

POLIO NETWORK NEWS

SUMMER 1996 ♦ VOL. 12, NO. 3



Sixth International Post-Polio and Independent Living Conference

Responding to Loss: A Practical Framework

Jack Genskow, PhD, Springfield, Illinois

Today I'm talking about loss related to disability, and grief related to that loss. This topic is unusual for me, since I generally focus on the positive — on what we have, rather than on what we've lost. And I think a positive focus is central to coping with, rather than succumbing to, the disability and life with disability. So before getting into loss, let me start with a positive focus.

In an odd way, polio supported this hopeful focus. Initially it took us down to our weakest point. But then, remember how in those first weeks and months after having polio, we were always getting better? Especially in the first six months, but even two years later some of us were getting neural return, which meant increased functioning.

The loss was there, obviously. But it wasn't the focus of our rehabilitation efforts. We focused on what we were getting back, on what we could do.

Today there's strong evidence that a positive attitude contributes to health and longevity. Humor and an optimistic outlook have especially been identified and studied as contributing to health. Not only are psychological factors influential in maintaining health, but, in fact, the powerful healer in many medical studies appears to be faith in the cure, sometimes called the placebo effect.

So, a positive focus is healthy and contributes to adjustment. But there is a reality of loss to disability. And some of us are facing new loss right now. Therefore to focus only on the positive, and to ignore the loss and its pain, cuts us off from being in touch with ourselves.

Looking back to 1955, I remember that my main struggle was in getting out of the iron lung and onto the chest respirator and rocking bed. This process took five months, and by the time it was accomplished, I was pretty well reconciled to my paralysis — it was by then a fact. I don't remember ever really grieving my loss.

How many of us really grieved our loss? For some the loss was temporary though initially frightening, yet recovery seemed complete so the fear was put aside.

Others were too young to know the implications of their loss. Many used defense mechanisms and coped. But how many of us went through the tasks of grieving and effectively grieved our loss?

Now many of us are facing new loss. If we didn't deal with our earlier loss, if we didn't "grieve" it, we might find our current situation complicated by unresolved feelings from the past. For example, the anxiety related to our early paralysis, later reduced by returning function, may recur as we face decreasing function. And we are facing significant loss through aging and through post-polio sequelae.

I've used the word "grieving" several times. What do I mean by this? Grieving is the process of adapting to loss. If grieving is incomplete, then further psychological growth and development can be impaired. Some theorists describe grief as a series of stages or phases that we go through when facing loss. Elizabeth Kubler-Ross, in her work with death, is probably the most familiar, with her stages of denial, anger, bargaining, depression, and acceptance. Some disagree with this approach. They question whether these stages are correct, whether all people experience any or all of them, and whether they are experienced in the same fixed sequence.

I'd like to focus on a practical approach to dealing with or grieving a loss which is based on tasks that we can work on, rather than stages which we simply go through. It is based on a model developed by William Worden, a Harvard psychologist, that he recommends for grief counselors and therapists to use with their clients who have experienced loss. Worden deals mostly with loss through death, but his approach also fits losses of all kinds, including loss through disability.

With Worden, we work through these tasks in our own style and at our own pace. No one size fits all. And we can take responsibility for ourselves.

Worden's four tasks are these: 1. Accept the reality of the loss. 2. Work through to the pain of grief. 3. Adjust to an environment in which that which was

lost is missing. 4. Emotionally relocate that which was lost and move on with life. Let's take these one by one.

First, accept the reality of the loss. Some losses are clear and unambiguous, such as death, job loss, amputation, or a severed spinal cord. But their reality may still be hard to accept. Defense mechanisms such as denial operate to shield us from being overwhelmed by the full impact of the loss. We simply cannot believe. We cannot accept that the loss is irreversible; we think it is temporary.

Coming to the acceptance of the loss takes time, since it means not only an intellectual acceptance but also an emotional one.

When the loss is less defined and ambiguous, then acceptance becomes even harder. This is the case with polio; originally we did not know what our final loss would be because we kept regaining function. With post-polio sequelae, the loss is gradual. Dealing with loss is even more difficult when it raises latent anxiety.

So we have to work at facing and accepting the reality of the loss — to face the facts! Perhaps the best way to do this is to talk about the loss, to put it into words. Talking about any loss makes it real.

The second task is to work through to the pain of grief. Identify and express the feelings related to the loss. Be in touch with yourself and what you are feeling — sadness, relief, whatever. The hardest feelings to work through are anger, guilt, anxiety, and helplessness. The common way to avoid this task is not to feel. Bury the feelings. But as someone once said, when you bury feelings, you bury them alive. And they will find some other ways of expressing themselves.

Anger can turn inward and cause depression or lowered self-esteem. Feelings ignored can contribute to substance abuse, stomach problems, skin irritations, or acting out behavior. Some writers are describing what they term a "chronic sadness" seen in some people with disabilities. It doesn't qualify as a depression, or even as dysthymia, but seems to be a sadness which underlies much of their behavior. This could be one outcome of not finishing work on task two.

Jacqueline Kennedy Onassis was a tremendous example on how to hold a nation together during a time of loss and grief. But with her stoicism, she was not a very good example of how to grieve in terms of experiencing and expressing feelings. We tend to compare our insides with other people's outsides; we don't know what they are feeling inside.

