

Beyond the Blues

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Like many survivors of childhood polio, I spent at least five years in mid-life denying that my body was losing strength and mobility. In 1981, I had surgery and later fell and broke my leg. After recovery, my gait had changed and my pace was slower. The palms of my hands ached from pressure on my crutches. I chalked all this up to fatigue from a busy life. I had lived with polio all my adult life and knew the drill: giving in to weakness or fatigue was deadly. Trying harder would strengthen and restore me.

Over the next six years I exhausted myself further. Finally, frightened by continuing losses, I sought help from a psychotherapist and discovered that my fears masked a long held depression about my initial polio losses. It has been twelve years since my therapy for depression, and I learned that depression can be treated and healed. Publication of my book, *Healing the Blues*, connected me with polio survivors, as did the 1997 GINI conference and the Internet. The richness of these associations, the repartee and gallows humor over worsening conditions, and the generous support and sharing of information have given me a deeper understanding of depression.

Most importantly, I have learned to recognize when I am vulnerable and to develop ways to avoid depression. Writing *Healing the Blues* was a first step in this process. Connecting with adult polio survivors has taught me to advocate for myself and others, a long way from where I started – young, fearful, immobile, often at the mercy of caregivers. As a child, I learned the value of coop-

eration and silence in the face of fear or pain. Now I am learning to speak my mind and heart, to care for myself as my body ages.

Noticing my own “danger” signs for depression is a critical first step in avoiding repeat episodes. I hope that sharing these signs may help you to notice, question, and see your own. I have also discovered techniques which help me replace negative feelings with positive actions. Again, in looking at your own life as you cope with losses, you will be the best judge of how to stem the tide of depression.

Depression with chronic disability is not unusual but sometimes goes unnoticed. Such failure results in expending precious energy “stuck” in misery or passivity. Depression increases fatigue. Negative attitudes further debilitate us and we simply cannot afford this. Healing of mind and heart and spirit can renew us if we become our own guardians.

In my quest for stable health, I distinguish between depression and sadness. When I am depressed, I feel low, lack energy for life, and lack expression. I feel deeply tired, irritable, and anxious. When I am sad, I feel a flood plain of emotion. The weight is painful, poignant, sometimes overwhelming. I used to be afraid to feel sadness. I thought if I allowed myself sadness, I would drown. Now that I allow sadness as much as I demand laughter and expect happiness, I see the feeling as something that will not kill me. After allowing myself a full measure of sadness, I am usually ready to seek some remedy. For me, the trigger feeling for depression is usually sadness; for you, it might

be anger, hostility, or some other emotion.

I am sad when:

- I am temporarily debilitated by a compromised physical condition such as a bad cold or flu.

- I experience excessive fatigue or strain from “keeping up” and ignoring limitations.

- I fall or suffer other physical accidents resulting in loss of capacity.

- I am confined by winter weather.

- I find I cannot do something I used to do – climb a set of steps; walk with only one crutch or none at all; walk more than a block when I used to walk as much as a mile; turn over in bed without using my arms to help me.

- Something major is relinquished because of the toll polio continues to take.

- I must give up gainful employment, especially when I have enjoyed the work.

- I must trade a favorite car for another one which will accommodate a scooter.

- I suffer negative body image, as aging combines with polio losses to affect my sense of self. I gain weight, lose my sense of attractiveness, sexual drive, or high energy level.

- I feel “stuck” with no outlet for expression of feelings, particularly isolation, fear, discouragement.

- I feel hypersensitive to others’ attitudes, particularly when they talk condescendingly about me in my presence, or treat me as if my wheelchair makes me invisible.

- My imagination is driven by fear of the future by seeing losses to come.

I think anyone would be sad in these instances. I think because polio veterans learned early to endure in silence, the return of the nightmare makes these losses

pack a special wallop. As one survivor friend told me, "They said we'd never get worse, only better. Dealing with this stuff now feels like betrayal. I think that's the hardest part to accept."

Facing sorrow, anger, or fear, I first "pay attention" to the feeling to see what it is telling me. When I fail to do so, I pay dearly. Ignored bad feeling sinks down and becomes covered with the heaviness of depression. I can slip into a depression, unconsciously draining good energy into a veritable wasteland if I do not practice vigilance.

Loss of energy is a waste for anyone but it is more critical for us. Preserving energy is central to maintaining wellness and slowing or reversing further deterioration. Until I experienced the late effects of polio, I kept my balance mainly through creating a structured, disciplined life. I cultivated wit and humor to heal my wounds. Now, practice at keeping mental and emotional balance has become the driving force in my "quality of life" defense.

Hoping that my "remedies" will help others, I offer these methods for confronting the mounting list of changes I face regularly. Using my skills has helped me accept and celebrate the life I have.

To begin with, I have revised my expectations to fit my physical condition. In the past, I could walk a mile, now barely a block; in the past, I completed all tasks using only a brace and crutches, now I need my scooter for outside activities; in the past, my upper body strength was enormous, now my shoulders, arms, and back are weakened and injured. Awareness of these changes keeps my expectations fluid instead of fixed. I do not have to like change, but when I respond appropriately, I can commend myself for good judg-

ment – a long way from toppling over into sadness.

I have learned to live with pain and to listen to what it is telling me, rather than denying or ignoring it. When I feel physical pain, I ask, "What is this about?" Usually I need to adjust a limb, shift positions, support my body better, take a nap, or reduce the quantity or duration of work. Occasionally heat or massage helps, sometimes medication. I pay attention to the duration and severity of pain and seek consultation when I need it. I neither deny it nor blindly endure it. The conscious decision to deal with my pain gives me a sense of control and personal power. This decision was inspired by Dr. Stanley Yarnell who presented his understanding and treatment of post-polio syndrome at the 1997 GINI conference. His intelligence, compassion, and wit gave me courage to trust that there was help for me.

