



Rancho Los Amigos

Post-Polio

Support Group

Newsletter - July 2005

Editor's Note: The following article by Dr. Ben Thomas is reprinted from our January 2005 newsletter. Several of our readers have offered their own personal perspectives which we hope to include in future newsletters. Starting on page 4 of this issue is a response from Dorothea Nudelman. Dorothea is a polio survivor, mother, and author of "Healing the Blues", a moving account of her own experience with psychotherapy. Dorothea spoke to our group several years ago.

What I've Learned From Polio

By Dr. Ben Thomas, for *Early To Rise*

Everyone is "challenged" in some way. My most obvious challenge is physical, but for others it may be emotional, or financial, or in how they relate to other people. I would like to think that some of the things I have learned from my experience with polio may be of value to you as you encounter and deal with your own problems in life -- no matter what they may be.

In my case, the story begins when I was four years old. I remember going to bed one night and waking up several hours later with a headache. By morning, my continuing fever prompted my parents to take me to our family physician. My mother tells me that, after examining me, Dr. Jaffe said he suspected I might have polio -- a disease caused by a viral infection of the nervous system. I was put in a hospital, and a few days later I was completely paralyzed from the neck down.

I was in the hospital for two years. However, with the support of my family and a lot of medical personnel, I eventually regained the ability to walk and use my arms and hands. I learned to hike and run, and eventually earned the rank of Eagle

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Scout. I learned to draw and paint, and worked during college as a biological illustrator and commercial artist.

Eventually, I earned my doctorate in pathology. I now work as a health and environmental consultant, and hold the academic rank of Professor on the adjunct faculty of the University of Texas Health Science Center at Houston.

Personally and professionally, I'm doing very well. Medically . . . well, approximately 40% of polio survivors get something called post-polio syndrome. And, as it turns out, I am one of them. That means I will get weaker.

But what's most interesting to me is not my personal and professional accomplishments or even my clinical prognosis. It's the fact that my story is not unique.

After meeting and talking with other polio survivors, it is clear that most (especially those who got polio at an early age) tend to be highly successful individuals. Our miraculous recovery from the initial effects of polio seems to have made us believe that everything is possible and that there is no problem that can't be overcome. You just have to identify your objective, plan how to accomplish it, put that plan into action, and amazing things happen.

It has been demonstrated over and over again that a person's ability to implement that specific process is the primary determinant of the success he or she will experience in his or her lifetime. That is an important lesson, but it is not the central message of this article.

Perhaps because of my training as a scientist, I am a careful observer of people. And one of the things I've observed is that there is another, smaller group of polio survivors whose experiences have been very different from mine. Angry, unhappy, and frustrated, they look at their lives and say, "Why did this have to happen to me? How unfair it is that polio cut me down in my prime, destroyed my career opportunities, prevented me from achieving my dreams, and kept me from finding someone I could truly love and who could truly love me."

Why is it that their lives have been so different from mine and from those of so many other polio survivors? The answer has to be "attitude."

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I am half-Japanese, and although I was reared as a Christian, my mother's side of the family is Buddhist, so I have also studied Buddhist beliefs and teachings.

Buddhists believe that we go through life struggling to resolve the conflicts between our experience as humans and our potential as spiritual beings. When a person focuses on his needs, his wants, his fears - that is, when he focuses his human side - that person experiences life as a source of pain and frustration. In response, he builds walls to protect himself from that pain and suffering. He hides behind those walls, but the walls further limit his ability to see opportunities and restrict his ability to maneuver to advance his position. This, of course, increases his frustration level even more. On the other hand, when a person focuses on the needs of others and the wonder that is the Universe -- that is, when he focuses on his spiritual side -- he sees and experiences the very best things in life. Focusing on his spirituality allows him to live in a world where walls, where limits, where frustrations are totally unnecessary.

My experience suggests that the Buddhists are on to something. There is one group of polio survivors who are choosing to be defeated by their disease and who will suffer greatly for the rest of their lives - and there is another group who view post-polio syndrome as just another challenge that they will deal with. I choose to be in that second group.

So, what insights have I gained from my experience with polio that may be useful to you?

The world is a wonderful place. Experience and appreciate all the good things life has to offer you, and learn from everything you do and see.

It is important to develop a clear vision of yourself - understand who you are, where you are going, and why that specific goal is important to you. Knowing your long-term objective will give you a framework from which to evaluate alternative pathways when they arise and to develop the specific tactics to achieve your goal.

