

Polio Network News

Fatigue is one of the three major symptoms described by the survivors of polio along with pain and weakness. Fatigue has many causes including over-use of muscles and joints, deconditioning, side effects of medications, and underventilation. Fatigue is also a sign of depression. Studies conclude that most polio survivors (see *Polio Network News*, Vol. 14, No. 3, page 5) do not experience depression more than the general population in which 3.3% are affected by major depression. The following articles are for those who do.

Recognizing Depression

Linda L. Bieniek, CEAP, Chicago, Illinois

Depression varies in its form, symptoms, and severity. Whereas common symptoms include fatigue, irritability, and difficulty concentrating and remembering, bipolar depression manifests itself through both manic and depressive characteristics. Any of these symptoms can impair an individual's functioning, health, careers, relationships, and financial stability, as well as adversely affect the lives of loved ones.

For polio survivors, recognizing and treating depression effectively

is critical because depressive symptoms like fatigue and sleep disturbances can exacerbate symptoms of the late effects of polio. One study reveals that none of the polio survivors who clinically met the criteria for depressive disorders were in counseling or taking antidepressant medication (Kemp et al., 1997). Outcome studies prove that depression is treatable (Gilbert, 1992), with the greatest improvements coming from a combination of psychotherapy and pharmacology (Hales, 1995).

Depression may develop from:

- Physiological causes such as a chemical imbalance;
- Ongoing or accumulated distress which depresses the brain's neurotransmitters (Hales, 1995);
- Chronic emotional or physical illness, addictions, neglect, or abuse in one's family history (Gilbert, 1992);
- Responses to losses such as a decline in functional abilities or loss of a job;
- Reactions to present day situations which relate to unresolved feelings from past experiences (Westbrook, 1996);
- Difficulties from an original illness or its effects later in life (Hale, 1996);
- Separations from primary caregivers during infancy and critical developmental stages (Plimpton & Rosenblum, 1987);
- Traumatizing experiences such as intrusive medical procedures;
- Certain medications, physical illnesses, or use of substances such as alcohol (Hale, 1996).

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Selecting a Counselor

Linda L. Bieniek, CEAP, Chicago, Illinois

Finding a suitable counselor whose expertise and approaches match the needs of a polio survivor is critical to a successful counseling experience. Although interviewing several counselors takes time, it will allow one to make comparisons among them.

The goal is to work with a counselor who responds clearly, directly, and respectfully to questions and feedback. This kind of response encourages openness - essential for a trusting, results-oriented process. Defensive, vague, evasive, or in any way disrespectful com-

ments may indicate characteristics that will eventually interfere with progress.

How a counselor responds to the following questions can help reveal the person's strengths, limitations, and, ultimately, suitability.

- What services do you offer? What are your areas of specialization?
- What is your education? What is your therapeutic orientation?
- Are you certified or licensed? By what organizations? For how long?
- How do you assess a client's treatment needs?

- What is your experience with disability issues?
- What is your philosophy of counseling/therapy?
- What kind of therapeutic approaches do you use?
- Do you set treatment goals and evaluate progress? How? How often?

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Historically, polio survivors are recognized for their achievements and adaptations to their disabilities. However, these same individuals who value being perceived as strong need to understand that depression is not a character defect and that seeking professional assistance requires courage and inner strength.

Those who deny feeling depressed may reveal the presence of symptoms when telling stories or answering open-ended questions. For example, patterns of overeating, drinking alcohol, sleeping excessively, and overworking are ways of sublimating feelings – irritability, loneliness, anxiety, or even excitement – that may mask some level of depression.

When depressive symptoms exist, a thorough assessment by a behavioral health professional is needed to identify the underlying causes of symptoms. These professionals, who vary in their approaches, include psychiatrists, psychologists, social workers, employee assistance professionals, and other counselors.

Treatment options that have demonstrated value include individual and group therapy using non-judgmental approaches; non-addictive medications such as anti-depressants; trauma resolution therapies; and various interventions. Complementary resources range from support groups to workshops, self-help books, and alternative therapies (Bieniek & Marshall, 1997), but any approach that claims to achieve absolute results signals a need for caution.