The important thing is to identify and be in touch with your feelings and to find your individual way to express them. Some people find keeping a journal helpful, to

write out their thoughts and feelings. Others use music or art. But do identify them, and do express them.

Once identified and expressed, your feelings must relate to some meaning. Sadness must be accompanied by an awareness of what was lost; anger needs to be properly and effectively targeted; guilt needs to be evaluated and resolved; and anxiety needs to be identified and managed.

The third task is to adjust to an environment in which that which was lost is missing; learn to live with what you have left after disability, and without that which you've lost. This task is familiar since it is the major focus of many rehabilitation programs.

Losses through disability include not only the physical and functional losses, but also the social losses of changed status, minority group membership, possible job loss, and possible self-esteem changes. If you have struggled through life to maintain an able-bodied group identification and suddenly find yourself needing crutches or a wheelchair, you are dealing with a loss greater than simple loss of function.

In rehabilitation, this means learning new ways of doing things, or accepting help where help is needed. It may mean using a wheelchair some of the time, or a ventilator to sleep. It may also mean changes in priorities and self concept, and less independence. These are things we have been hearing about for years: Conserve and preserve. But they are also part of the grief work, and things we can do and can work on. We can all probably list things that we need to work on. It may mean seeing a counselor or joining a peer support group to work through some of the changes we find ourselves resisting.

The fourth task is to emotionally relocate that which you have lost, and move on. Find a special emotional place for the way you were, and then reinvest in life, get on with living, the way you are. This is the key to successful completion of grief work.

Do what you can do, now. Do not get quagmired in the way things were; value that, but move on to what is possible. Find new relationships and activities that you enjoy and that are fulfilling; find new ways of doing what you previously enjoyed.

Now remember, these tasks were identified to be used by counselors in grief work. But their focus is on practical tasks that each of us can do. There are people who are stuck in their grief work, and they may need to see a counselor to work through their blocks. But either way, working through these tasks on your own or seeking help, I see as taking self responsibility.

Although a positive focus is helpful in adjusting to disability and increasing loss, we need to be in touch with ourselves and our feelings, recognizing the negative feelings as well. We need to work through our feelings, and deal realistically with our situation: to grieve our



Disability as a Life Course: Implications of Early Experiences for Later Coping

Mary T. Westbrook, PhD, Faculty of Health Sciences, The University of Sydney, Australia

“We had the experience but missed the meaning” wrote the poet T.S. Eliot, (1952), an observation that is indeed true of many people who became disabled from polio in their youth: they have never evaluated the events that happened to them and their reactions to those events.

In youth, polio survivors adapted to their disabilities, and their coping strategies served them reasonably well until they encountered a crisis in post-polio syndrome. Psychologists define a crisis as an event that threatens a person's way of life and from which there is no escape. Because the usual methods of coping are ineffective, crises cause considerable distress and tend to trigger emotions experienced in earlier crises. We often respond to our present problems with feelings and behaviors that relate more to the past than to the reality of the present (Miller, 1992).

Two important assets in coping with post-polio syndrome are a strong sense of self-worth and supportive social relationships. Although early experiences with polio often damaged our self-esteem and trust of other people, these feelings remain as a largely unrecognized legacy. Only by understanding the meaning of past experiences can we begin to free ourselves from their often malignant long-term effects.

I will briefly outline typical experiences with polio and then go on to describe the effects of these experiences in the lives of 176 people with post-polio syndrome who I have studied for five years.

For most survivors, the initial experience with polio involved long separations from their families and suffering from paralysis, pain, and frightening procedures while being cared for by distant and sometimes abusive staff. Asper (1993) has described how such emotional abandonment in youth shapes the adult personality. She

loss and to move on. If we live in denial, or cut off a large part of our experience from ourselves, leaving it unresolved, we will live emotionally shortchanged.

I will end with a quote from Virgil: “Here's Death, twitching my ear: ‘Live,’ says he, “for I'm coming.” So, live! ... in *all* dimensions of your being. □

Worden, J.W. (1991). *Grief counseling and grief therapy: A handbook for the mental health practitioner*. New York: Springer.

found that as adults such people typically exhibit the following behavior:

- ◆ Fail to acknowledge the degree of their early abandonment and suffering;
- ◆ Fear later abandonment;
- ◆ Are out of touch with their feelings;
- ◆ Display false self-sufficiency;
- ◆ Demand impossible standards from themselves;
- ◆ Feel excessive shame;
- ◆ Respond to others' needs but have little idea of what is good for themselves;
- ◆ Are unable to ask for or to accept help because they fear repetition of their early experiences;
- ◆ Lack compassion for themselves.