Know and believe that you are OK. Be comfortable in the knowledge that you will never know everything . . . that you will be embarrassed many times . . . that you will make decisions that don't work out as you had hoped. But at the end of

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the day, know in your heart that you will survive and that what you learned from the experience will allow you to do better tomorrow. Eventually, you will learn that you can only be hurt if you want to be hurt, that you can only fail if you choose to fail, and that you can only be loved if you choose to love someone else.

Train your mind to see the good in everyone you meet. Recognize that every person is trying to find something that is important to him. You may not understand why a person makes a particular decision, but accept that, from his experience and perspective, it was the best decision possible . . . perhaps the only decision possible. Acknowledge that it was, in fact, his decision to make, not yours.

And, finally . . .

All of us will encounter numerous challenges in the coming years, and all of us will have to find a solution to each challenge on our own. Life not only presents us with problems, but also gives us the freedom to choose how we will deal with those problems. Spend a little time today thinking about how you have been choosing to deal with the biggest financial, social, health, and personal problems you have. Consider how you can solve those problems by setting goals, becoming more productive, and caring about the comfort and happiness of others.

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A response from Dorothea Nudelman:

Thanks so much for publishing the article by Dr. Ben Thomas from *Early to Rise*. I've been thinking of our newsletter audience, myself included, and feeling that there might be a whole range of reactions to what Thomas had to say. I'm writing this because if you do have a variety of responses, they might form a kind of "forum" for your publication to serve those of us who cannot easily attend your meetings because we live too far away.

I like that Dr. Thomas is doing well both personally and professionally after an obviously severe bout with childhood polio, and even while recognizing the onset of post-polio syndrome. I, too, had a successful personal and professional life, but was not nearly as gracious in my acceptance of pps. It led to a long dialogue of

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psychotherapy and a struggle for acceptance as illustrated in my 1994 book *Healing the Blues*.

I think Thomas has both a professional and religious advantage over many of us who were raised in strictly linear, western cultural thinking. This is made clear when he wonders about the “angry, unhappy, and frustrated” people who are stuck asking “why me?”

There is little in the rearing of the typical American that prepares us to deal with the realities of loss, pain, and suffering. Mostly we are taught to be brave and bury our feelings about such things. We learn to “soldier on” through disaster whether it is polio or a hurricane.

The truth is that those of us who do look at our lives and allow ourselves to move through the pain, admit the loss and sense of failure, outlive the suffering to discover that the life that lies ahead of us can be as full as we would have otherwise have made it. Maybe more so. But it is not just the individual who makes the choice freely or not. It is the society that encourages us and gives us ways to work out the difficulties that must also be brought to account. In our society we often define success as strictly monetary, or based on material popular “wins.” This doesn’t leave much space for a person who lacks normal physical powers or who is even physically deformed and terribly limited by his illness. These disparities often lead directly to a kind of spiritual and emotional shriveling.

That is where Eastern thought holds a strong card and can really help us. I was raised a Catholic and was taught on some level to personalize my polio, not by thinking I’d been punished by God but by thinking God had chosen me to suffer and therefore this was a good thing, an honor. Honestly, that didn’t hold up very long. As an adult, I, too, learned about Buddhism and found it far more genuine and “connected” to the real human experience of life. During and after my therapy (which was not “religion” oriented), I found myself discovering the largeness of my life, the connection I had to the rest of the human race, the gratitude I felt for all I had. Now, far beyond my initial therapy, I am no longer walking. I spend almost all my time in my wheelchair and find it is not the disaster I once thought it would be. That is not to say my comings and goings are easier than they were on foot with braces and crutches.

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It is my attitude that has changed! What I feared most has happened, but I am not truly suffering about it. It is simply a fact of my life. I do less. But there is more wholeness in the silences that I can tell you. And joy as well. What I am now working on “growing” is my spiritual potential and my ability to reach out to others and learn how to love other human beings well. I don’t “hide” from myself or others anymore. And, miraculously, I no longer worry about what will happen to me. I have not changed religions, but I have learned, through my understanding of Buddhist thought, a lot more about why God sent us the human Christ on earth. And I am so grateful to have had a chance to see that and live the life I’ve been given.

I’ve probably written far too much here, but I hope I haven’t “preached.” It’s just that I understand the anger that so many have felt because I, too, have felt it. And I wanted to thank you for allowing Ben Thomas to bring his insight to the dilemma of living this last part of our lives with a feeling that some kind of trick has been played on us, that we must escape it. We do have a choice to move on. In this way, we are exactly like all other human beings.

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What have you learned from polio? Please send your perspective to the address on the back page of this newsletter - either e-mail or regular mail.