RECOGNIZING DEPRESSIVE ILLNESS

Clinical depression is a “whole body” disorder that affects body, feelings, thoughts, and behaviors. Depressive illnesses come in various forms. Some people have a single episode of depression;

others suffer recurrent episodes. Still others experience the severe mood swings of bipolar disorder, sometimes called manic-depressive illness, alternating between depressive lows and manic highs. Others have ongoing, chronic symptoms.

When four or more of the symptoms listed below for depression or mania persist for more than two weeks, an accurate diagnosis and professional treatment should be sought.

SYMPTOMS OF DEPRESSION

- A persistent sad, “empty,” or anxious mood
- Loss of interest or pleasure in ordinary activities, including sex
- Decreased energy, increased fatigue, being “slowed down”
- Sleep disturbances (insomnia, early-morning waking, or oversleeping)
- Eating disturbances (loss of appetite and weight, or weight gain)
- Difficulty concentrating, remembering, making decisions
- Feelings of hopelessness, pessimism
- Feelings of guilt, worthlessness, helplessness
- Thoughts of death or suicide, suicide attempts
- Irritability
- Excessive crying
- Chronic aches and pains that do not respond to treatment

SYMPTOMS OF MANIA, ranging from moderate to severe:

- Inappropriate elation or irritability
- Decreased need for sleep
- Increased energy
- Increased talking, moving, and sexual activity
- Racing thoughts
- Disturbed ability to make decisions
- Grandiose notions (National Institute of Mental Health, 1992) ■



Linda Bieniek is a certified employee assistance professional who augments her professional ability with her personal experience as a polio survivor and a ventilator user.

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- How do you determine when treatment is successful?
- What do you consider your role and responsibilities as the counselor/therapist? What about the client's?
- How would you describe yourself as a counselor/therapist?
- Are you affiliated with any hospitals, group practices, or treatment centers?
- Do you refer people to outside resources like workshops, books, or support groups?
- Whom do you use as a consultant or supervisor? (Even an expert counselor needs to have a consultant to discuss complicated dilemmas.)
- Have you ever had a complaint filed against you (e.g., with a licensing board, ethics committee)? For what reason? What was the outcome?
- What are your fees? Are you covered by my insurance? Do you offer a sliding scale? How long

- are your sessions? What is your cancellation policy?
- Are you available for emergency or phone consultations?
- Who is your backup when you are unavailable?

To obtain referrals of counselors/therapists, contact the following sources:

- Employee Assistance Programs (EAPs), confidential assessment and referral services offered by some employers and unions. Normally, family members and individuals in the same household also are eligible to use these services. In a sound program, certified professionals thoroughly assess a client's problems, identify treatment needs, refer to suitable providers, and follow up to ensure that the client's needs are met. Some offer short-term counseling and can assist in arranging for work-related accommodations;
- Preferred Provider Organizations (PPOs) and Managed Care

- Corporations, networks and directories of providers who meet certain criteria;
- The departments of psychology, psychiatry, or social service and/or pain clinics of rehabilitation centers, medical centers, and universities;
- Information and referral services of disability organizations and consumer advocacy groups;
- Professional licensing or certifying associations (e.g., National Association of Social Workers, American Psychological Association);
- Issue-specific professional organizations (e.g., health psychologists, trauma-related);
- Well-respected professionals and individuals; and
- People who have had successful counseling/therapy experiences. ■

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I'm Not Depressed, But Someone I Care About Is!

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You know about clinical depression being a treatable physical illness, but does the person you care about know? If not, you are faced with a problem. Education is the key. The person afflicted has to gain an understanding of the illness to realize that there is no reason to be ashamed any more than they would be ashamed if they had hypertension, for example. (Of course, the situation is different if you have reason to believe a person is suicidal; get that person to an emergency room immediately.)

You have to be aware that approaching the depressed person is not without dangers to your relationship. You have heard the expression, 'Kill the messenger!' However, you mean well and you are trying to improve the quality of your loved one's life and, possibly, even to save it. The person you care about may recognize this and may even find comfort or relief in your support.

You can approach this person carrying a book while saying something like, "I was looking through this book and you would

not believe just how many of the symptoms in here seem to match what you are going through. Why don't you take a look and see what you think?" You might also suggest that the person see how many of the symptoms of the checklist match his/her own. It must be made clear that you are only doing this because you care and hate to see the person in so much pain and trouble. Remember that your timing and tone are also important. You would not want to try this when the person is particularly upset. You will benefit most from a tone which is concerned but matter-of-fact versus one that is critical or distressed.