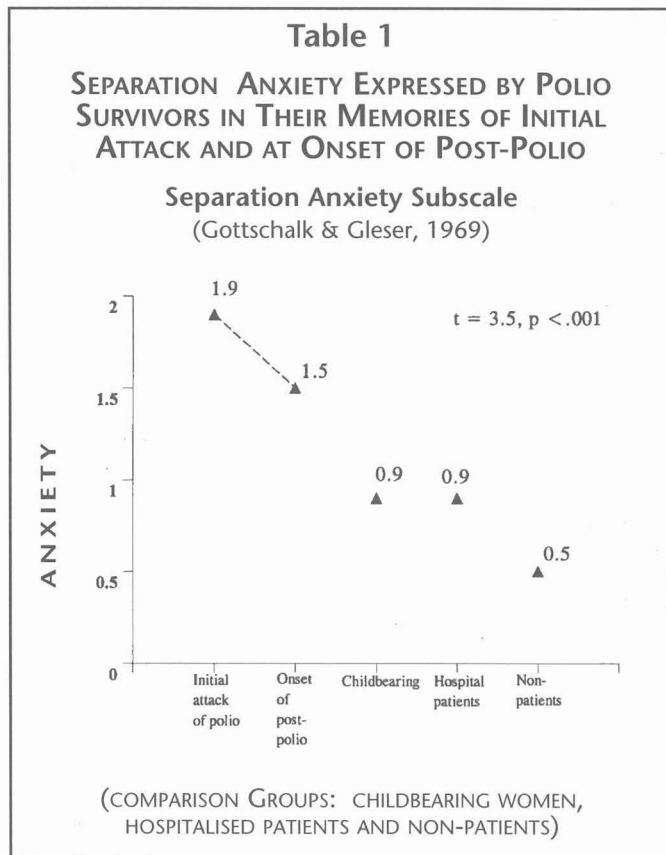
Our second negative experience with polio occurred when we returned home from rehabilitation. Polio survivors were the first major group of people with disabilities to be integrated into western society (Trieschmann, 1987). Negative attitudes toward people with disabilities were far more prevalent in those early days than today (ICD, 1986). Some of us probably experienced these primarily as exclusions that echoed earlier abandonment, e.g., the parties we were not asked to, the friends who dropped away, the physical barriers that excluded or exhausted us, the devaluing assumptions that “normal” people made about us. Others experienced overt rejection, e.g., teasing and aggression from other children and occasionally from even their own families. Phillips (1990) claims that Americans regard people with disabilities as damaged goods. As members of society, we tended to adopt its standards and to agree that we did indeed fall short.

Of course, we did not acknowledge these painful and uncomfortable feelings very often, but they spurred us on to become super-achievers. Our mental equation seemed to be that if we were better than average in everything we did, we would cancel out the deficiency of our disability. For some of us, the nicest compliment we could receive was, “I never think of you as disabled.”

Leaving rehabilitation meant, too, that most of us lost contact with other polio survivors; thus, we had no one in our social group who had had experiences similar to our own and with whom we could discuss and evaluate the past. Also, as Zola (1982) pointed out, there is a strong social taboo against talking about one's disability.

I myself remember returning to school two years after having had polio and being told not to talk to the other students about what had happened to me because "Reverend Mother does not want them to know about things like that."

Wright (1983) has compared being disabled with membership of other minority groups. Unlike members of most minority groups, a person with a disability is usually the only member of his or her social circle who has a disability. Not only does no one else fully appreciate their experiences, but no one else can give them useful advice on how to cope. Furthermore, in most minority groups, the members are valued within their immediate circle even though their characteristics may not be valued by the wider society. Thus, a black person in a racist community typically has a family sharing experiences, giving tips on coping, and instilling pride in racial identity. No one ever told us that disabled was beautiful.



For five years I have worked with a group of 176 Australian post-polio survivors, investigating, along with many other issues, ways in which feelings associated with early polio experiences persist and interfere with later coping. Among other data, I gathered written accounts of respondents' earliest memories of having polio, accounts of how they felt at the onset of post-

polio syndrome, and answers to questions about how they have coped with post-polio problems. I analyzed the written accounts using scales developed by Gottschalk and Gleser (1969), which have been shown to provide valid and reliable measures of feeling states when applied to verbal material.

I used the Gottschalk-Gleser Separation Anxiety Subscale that scores references to desertion, loss of support, loneliness, etc. *Table 1: Separation Anxiety Expressed By Polio Survivors in Their Memories of Initial Attack and Onset of Post-Polio* shows the degree of separation anxiety expressed in the memories of polio survivors of the initial attack of polio and their accounts of the onset of post-polio, as well as the separation anxiety expressed by three other groups I have researched. The table indicates that when they wrote of their feelings about developing post-polio symptoms, the group's level of separation anxiety was significantly less than that expressed in their early memories. However, it was significantly higher than the separation anxiety I have observed in past research investigating women's memories of recent childbearing, the feelings of patients hospitalized with a chronic condition who were asked to speak about their current situation, and a group of non-patients who were asked to do likewise (Viney & Westbrook, 1986; Westbrook & Viney, 1977, 1983).