When I need help, I ask for it directly. I no longer work to maintain the illusion of physical independence. Seeing situations realistically, I know when to ask for help and when to tackle a task alone. For example, I enjoy entertaining at home a great deal. I used to shop, prepare, and serve my guests mostly on my own. Now, I ask my husband and friends to help, reminding them, if necessary, that I do not carry dishes from the dining room to the kitchen. My parties thrive and I enjoy them more because I ask for and get help. This enables me to live a fuller life and feel better about myself rather than focusing on what I cannot do.

To maintain daily balance, I create structure in my life where there would otherwise be none. I started doing this after I retired and had free time. This was the first time I had no professional obligations

and for about six months I "played hooky" from morning alarms, mealtimes, and bedtimes. Eventually I tired of this. I felt disconnected from the outside world. I missed seeing people and having stable patterns of waking, eating, reading, and socializing. I found it easy to fall into brooding and withdrawing. Having simple routines (like bathing, exercising, and accomplishing something tangible before noon) make me feel on track and alert and satisfied. It does not matter whether what I have accomplished is paying bills, reading a book, writing a poem, or visiting with a friend. What matters is that I have lived my

CONTINUED ON PAGE 6

International Polio Network

Polio Network News (ISSN 1066-5331)
Summer 1999 ■ Vol. 15, No. 3

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.

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COORDINATED AND PUBLISHED BY:
Gazette International Networking
Institute (GINI)

EDITOR: Joan L. Headley, Executive Director

GRAPHICS/ASSISTANT TO THE EDITOR:
Sheryl R. Prater

SPECIAL THANKS TO: Ellen Peak

Annual subscription:
USA: \$20 ■ Canada, Mexico, and
Overseas surface: \$25 (US dollars only)
Overseas air: \$30 (US dollars only)

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Networking Institute (GINI)

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life well in that time. I experience pleasure, big time, this way. Structured days give me affirmation.

While I enjoy spending time alone, I seek the community of other people to encourage mental, emotional, and spiritual growth. Shortly after I retired, I invited some colleagues to start a reading group to discuss literature. Our meetings are mentally stimulating and socially rewarding. Last year, I joined a small spiritual community focused on personal and spiritual growth. Through this group I have learned to use the powers of my imagination to increase my sense of vitality, creativity, and gratitude for life and not to frighten myself with fear of the future.

I have learned to forgive myself for getting stuck, again and again and again! This practice increases my compassion for myself and others. It gives me confidence in the simple reminder that everyone makes mistakes. My sense of humor used to deflect emotional pain. Now humor makes pain something I live with for a while and then get over. Laughter laced with kindness and wisdom is healing. Soon I will travel to Paris for the first time in 30 years. In my youth, I was able to walk around Paris. Now "mobility anxiety" had me seeking scooter rentals in France. During my search, a dear friend gave me a card with a photo of a woman's feet in high heels and on the tips of her stiletto heels tiny wheels were mounted as if for gliding. Inside she wrote, "Wouldn't you love these shoes for traveling down the Champs Élysées?" In one stroke, the absurdity of this picture turned my apprehension into laughter. I was ready to move on.

By practicing regular acts of kindness towards myself, I am develop-

ing a loving sense of acceptance for all things, including my body. Most of us will spread or droop here and there if we live to middle age. When we can look at ourselves with gratitude and with appreciation for how well we have lived in these bodies in spite of the ravages of age and illness, we can see our own beauty. It takes time but this is possible. Simply staying open to the possibilities of sexual and personal aliveness is a good place to start. If we have to surrender anything, we should surrender society's false sense of beauty — it is simply too narrow for both sexes, and it is destructive.

In writing *Healing the Blues*, I took the first tentative steps towards a great mid-life harvest. Now in the thick of it, I am beginning to understand that the process of moving through life is the greatest gift we receive. Each day is part of that journey. There will always be grief and loss, but when we see and accept the wholeness of life, joy and light can illuminate our skies making us winged creatures who fly free. ■

Readers Write

"According to a sleep study, my body is retaining a high amount of carbon dioxide and the doctors are urging me to have a tracheotomy, which I desperately do not want. I have not been able to use my voice for over a month now. This is the third extended period that I have been unable to speak. The first time was for two months in 1992. It happened again last August and lasted three months.

"Each time I have lost my voice, I have relied on my own judgment when it is safe to start speaking again, which is when I stop hurt-

immediately, "I have almost all of these symptoms. I should call a doctor." More likely you are going to have to fight a war of attrition; constantly working on them and wearing them down until they are willing to go for help. Remember, your goal is only to get them to a competent physician trained in the diagnosis and treatment of affective disorders. In order to do this, you will have to work hard to overcome the still existing stigma of depression, while not overwhelming the depressed person with information. Suggest accompanying them on at least their first visit to the doctor. It may help to overcome reluctance, and it is also a very important aid in proper diagnosis.

It is generally not easy. It generally takes time. It generally takes a lot of effort and patience on your part with no real assurance that, ultimately, you will prevail. But, if you care enough, it is worth trying. In the meantime, it is very important to take good care of yourself. You might even try visiting a support group that offers support for people in your situation. ■

ing. However, each time it has happened, it has left me more limited in how much I can use my voice. The right vocal cord, which is partially paralyzed, has just been overworked too often. The left cord is paralyzed mid-line, but it never hurts when overused.

"I need a keyboard and communication device which I am working on getting. My HMO does not want to cover it, but I am still trying. I need it now while I am unable to speak and to supplement, like a crutch, when I am able to speak again.