In the best of all possible worlds, your loved one would respond

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Beyond the Blues

Dorothea Nudelman, Portola Valley, California

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

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International Polio Network

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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.

"Getting back to my breathing problem – after explaining about my vocal cords, you can understand that my opening there is very limited. When I am walking slowly, I have no problem breathing, but I become very short of breath when climbing steps, house-cleaning, walking quickly, etc.

"In addition, one side of my diaphragm is not functioning properly which contributes to my breathing problem. Could the slowing down of the bodily functions during sleep, which is when I am retaining carbon dioxide, be more from my diaphragm problem than my vocal cord problem?"

"Have you heard of any other bulbar polio survivors who have lost their voice completely?"

BEVERLY, PENNSYLVANIA

"I had a stroke in 1997 and have recently joined the ranks of those who are not only physically disabled, but are also unable to speak clearly or quickly. This is a new and very frustrating experience for me.

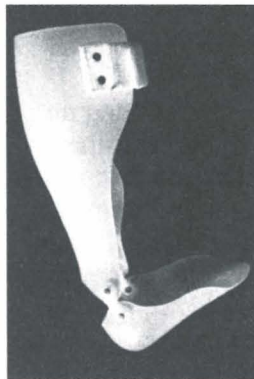
"Sometimes I feel like I am on an island where people are all around me, but I feel alone. It is almost as if I am not really here. Even if I could speak clearly, I am too emotional and the words will not come out right. I feel very alone because of my inability to respond. Perhaps people do not know what to say to me, so they say nothing. It is important for others to know that I would like to be treated as if I were able to speak and respond like any other person.

"I have very limited ability to breathe and am trached and use a ventilator 24 hours a day. My facial muscles are almost gone, which makes it very difficult for me to speak. If anyone has any

suggestions or comments, please contact IPN."

LEAH, MINNESOTA

"A few months ago I was sent for an evaluation of my ankle-foot orthosis (AFO) and discovered a hinge-type device marketed for braces that separates the foot from the leg segment of the brace. The hinge allows flexibility of my foot and increased motion.



"I was thrilled to find that walking up and down ramps or inclines was much easier, and that once again I could use

the foot pedal on my sewing machine! This hinge also makes walking less stressful because I have a more normal heel-toe strike pattern.

"I hope others will find this information useful. These braces have opened up things to me that I found impossible in my old fixed-ankle AFOs.

"For those in the Chicago area, my braces were made by Dreher Jouett at Dreher Jouett Orthotics which has recently become affiliated with Sheck-Siress."

ROBERTA, ILLINOIS

"I am a retired rehabilitation counselor who had polio in the late '30s. While not specific for those with disabilities, the *Consumer Reports* #9554 from March 1997 evaluates mattresses. This can be obtained for \$7.75 charge via credit card from their Fax Back Service at 800-999-2793."

CHARLES, CALIFORNIA

"I had polio in 1918 when I was 18 months old and was the only case in Kansas City that year. Now at 82, after college, employment with the Federal government, marriage at 35, motherhood, and other activities, I am interested in getting as much help as possible. It was always my desire to be in the mainstream. Now I suddenly feel disconnected and want to share my experience with others of my generation. Would you ask individuals who may be interested in communicating to send their names and addresses to IPN?"

HELEN, ILLINOIS

"Several individuals in our support group have mentioned problems with constipation. I use a concoction I read about in an article by Dr. Donohue, a physician who writes a newspaper column. Mix 2 parts applesauce, 2 parts bran, and 1 part prune juice. Keep refrigerated and use 1 tablespoon as needed."

DORIS, MISSOURI

"I assist individuals in getting their new equipment covered by existing insurance benefits. While working in the durable medical equipment industry, I was bothered by the fact that families had powered wheelchairs they could no longer use and had no way to get them to someone who did. I now maintain a bulletin board for free used power chairs (not manual) and try to make a match."

THOMAS M. THURLOW,
SENIOR WHEELS, 800-360-8765,
INDIANAPOLIS, INDIANA

MOVING?

If so, be sure to send your new mailing address to:

International Polio Network
4207 Lindell Boulevard, #110
Saint Louis, MO 63108-2915

Coming Home Again!