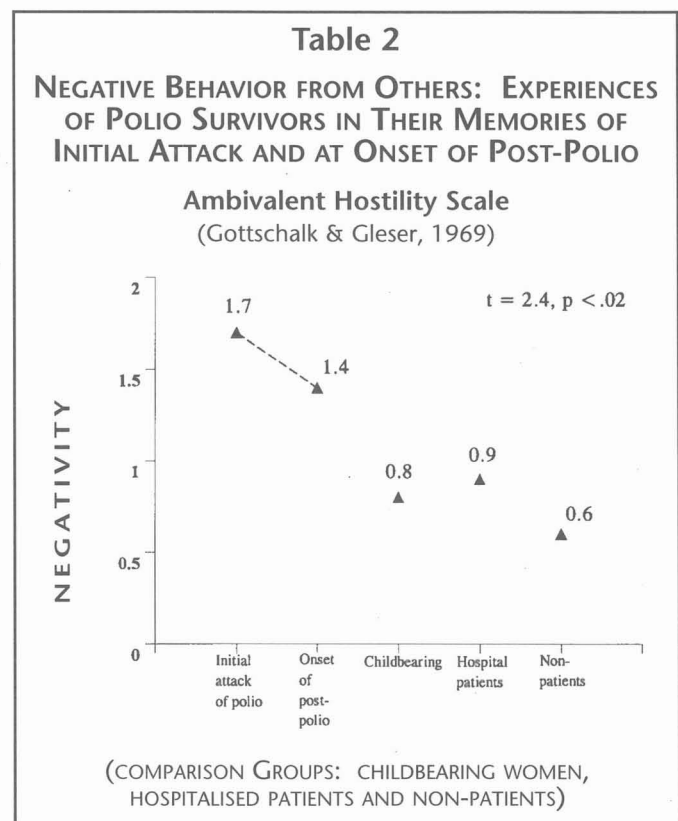
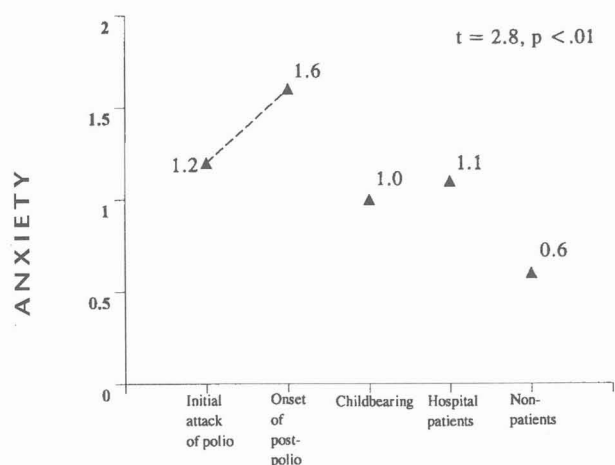


Table 2 shows the results of applying the Ambivalent Hostility Scale (Gottschalk and Gleser, 1969) to people's accounts. This scale measures the degree to which we see others as directing negative thoughts and actions at us, e.g. disappointing or depriving us, expressing dis-

Table 3**SHAME ANXIETY EXPRESSED BY POLIO SURVIVORS IN THEIR MEMORIES OF INITIAL ATTACK AND AT ONSET OF POST-POLIO****Shame Anxiety Subscale**
(Gottschalk & Gleser, 1969)

(COMPARISON GROUPS: CHILDBEARING WOMEN, HOSPITALISED PATIENTS AND NON-PATIENTS)

like. This table reveals that perceptions of others' negativity were very high in people's memories of their initial attacks of polio. Although such perceptions were significantly lower in people's accounts of their reactions to the onset of post-polio symptoms, they remained very much higher than the perceptions of negativity by the three other groups I have mentioned. However, I think that it is important to note that many survivors' current perceptions of negativity from others are reality based: families often resist change, friends can be insensitive to needs, health professionals may discount legitimate symptoms.

Table 3 shows the results of applying the Gottschalk-Gleser Subscale of Shame Anxiety to the polio survivors' accounts. The accounts of reactions to the onset of post-polio syndrome reveal significantly higher levels of shame anxiety than those associated with the initial attack or with the other three events investigated.

Such feelings of shame and fears of abandonment and negative responses from others interfere with survivors obtaining support from their social networks, of course, a fact apparent in respondents' answers to specific questions regarding strategies they use to cope with post-polio.

While 75% of the total sample had talked with family members about post-polio, only 30% of the total sample found such talking to be very helpful. (The two other rating options provided were "some help" or "no help.") Almost the same percentage (74%) had spoken to friends about post-polio but only 17% found this very helpful. Only 39% had requested a family member

to assist them with post-polio problems, and 20% of respondents found this request to be very helpful.

Relatively few (19%) had asked a friend to help with problems and 10% said that this was very helpful. Only two-thirds of the sample (68%) had spoken about post-polio with another polio survivor and 29% reported that this was very helpful.

Survivors were more likely to seek help from non-human sources. Ninety percent of respondents have read about post-polio as a means of coping and 54% rated this as very helpful. Almost as many (89%) subscribed to a post-polio newsletter and 50% reported that it was very helpful. These results indicate that many

Table 4**COPING STRATEGIES ADOPTED AND DEGREE TO WHICH FOUND HELPFUL IN COPING WITH POST-POLIO PROBLEMS**

Strategy	Percentages of total sample of survivors who	
	used	found it very helpful
Talked with family	75%	30%
Talked with friends	74%	17%
Asked family for help	39%	20%
Asked friends for help	19%	10%
Talked with another polio survivor	68%	29%
Subscribed to a polio newsletter	89%	50%
Read more about polio	90%	54%

survivors are not using their social networks to obtain support, particularly practical help. Those that do seek social support usually achieve less than optimal outcomes. In short, survivors need to develop skills to increase and enhance the social support in their lives.

There are no simple answers as to how we can develop these skills. Asper (1993) argues that if survivors of youthful abandonment face the pain of their earlier experiences, they may be able to develop empathy with themselves and increase their confidence in themselves and their joy in living. Some people have found counseling a helpful support in facing their past.

