueberry pie have to do with this reflection? I'll tell you later.

Through these nerve-wracking days this fall, I have appreciated President Bush's clarity and resolve in the midst of such alarm, confusion and fear. Then one day, I quietly realized that the process of dealing with polio's late effects, which we, as polio survivors, know intimately, is directly comparable to what we as Americans have suddenly experienced as a nation. We, our parents, husbands, wives, children, brothers and sisters, neighbors and friends, as well as our close allies have collectively been taken off guard and wounded. We have all experienced the alarm, confusion and fear as a country under siege. We as polio survivors have also experienced personal alarm, confusion and fear since the news came out almost 20 years ago about the late effects. Our bodies have felt the blows of age combined with gradual, yet early muscle and nerve breakdown. We did not expect it. In a sense, Nature itself has terrorized us. But in the midst of assaults, we have sought encouragement, healing, and hope and we have found them. The process our country has been through the past two months parallels the process we have been through and continue to experience. It is my hope that by sharing my interpretation of the phases we have lived through as a nation and as polio survivors, we will come to better understand the process of coping with polio's late effects and how to forge ahead...how to turn what seems to be unspeakable devastation into a search for goodness and new growth. There are six phases that we as polio survivors and American citizens have in common: the blow, the feelings, the mourning, new perspective, new action, and life adjustment.

## 1. The Blow

It started with the blow. It was the bombing of the World Trade Center for our country. As polio survivors, we each experienced a personal bomb when our physicians announced that we did indeed have the late effects of polio and that it could be progressive. We had no idea that this would happen to us. Nobody told us when we were growing up that things would change so much as we grew older. In the mid-1980s I was told that I had scoliosis, inflamed tendons, a rotated pelvis, some arthritis, some deformities...lose weight, take aspirin for pain, go to physical therapy, use an electric cart, get a right shoe life, and conserve energy. Since then more bombs have hit: a broken leg, carpal tunnel syndrome, sleep apnea, a torn rotator cuff, borderline high blood pressure, more arthritis and a uterus that had to come out. Wear wrist splints, use a C-PAP machine at night, go to physical therapy, manage stress, take Anaprox, get new leg braces and have major surgery. Those are just my bombs. I know that each one of us here today has a personal bomb story that we could easily share.

## 2. The Feelings

After the bombs were dropped on the World Trade Center, our country experienced a set of feelings, which we all as U.S. citizens continue to experience. The shock, the disbelief, the sorrow, the anger, the fear and still the genuine pride in who we are. Whether it's at a global level or at the individual personal level, the feelings we experience after the blow are much the same.

The shock was evident on September 11<sup>th</sup>. I remember watching Peter Jennings on T.V. that morning and then hearing his long silence as the towers collapsed first one, then the other, before our eyes. Dear God, what was happening?! That's how I felt when I first started feeling the gradual onslaught of new pain, weakness and fatigue in my mid-thirties. Dear God, what was happening?! Five different doctors, all with different opinions. Then it was all identified. And because it had a name, like Post-Polio Syndrome, it suddenly seemed so real, and then, so alarming.

Another feeling we have experienced is disbelief. How many times did we hear people interviewed on TV in September say, "this all seems like a nightmare... I wish I could wake up and find that it never happened."? When I first found I had the late effects of polio, I did not want to believe it either. I felt like some ugly witch came by and swiped me with a broom of switches. What did I do to deserve this? I was doing fine in the very best way I could and I thought things would be the same for me physically until I got really old. I was at the peak of my earning career—only 35. How could this be? Nobody ever warned me. I still experience brief times of denial now when I am told about a new health problem I have to face. It takes time for bad news to sink in.

Sorrow has permeated our souls as we hear the accounts of 6,000 innocent victims who were on time for work that day. The painful stories of human loss from their loved ones. The heroes who went down in New York and Pennsylvania. Their staggering numbers only magnify our individual emotional pain—for we understand unexpected loss in our own way. As I cope with each new symptom, I feel unpredictable degrees of agony. My hands are going numb. Will I ever get used to this 'Sleep Machine'? These braces are pinching and cutting my skin. I wish I had more energy. God, it hurts. Why me? Again? Grief seeps through my abdomen and comes out in my eyes.

Another feeling we know collectively is anger—sometimes qualifying as rage. It lurks its ugly head as we continue to see the ruins of the World Trade Center smolder. Why, in God's name, did you attack us? How dare you Taliban degrade and desiccate women that way? Nothing warrants these unspeakable terrorist atrocities. Over the years polio has become a personal terrorist to me. First I almost died with the acute onset, and now it sneaks in and hurts me again. Why, in God's name did nature do this to me? I hate becoming a crippled cripple! I am repeatedly raped by nature. Damn abusive nature! It's not fair.

