

ignorance, insensitivity, and anxieties of the non-disabled. Many of their ideas are applicable to adults with disabilities and could be a useful basis for discussion in the context of support groups. Such discussions could also examine the values which underlie much of our self-defeating behavior, particularly our over-valuation of control and independence, which Trieschmann (1992) has identified as major hindrances to aging with dignity and self-esteem in America.

Finally, reading in the area of disability studies — particularly about the disability rights movement — can help us to capture the meaning of our past experiences. For example, Jenny Morris's (1991) book *Pride Against Prejudice* has been described as "a celebration of our strength and a part of our taking pride in ourselves, a pride which incorporates our disability and values it." □

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## Sixth International Post-Polio and Independent Living Conference

### Spiritual Response to Traumatic Illness

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I am here not just as a presenter, but also as a survivor. I had polio when I was ten years old, in 1953. I am one of the fortunate people who was able to recover a great many of my motor abilities and lived a relatively "normal" life. I passed! And I believed that I had no effects from polio at all until 1988, when I was diagnosed with post-polio syndrome.

For those 35 years, I literally did not consider myself different in any way from anyone else whom I considered physically able. Thus, only when I began to face the impact of the illness on my life could I develop a personal history that was consistent with reality.

During those years, I worked very hard to be successful and ultimately became a family therapist. I found myself working more and more with families in which there was chronic illness. When I was finally diagnosed with post-polio and took a long, deep look at my own experience, I began to appreciate my affinity for those with chronic illness.

As a therapist, I basically consider myself to be someone who supports and enables families and individuals to do the work that they would normally do, if they had not somehow been prevented from doing it. Although

I am by training, experience, and license a therapist, I like to think of myself as a "consultant" who helps people solve their own problems.

Now I want to share with you some of that work I've done over the years. I also want to raise some issues that have emerged for me in my work and ask you to explore them for yourself. Then I want to make some suggestions about some things that have worked for me personally and for the people with whom I've "consulted."

Essentially, I believe that living with a chronic illness, which is a real trauma, results ultimately in a spiritual crisis — not a religious crisis per se, but a crisis in our view of the world. Our world view determines how we approach life, understand it, are challenged by it, and master it; in short, our world view determines the quality of our lives.

Some of the basic assumptions that we make as children about the world we live in, the sense of "order" in the world, and ourselves as valued people, are very much challenged by trauma. How we cope with that trauma determines, in part, the quality of our lives. I'm not talking about pathology either, because I've not found that chronically ill people have any more pathology than

anyone else. I think that the world view of chronically ill people, including polio survivors, is challenged by what they've lived through.

In my clinical work, I apply the ideas of many other people who have studied trauma issues to the issues of chronic illness. This application is particularly useful with polio because, in my own case and in many others, developing the late stage of the illness is very much like having a second trauma.

For me, having to remember and relive those traumas, never having resolved many of them when I was younger, caused me to struggle in a much different, deeper way. I don't minimize the trauma of the first experience for anyone, but I do think that the trauma of the late effects is particularly difficult. Personally, I thought I had put my life together. I thought it had a course that was going in a certain, reasonably comfortable way, but all that changed dramatically for me in 1988.

As I've said, I didn't deal with the trauma the first time around. I was a passer. For me, denial, which was the way I coped, was very, very helpful. I was able to live in a way that worked for me. I was lucky, and those of us who have been able to use denial have been able to gain from it. Unfortunately, what worked for me at a certain point in my life did not work later on. If you keep applying the same coping devices throughout your life, you run the risk of having a very small repertoire of skills. When you can't cope that way anymore, when denial stops working successfully, you are in much deeper trouble.

I don't see many people who come into my office with issues of polio. They come in with other complaints. I see what are called co-morbid factors/issues that are directly related but are different. Often I see the children of polio survivors who see a reality for themselves that is not consistent with what their parents saw. I see marital problems complicated by issues of polio. I see families in which serious physical deterioration is occurring, but the polio survivor refuses to get any kind of help, usually clinging to an outmoded coping mechanism.

Let me make a few suggestions. I have observed — and the research clearly supports this — that people who have strong support systems recover best from any kind of trauma. The first lesson for us polio survivors to learn, if we want to develop a lifestyle that enables us to cope as well as possible, is that we need to develop support systems. We need to go out and become involved with others who have had similar experiences. I can remember the first polio support group I ever attended. I can remember the first man I ever talked to who had had polio. That conversation was very important to me.

A second suggestion, from a family therapist and a family member, is to develop as healthy a family as you possibly can. That means not only your nuclear family,

your spouse/partner and children, but also your parents and other relatives. You need to understand your own family, what you've lived through, and what that family means. My experience is that healthy people have a clear understanding of what their family experience has been and work hard at staying connected in the healthiest ways they can.

I think it's also important to develop very strong friendship networks. I encourage you, even when you feel uncomfortable, to go on, to push yourself to make that connection. My experience — again supported by research — is that when we are in crisis, the support of others makes a tremendous contribution to our recovery.

Exploring the "why" question is important, too. "Why did this happen to me?" is an essential question, and people who recover well from trauma come up with all kinds of answers. Your answer is not my answer, but it is valid for you. Individuals, particularly polio survivors, need to respect others whose answers work for them. We are all evolving an understanding of our lives, and what works today may not work tomorrow.

Positive attitudes and responses are essential, as well. If you have trouble finding them, keep looking. Sometimes they're very difficult to find. I know that, having now developed the symptoms associated with the late effects of polio, I've had to re-evaluate my life and make some hard choices about what is important to me. What do I want to do with the rest of my life? What are the things I've never done before and want to accomplish before I'm gone? Having now gained an understanding that I am running out of time, particularly with my body and my motor abilities, I make a special point of such considerations.

I make a strong final point of developing a self-care plan. We must all step back, look at who we are now and what our needs are now, and develop a plan of self-care. It should involve both ourselves and others as well. When crises occur, we need to have a plan that's proactive and that we can easily use immediately. □

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