At a practical level, we need to explore strategies for telling others about our needs and feelings in ways that lead to positive outcomes and do not diminish our feelings of self-worth. Although there is a dearth of "How-to-be disabled" books, Fullwood and Cronin (1986) have written an excellent book called *Facing the Crowd*, which provides parents of children with disabilities with numerous practical strategies for coping with the

continued on page 6

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." □

REFERENCES:

Asper, K. (1993) *The abandoned child within: On losing and regaining self worth*. New York: Fromm.
Eliot, T.S. (1952) *Four Quartets*. London: Faber & Faber.

Fullwood, D. & Cronin, P. (1986) *Facing the crowd*. Melbourne: Royal Victorian Institute for the Blind.
Gottschalk, L.A. & Gleser, G.C. (1969) *The measurement of psychological states through the content analysis of verbal behavior*. Berkeley's University of California Press.
International Center for the Disabled (1986) *The ICD survey of disabled Americans: Bringing disabled Americans into the mainstream*. New York: L. Harris & Associates.
Miller, A. (1992) *Breaking down the wall of silence*. London: Virago.
Morris, J. (1991) *Pride against prejudice*. London: The Women's Press.
Phillips, M. (1990) Damaged goods: Oral narratives of the experience of disability in American culture. *Social Science and Medicine*, 10, 849-857.
Trieschmann, R. (1987) *Aging with a disability*. New York: Demos
Trieschmann, R. (1992) Aging with dignity and control. *New Mobility*, 47
Viney, L.L. & Westbrook, M.T. (1986) Psychological states in patients with diabetes mellitus. In L.A. Gottschalk, F. Lolas and L.L. Viney (Eds). *Content analysis of verbal behavior: Significance in clinical medicine and psychiatry*. Berlin: Springer-Verlag.
Westbrook, M.T. & Viney, L.L. (1977) The application of content analysis to life stress research. *Australian Psychologist*, 12, 157-166.
Westbrook, M.T. & Viney, L.L. (1983) Age and sex differences in patients' reactions to illness. *Journal of Health and Social Behavior*, 24, 313-324.
Wright, B.A. (1983) *Physical disability: A psychological approach*. New York, Harper & Row.
Zola, I. (1982) Denial of emotional needs in people with handicaps. *Archives of Medicine and Physical Rehabilitation*, 63, 63-67.



Sixth International Post-Polio and Independent Living Conference

Spiritual Response to Traumatic Illness

Thomas W. Hale, EdS, LPC, Williamsburg, Virginia

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. □

Post-Polio Bibliography

- Agre, J., Grimby, G., Rodriquez, A., Einarsson, G., Swiggum, E., & Franke, T. (1995). A comparison of symptoms between Swedish and American post-polio individuals and assessment of lower limb strength — a four-year cohort study. *Scand J Rehab Med*, 27, 183-192.
- Stålberg, E., & Grimby, G. (1995). Dynamic electromyography and muscle biopsy changes in a 4-year follow-up: study of patients with a history of polio. *Muscle & Nerve*, 18, 699-707.
- Habel, M., & Strong, P. (1996). The late effects of poliomyelitis: nursing interventions for a unique patient population. *MEDSURG Nursing*, 5(2), 77-85.
- Ivanyi, B., Nelemans, P., de Jongh, R., Ongerboer de Visser, B., & de Visser, M. (1996). Muscle strength in postpolio patients: a prospective follow-up study. *Muscle & Nerve*, 19, 738-742.
- Grimby, L., Tollbäck, A., Müller, U., & Larsson, L. (1996). Fatigue of chronically overused motor units in prior polio patients. *Muscle & Nerve*, 19, 728-737.

SELF-HELP Philosophy*

The goal of a self-help group is to empower its members with the tools necessary to make adjustments needed to continue a life of dignity and independence.

Self-help group(s) ...

- ... share a common health concern
- ... govern themselves and their agenda with success dependent on each member's feelings of ownership.
- ... may use professionals as resource persons but not as leaders.
- ... **provide non-judgmental emotional support.**
- ... gather and share accurate and specialized information.
- ... membership is fluid; newcomers are helped by veterans and become veterans who may outgrow the need for the group.
- ... have a cause and actively promote that cause.
- ... increase public awareness and knowledge by sharing their unique and relevant information.
- ... charge small or no dues for involvement and typically struggle to survive.

*International Polio Network, 4207 Lindell Blvd., #110, St. Louis, MO 63108-2915

Did you realize that when we listen to someone, we generally concentrate more on what we're going to say rather than on listening? Have you noticed that our first response usually includes the words "I" or "me"?

Listening involves more than just hearing. Many of us don't realize what is involved in being a good listener. Many times people share important things with us, but instead of really listening, we give them advice or solutions or we are too distracted to give our full attention.

There is a strong temptation for these things to happen in a support group where people are regularly talking about the concerns in their lives. Do members of your support group make statements one after another without being acknowledged by the other group members?

Below are some ways that we listen and don't listen to people.

You are not listening to me when ...

- You say you understand before you know me well enough.
- You have an answer for my problem before I've finished telling you what my problem is.
- You cut me off before I finish speaking.
- You feel critical of my vocabulary, grammar, or accent.
- You are dying to tell me something.
- You tell me about your experience, making mine seem unimportant.
- You are communicating to someone else in the room.

- You refuse my thanks by saying you really haven't done anything.

You are listening to me when ...