Fear becomes an insidious intruder and the terrorists want it to eat away at our spirits. Airplanes, anthrax, and Afghanistan all play on our minds to one degree or another while we are awake and while we sleep. As I experience polio's late effects I wonder what's going to happen to me physically in five years, ten years, after I retire? Will I be able to live independently? What

will happen to my ability to take care of myself? Will my mental acuity dwindle dramatically? Will my pain get so bad that it stops me from doing the things I love to do? Financially, what's going to happen next? Will I be okay? It's scary.

But underneath all of these initially dominant feelings and responses there is a sense of pride that we have never seen before. USA! USA! USA! Our red, white and blue flag is everywhere—on our cars, our sweaters, our front doors, our back doors—everywhere! We really do love this amazing nation and are so proud to be part of the great American family. We may bicker, but when it comes time to be a family we are there for each other. I, too, am proud to be a polio survivor! I am proud that I have worked so hard and done the best I could with what I have had to work with. I am proud that Jonas Salk discovered the polio vaccine and that so many famous people like Franklin Roosevelt and Itzak Perlman are polio survivors. We have figured out how to make life work and how to reach out to help family and friends make their lives work a little better too. Our presence and connectedness in this room today is just one example of polio survivors and their loved ones gathering together to improve life. We embrace and support one another. That's the blueberry pie! But more on that later.

### 3. The Mourning

As Americans and as polio survivors, we have felt the blow and experienced a range of resultant feelings from it. George Bush helped us regain focus and then take time to experience the next natural phase—he declared a national period of mourning. The flags waved at half-mast for at least two weeks. The memorial services held across the country in stadiums and places of worship have helped our wounds begin to heal. Acknowledging what has happened and expressing our profound grief has been helpful. As polio survivors, we too, have needed to have times of mourning. In our own privacy, and with our families, friends, and support group members, we have had to say good-bye to how we used to be and how we thought our lives were going to turn out. Personally, I said good-bye to thinking I'd never have to go to a hospital for anything again that was related to polio. I mourned losing the ability to walk across a college campus or from one end of Oakland Mall to the other. I also grieved the dissonant whirling entrance of wheelchairs, Amigos, C-Pap Machines and stair glides into my life. As we mourn, we honor the past, grieve its disappearance, and prepare to move ahead to a new perspective.

### 4. A New Perspective

How many times have we heard from those around us lately that “things will never be the same.” We, as Americans, were like fluffy sheep, minding our own business, grazing peacefully in a green meadow on a late summer's day (I remember how gorgeous and warm the sunny blue skies were here on September 11<sup>th</sup>), when suddenly the wolves charged down on us, wounding the flock. The meadow will never be the same. The messages in the newspapers have been so ambiguous and conflicting. It's safe to fly, but we could be held hostage at any moment by a terrorist on a commercial flight. Go on with your lives as normally as possible, but watch out for anything suspicious—especially at your mailbox! Life is not the same. It is not the same for us as polio survivors either. We are managing a whole new set of health issues that we did not have 20 years ago. We have need to see physicians and physical and occupational therapists. We need new equipment and strategies to help us through our daily activities. Things change and with that change, we have developed a new perspective. I know now that I need to be ready to meet the medical challenges I will face as I grow older with polio's aftereffects. Because I have felt the

adult pain that new disability can bring, it is more important to me, now, to work on behalf of people with disabilities, than it ever was 30 years ago. That fresh perspective has brought me many new joys. My friends and family have always been the dearest thing to my heart, but now I want to be closer and closer to them. I want to talk with them, be with them, give them presents, and help them out. My priorities are shifting because I am not sure what polio or Bin Laden will do next. A man from the neighborhoods of New York was helping clean up in the ruins. A television reporter asked him why he was working so hard. He said “It’s simple. We gotta love other people or die. That’s all there is to it.” It was the wisdom of the ages in one sentence. Tragedy helps us to identify a new perspective and then live it.

## 5. New Action

Throughout the past seven weeks, President Bush has helped us in finding our clarity, courage, and resolve as a nation. Basically his message is “don’t let this stop us!” We must move forward and take new action. Everyone wants to know what they can do to help. Some send money. Some drive to New York with clean up equipment. Some go into military combat. Some pray. As with the late effects of polio, we draw together and make a commitment to doing whatever we can. Each one of us has drawn upon our best resources to contribute to the cause. We may work to combat the ignorance that surrounds us on many fronts. Personally, I have found that helping others has helped me feel better and stronger. Having been drawn to the institutions of higher education for the past 15 years, to help with post-polio research, I wanted to build alliances among scientists and clinicians to address how to most effectively treat the late effects of polio. Our study on Wellness for Women with Polio, for example, helped us discover that a wellness workshop can help polio survivors improve their health behaviors and that a positive attitude is extremely important. Our earlier study helped identify the secondary conditions that people were having so issues like new pain, weakness, fatigue and respiratory problems could be better addressed by physicians and therapists.