- You come quietly into my private world and let me be me.
- You really try to understand me even if I'm not making much sense.
- You realize the hour I took from you has left you a bit tired and drained.
- You allow me the dignity of making my own decisions even though you think they may be wrong.
- You don't take my problem from me, but allow me to deal with it in my own way.
- You hold back your desire to give me good advice.
- You give me enough room to discover for myself what is really going on.
- You accept my gift or gratitude by telling me how good it makes you feel to know you have been helpful. ☐

Active Listening

Shelly Ziegler
Community Services
Coordinator,
Self-Help Network

Reprinted with permission from *Helping Hands*, a publication of the Self-Help Network of Kansas, Department of Psychology, Wichita State University, 1845 Fairmount, Wichita, KS 67260-0034 (800/445-0116).

Polio Eradication

■ In 1995, the incidence of reported polio cases worldwide was the lowest ever – 6197 cases — representing an 82% decline from the 35,251 cases in 1988.

■ In the United States, three suspected cases of paralytic poliomyelitis with onset in 1996 have been reported to date. Two cases with onset in 1995 have been confirmed; these cases were vaccine-associated. An additional six suspected cases with onset are under investigation. Five cases with onset in 1994 were confirmed; all were vaccine-associated. (Source: *Morbidity & Mortality Weekly Report (MMWR)*, 1996; 45: 370-373, 592.)

■ The Advisory Committee on Immunization Practices (ACIP) met in Atlanta in June 1996. During this meeting, the committee heard public comment about the proposed change in ACIP policy for routine polio immunization.

The committee voted to finalize its recommendation to state that two shots of inactivated poliovirus vaccine (IPV) followed by two doses of oral poliovirus vaccine (OPV) will be the recommended childhood immunization schedule. An all-IPV or all-OPV schedule will be acceptable alternatives.

The Centers for Disease Control and Prevention (CDC) will be asked to study the impact of the new schedule(s) on childhood immunization coverage and on the number of cases of vaccine-associated polio, and to monitor the adverse events associated with IPV use.

These recommendations are pending CDC approval; if approved, implementation would probably occur in 1997. Implementation will require education of providers and the general public. Materials and strategies are being developed.

Related addresses and phone numbers:

National Vaccine Information Center
512 W. Maple Ave., #206, Vienna, VA 22180
(703/938-0342, 703/938-5768 FAX).

To report an adverse reaction to a vaccine:

Vaccine Adverse Event Reporting System (VAERS)
800/822-7967.

For a copy of "The Vaccine Rules" for individuals wanting to file a claim for a vaccine injury, contact U.S. Claims Court, 717 Madison Place, NW, Washington, DC 20005 (202/219-9657). □

Readers Write

Please send your responses to International Polio Network.

"Are there others who are now experiencing agoraphobia (abnormal fear of open spaces; contrasted with claustrophobia)?" MARION, ILLINOIS

"I've read in *Spontaneous Healing* by Andrew Weil, MD, that Trager work can be helpful. Also, my triple arthrodesis was done in 1952. This year the diagnosis was osteomyelitis due to this operation. Are there others who have had experiences with either?" JO, CALIFORNIA

"I am looking for information about the PolyClinic and Welfare Island in New York City during the 1930s, and Dr. Margaret Reynolds." MARY, NEW YORK

"I'm trying to find fellow polio survivor Gordon R. "Sam" Overton, who worked for the California state attorney general's office." ALEX, IDAHO

"I've lost contact with Sandy Goldstein, San Antonio, who used to make my lumbosacral corsets. They were the best. Does anyone know how to locate her? Does anyone have other recommendations for good corset makers?" KAY, MINNESOTA

"I have swelling in the calf of my atrophied leg. C.A.R.E.*TM Anti-Embolism Stockings distributed by Baxter Healthcare Corporation ordered by my physician really help. Similar brands can be purchased without a prescription." DAVID, OHIO

"I use stockings (not pantyhose) for support. I can no longer find stockings that are 30 inches long. It would be great if the leg opening was 23 inches wide." HARRIET, MASSACHUSETTS □

INTERNATIONAL POLIO NETWORK

4207 Lindell Blvd., #110
St. Louis, MO 63108-2915 U.S.A.
314/534-0475
314/534-5070 Fax
gini_intl@msn.com

ISSN 1066-5331

Polio Network News is an international newsletter for polio survivors, health professionals, and resource centers to exchange information, encourage research, and promote networking among the post-polio community.

ISSUED QUARTERLY

EDITOR/EXECUTIVE DIRECTOR: Joan L. Headley

PUBLISHER:

Gazette International Networking Institute (G.I.N.I.)
4207 Lindell Blvd, #110, St. Louis, MO 63108-2915 U.S.A.

SPECIAL THANKS TO:

Jack Genskow, PhD and Ellen Peak

ANNUAL SUBSCRIPTION:

U.S.A ♦ \$16 (U.S. dollars only)

CANADA, MEXICO & OVERSEAS (Surface) ♦ \$21
(U.S. dollars or Canadian equivalent)

OVERSEAS (Air) ♦ \$25 (U.S. dollars only)

Copyright ©1996 by Gazette International Networking Institute
Permission to reprint portions must be obtained from the Editor.

October will be National Disability Employment Awareness Month

coordinated by President's Committee on
Employment of People with Disabilities

Ability for Hire

HOW DO I KNOW IF MY WORKSITE IS ACCESSIBLE?

The following are some questions to keep in mind when determining physical accessibility:

- ◆ Are there designated parking spaces for persons with disabilities that are close to the entrance of the worksite?
- ◆ Is there a pathway without abrupt level changes or steps that leads from the parking area to the entrance?
- ◆ If ramps are used to provide access, are they appropriately graded and are handrails provided?
- ◆ Are the doors wide enough (36 inches) for people using wheelchairs? Are they easy to open (e.g., not excessively heavy, with easily grasped handles, or automatic)?
- ◆ Is the personnel office in an accessible location?
- ◆ Are pathways to the bathrooms, water fountains, and public telephones accessible? Can people with disabilities use them?
- ◆ Are elevators accessible to all persons with disabilities (e.g., control panels lower than 54 inches from the floor, raised symbols or numbers on the control panels)?
- ◆ Is all signage appropriate and accessible for persons with visual, learning, and cognitive disabilities (including the use of symbols and graphics)?
- ◆ Does the emergency warning system include both audible and visual alarms?

HEALTH INSURANCE

The Equal Employment Opportunity Commission implements those parts of the Americans with Disabilities Act that prohibit discrimination in employer-provided health insurance. An employer may not deny an individual with a disability equal access to insurance, or require such an individual to have terms and conditions of insurance different than those of employees without disabilities.

The ADA does not require employers to provide health insurance. However, if an employer chooses to offer health insurance to employees, the ADA requirements apply.

What is the interim enforcement guidance?

On June 8, 1993, the EEOC issued Interim Enforcement Guidance on the Application of the ADA to Disability-Based Provisions of Employer-Provided Health Insurance. This document identified four basic ADA requirements in the area of health insurance.

1. Disability-based insurance distinctions are permitted only if the employer-provided health insurance plan is bona fide, and if the distinctions are not being used as a subterfuge for purposes of evading the Act.
2. Decisions regarding employment of an individual may not be motivated by concerns about the impact of the individual's disability on the employer's health plan.
3. Employees with disabilities must be accorded equal access to whatever health insurance the employer provides to employees without disabilities.
4. An employer cannot make an employment decision about any person based on concerns about health-plan costs because of the disability of someone with whom that person has a relationship.

Workers' Compensation and the ADA

Workers' compensation laws are designed to provide needed assistance to employees who are injured on the job, whereas the ADA's purpose is to protect people from discrimination on the basis of disability. The ADA prohibits an employer from discriminating against a person with a disability who is qualified for a job. The EEOC regulations prohibit employers from making medical inquiries of employees that are not job-related and consistent with business necessity. However, the ADA is consistent with an employer taking reasonable steps to avoid increased workers' compensation liability claims while protecting persons with disabilities against exclusion from jobs they can safely perform.

Are all injured workers protected by the ADA?

Whether an injured employee is protected by the ADA will depend on whether the person meets the ADA definitions of an "individual with a disability" and "qualified individual with a disability." The person must have an impairment that "substantially limits a major life activity," or have a "record of" or be "regarded as" having such an impairment. The worker also must be able to perform the essential functions of a job currently held or desired, with or without a reasonable accommodation.

The fact that an employee is awarded workers' compensation benefits, or is assigned a high workers' compensation disability rating, does not automatically imply that she or he is protected by the ADA. Not every employee injured on the job will meet the ADA definition. An employer must consider work-related injuries on a case-by-case basis to determine if a worker is protected by the ADA.

For an "Ability For Hire" educational kit, contact:

President's Committee on Employment of People with Disabilities (202/376-6200 V, 202/376-6205 TTY/TTD, 202/376-6219 FAX).

For additional information, contact:

President's Committee on Employment of People with Disabilities' Job Accommodation Network (JAN) (800/526-7234 V/TTY/TTD, 304/293-5407 FAX, or jan@jan.icdi.wvu.edu).

Disability and Business Technical Assistance Centers (DBTACs) (800/949-4232 V/TTY/TTD, 703/525-6835 FAX).

Access Board (800/872-2253 V, 202/272-5449 or 800/993-2822 TTY/TTD, 202/272-5447 FAX).

Equal Employment Opportunity Commission (800/669-4000 V, 800/669-6820 TTY/TTD, 513/489-8692 FAX).

**October 20-26
will be
National Adult Immunization
Awareness Week**

Facts about Adult Immunization:

FACT: Each year in the United States, as many as 50,000-70,000 adults die needlessly from vaccine-preventable diseases or their complications.

FACT: Influenza and pneumococcal pneumonia together are the sixth leading cause of death in the nation.

SHOULD ALL ADULTS BE IMMUNIZED?

YES! As a general rule, all adults require measles, mumps, rubella, tetanus, and diphtheria immunizations. All adults age 65 or older, and those with chronic cardiovascular, pulmonary, or metabolic disorders (for example, diabetes) need protection against influenza and pneumococcal pneumonia, and should consult their doctors regarding their need for these shots. Hepatitis B vaccine is indicated for adults in certain high-risk groups, such as health care workers and persons with multiple sex partners. Hepatitis B vaccine is also recommended for all adolescents who have not received it as infants. Hepatitis A is recommended mainly for travelers visiting developing countries where Hepatitis A is common and where clean water and proper sewage disposal are not available, and for men who have sex with men.