We each have to take our health care into our own hands and partner with our helping professionals to manage new symptoms. This past summer, I had to have a hysterectomy, which was pretty scary because I was not sure how the recovery would go. Before the surgery on April 30<sup>th</sup>, I found myself making written plans for surgery and the time of rehabilitation. I decided to take control and write up a series of questions for an experienced physician to answer with me in order to prepare for the experience. It really helped. I asked him things like, “Medically, what can I expect? What will the stages of healing be—especially as related to function? Will I need to be an inpatient on the Rehab Unit after a few days in the surgical unit? What will my rehab plan/activities include while in the hospital? How long will I be in the hospital?” I treated my surgery like a project I was coordinating. Needless to say, the doctor was a bit astounded, but this was the kind of action I could take, and I found it really helped.

Perhaps the most powerful form of action we can take to fight polio’s effects is to draw together. “Love people or die,” the man said. During my painful healing period after surgery I went to stay with a friend who lives in the Pennsylvania countryside. While I was there, she took time to bake us wonderful blueberry pies from scratch. It seems that baking pies from scratch is such a lost art in our quick-quick-rush-rush days. I would watch her get out her best baking dish, then pour out her measured secret crust ingredients—which she would come to share only with me. She would work the dough with her hands in her big pottery bowl. Then she would have me

read her the instructions for mixing the fresh blueberry filling to pour into the crust, which had been quickly and adeptly shaped and pressed into the baking dish by now. Once the filling was added, we tittered about how to decorate the top of the pie with cut outs and colored sugar to give it our best creative touch. These intimate moments in the kitchen between two old friends helped me heal. She told me about the pride of baking a wonderful fresh pie from scratch. It was an old-fashioned moment in a high-tech life. She took the time for me. She wanted me to recover from surgery and be healthy. I knew that the sweet-smelling blueberry pie that she pulled from the oven and we soon devoured was really more than a dessert. It was a symbol of an especially loving comfort time spent among lifelong friends. It was her way to reach out to me. And it naturally became my hope that I would soon become strong enough to make a blueberry pie in my own kitchen once I returned home. Because I was not only mending from major surgery, but also breaking in a new pair of mal-fitting leg braces, I was worried. I prayed that I could stand up long enough and that I would again have the functional endurance to get the pie ingredients out, mix them together and get the pie into and out of the oven. By the end of the summer, after many pain-driven trips to the doctor, to the tables of physical therapists and the orthotists, I made a fine oozing blueberry pie and shared it with friends fresh out of the oven. What a victory that was! Perhaps that blueberry pie and what it symbolizes is, for me, is the most vitally important message about coping successfully with the late effects of polio. We need to nurture and comfort each other now more than ever. Take action. Each of us has our own way to move forward and we are doing it.

## 6. Life Adjustment

As Americans we do not quite know how to adjust to this change in our way of life. But we know that being brave can lift the veil of uncertainty. We are looking to the Irish and the Israelies to teach us how to live with the constant threat of terror. We are doing little things like canceling travel plans and not canceling travel plans. We are trying to shop more. We are buying disinfectant to wash our hands more often at the office. We are making plans for attacking terrorists if they try anything on planes or busses.

Creating a different lifestyle takes time and trial and error. As polio survivors, we know that life is a never-ending series of adjustments. We have an inner voice that reminds us: "don't look at what you've lost, look at what you have left. Be flexible. Be creative. Turn this negative into a positive. Don't look back. Yes, things are not the same. But in many ways they can improve. Take a good look. In many ways for us, life is better. Look at all we have gained in the last 20 years. Look at all the goodness and new growth we have experienced. We have so much to be thankful for. In spite of my new health problems, my world is much richer, fuller and more creative than it ever was before I had the late effects of polio. It has simply taken on a different shape. I never thought I'd swim in the South Pacific, have saffron ice cream in India, or hear elk bugle in the Rocky Mountains. And the wonderful new people I've met along the way. What a privilege!

We have been reflecting on the phases of coping with September 11<sup>th</sup> and the late effects of polio. As we continue to re-assess and re-focus, we will also continue to make adjustments. We will make life work. George Bush unknowingly helped me outline this speech. If he were in this room today, I think he would also say that our enemies are not just Taliban terrorists but they are those among us who obsess with fear, doubt and negative thinking. Our positive search for

encouragement, healing and hope moves forward. As Americans and as polio survivors we know how to find them. We have done it in the past. We know that encouragement, healing and hope are in the faces and hearts of those who care about us. They are all around us--at the grocery store, in the neighborhood, in books. They are right here, right now, inside us.

I found it's a blueberry pie kind of thing. As we draw very close to one another and take the initiative to express encouragement to others, and then demonstrate our hope by our choices and everyday actions, our vision improves and our spirits have magically grown. That's when the healing happens.