**Immunizations for Older Adults
and for Those with Chronic Illnesses**

INFLUENZA (FLU)

Given yearly in the fall to people age 65 or older. Also recommended for people younger than 65 who have medical problems such as heart disease, lung disease, diabetes, and other conditions, and for others who work or live with high-risk individuals.*

PNEUMONIA

Given at age 65 or older. A repeat dose 6 years later may be given to those at highest risk.* Also recommended for people younger than 65 who have chronic illnesses such as those listed for influenza, and also those with kidney disorders and sickle cell anemia.*

Both the influenza and pneumococcal pneumonia shots are paid for by Medicare.

**Consult your doctor to determine your level of risk.*

What shots do I need if I'm traveling abroad?

Contact your doctor or the public health department as early as possible to check on the immunizations you may need. Vaccines against certain diseases such as Hepatitis A, yellow fever, and typhoid fever are recommended for different countries. The time required to complete the immunizations will depend upon whether you need one booster dose or a vaccine series. You may also call the Centers for Disease Control and Prevention information line for international travelers at 404/332-4559.

For more information about National Adult Immunization Awareness Week, contact the **National Coalition for Adult Immunization**, 4733 Bethesda Ave., Suite 750, Bethesda, MD 20814-5228, 301/656-0003, 301/907-0878 FAX.

November ...

Tuesday, November 5, 1996, is general election day for the United States of America.

Go Vote: A Disability Guide to Election '96 has been compiled by *Mainstream*, Cyndi Jones, publisher. The guide offers information to non-profits about voting rights, procedures, and getting out the vote. One-5 copies, \$2 each; 6-25, \$1 each; 26-99, 80¢ each; 101 and over, 60¢ each.

For more information, contact *Mainstream*, 2973 Beech Street, San Diego, CA 92102, 619/234-3138, 619/234-3155 FAX, publisher@mainstream-mag.com. The guide is available in print, audio, and computer disc. □

OMB and SLMB Programs in USA

If you are elderly and poor or disabled and poor and eligible for Medicare, your state may pay some or all of your Medicare expenses. Federal law requires that state Medicaid programs pay Medicare costs for certain elderly and disabled persons with low incomes and very limited assets.

Two programs help people pay their Medicare expenses. One is called the "Qualified Medicare Beneficiary" or "QMB" program. The QMB program is for persons with limited resources whose incomes are at or below the national poverty level. The other is called the "Specified Low-income Medicare Beneficiary" or "SLMB" program. The SLMB program is for persons whose incomes are slightly higher than the poverty level, but not more than 20 percent higher.

If you already have Medicare Part A and think you qualify for either QMB or SLMB assistance, you must file an application for Medicaid at a state, county, or local medical assistance office - not a Federal office. You can get the telephone number for your medical assistance office by calling 800/638-6833. Give the operator the name of your state and county. Explain that you want the telephone number for the nearest office that can help you file for assistance under either the QMB or SLMB program.

If you are age 65 or older and think you qualify for this assistance but do not have Medicare Part A, you should first contact a Social Security Administration office. You may need to file an application for Part A. The address for the nearest Social Security Administration office can be found in your telephone book. □

New Post-Polio Contacts — A new group has formed in England with the goal of sharing information. Contact Lincolnshire Polio Network, 69 Woodvale Avenue, Lincoln, Lincolnshire, LN6 3RD England (01522 500134, 01522 885115 FAX; linpolio@legend.co.uk)

Post-Polio Syndrome Research Center, St. Vincent Hospital Medical Center, 153 West 11th Street, New York, NY 10011; Harry Bartfeld, MD (212/604-8314); Howard Sander, MD (212/604-7453).

Calendar

— 1996 —

Fall Conference: Together, Learning, and Coping, October 11-12, Ramada Inn, Anderson, Indiana. Contact: Jim Felix (317/649-0084) or Ellen Crim (317/649-3648).

Second Northwest Post-Polio Conference, October 18-20, Sheraton Portland Airport Hotel, Portland, Oregon. Contact: Sheila Maxwell, Easter Seal Society of Oregon, 5757 SW Macadam Avenue, Portland, Oregon 97201-3797 (503/228-5108 or 800/556-6020 Oregon only).

Living with the Late Effects of Polio, November 8-10, Sydney, Australia. Contact: Post-Polio Network (NSW) Inc., P.O. Box 888, Kensington, New South Wales 2033, Australia (612 636 6515).

Post-Polio Syndrome: It Can Take Your Breath Away, November 9, Ocala, Florida. Contact: Carolyn Raville, North Central Florida Post-Polio Support Group, 7180SW 182nd Court, Dunnellon, Florida 34432 (352/489-1731).

— 1997 —

SEVENTH INTERNATIONAL
POST-POLIO
AND
**INDEPENDENT
LIVING
CONFERENCE**
ST. LOUIS, MISSOURI, USA

G.I.N.I.'s Seventh International Post-Polio and Independent Living Conference, May 29-31, 1997, St. Louis Marriott Pavilion

Downtown. Subscribers to G.I.N.I. publications will receive registration packets when available.

Been There, Done That, Movin' On, September 12-13, Atlanta, Georgia. Contact: Bonnie Bonham, Atlanta Post-Polio Association, 2020 Peachtree Road NW, Atlanta, Georgia 30309 (404/350-7631; 770/232-7178 FAX).