Audrey King, Don Mills, Ontario, Canada

A bout with pneumonia last winter landed me in a critical care unit where attempts were made to manage the illness with my usual mode of ventilation, a PLV-100 ventilator with face mask and an in-exsufflator, followed by several attempts at intubation. Finally, ventilation via tracheostomy, a mode completely foreign to me (and a decision my pulmonologist reluctantly made, knowing me to be a long-standing advocate of noninvasive ventilation), was tried.

When I had polio in 1952, we had no highly specialized hi-tech ICU, and "home care" simply meant coming home after two years to my family who, by themselves, met my increased physical needs while still expecting me to maintain the same independence, self-reliance, and achievement that they had always expected.

I was in an iron lung for six weeks followed by five ventilation-free years; then I used nocturnal ventilation support via cuirass. As an adolescent, I hated this embarrassing secret, and I always wondered if I really needed it. After completing university, I came to Toronto to work and to seek an answer to this question.

Somehow in this quest I was routed to orthopedic doctors who stabilized my spine and decided that my breathing was no longer at risk. In short, following surgery, I was told by the orthopedic surgeon that I did not need the ventilator – I had just been psychologically dependent. Although mortified and embarrassed, I was thrilled to be rid of the monstrosity.

Within a few weeks, I started having bad morning headaches.

At the time, I did not know their significance, and they were not taken seriously by the hospital staff. Within six months, I was back to work. I relished my newfound freedom, getting on with my career in psychology at the Ontario Crippled Children's Centre and traveling a lot. But symptoms of respiratory insufficiency gradually increased – morning headaches, waking up at night trying to get back the rhythm of breathing, falling asleep in the daytime while at work, on the phone, even when shopping. Night-time urinary frequency finally led me to a urologist, then to a physiatrist and a respirologist who gave me hell for thinking I could manage without ventilation.

I had grown up assuming that "doctors know best," but at this point I realized that my very survival depended on me: I had to learn as much as possible about post-polio respiratory insufficiency.

I came home with a cuirass – again. It did not fit, causing sores and leaks. I received no equipment maintenance plan, and it stopped working altogether on a holiday weekend in Michigan. Fortunately, a neighbor who was a vacuum repairman replaced worn brushes and got it going again.

My problems with the cuirass seemed so unending that I felt like the last polio "respo" in the world – yet common sense told me otherwise. I eventually discovered a large group of respiratory polio survivors in Edmonton, Alberta, with a well-established respiratory home care service. I also discovered the *Rehabilitation Gazette* containing a notice of the 1981 GINI conference in Chicago enti-

tled, "Whatever Happened to the Polio Patient?"

For me, the conference was a watershed event, a turning point that empowered me with enough information to set my course. It was a meeting of knowledgeable physicians and ventilator users in a relationship of mutual learning and respect. I learned how to "frog breathe." I learned about customized gadgets and devices and positive pressure via mouth-piece or mask. I came home convinced that noninvasive positive pressure ventilation was the solution to my problems. And so it was. The switch to positive pressure (LP3) solved my problems and enabled me to get on with my career and advocacy initiatives, particularly those involving the long-term needs of ventilator users in Ontario. I had nearly 18 years of problem-free breathing until this recent episode of pneumonia.

... at this point, I realized that my very survival depended on me ...

I do not recall much of my several weeks in the ICU except for a terrifying fear that would not let me go to sleep: I was sure that I was of lesser priority for critical health care in today's severely restricted health care environment because of my significant disability. I was sure the staff would turn the monitors off if I went to sleep. Curiously, the only "rescue and relief" during this ongoing nightmare was my imagined midnight arrival of physician and respiratory therapy friends from that first 1981 GINI conference.

It was terrifying to be helpless and unable to communicate my positioning needs so as to maintain some function, however limited.

Although extremely ill, I apparently made heroic efforts to carry on “self-directing” my care. Even when unable to speak, I gestured to be sat up or put in my chair, where I wanted to stay for hours. In their efforts to be “patient-centered,” the staff listened until I simply fell over, being neither rational nor reasonable, at which point they called the shots.

My transfer from critical care to a medical ward was a real nightmare. Although I was in an observation room near the nursing station, the nurse/patient ratio was 1 to 8. No one yet understood my “disability” needs. I could neither move myself nor lie in one position for more than an hour. I was still too weak to call for help, self-direct, or explain. Miraculously, friends and colleagues really came to my rescue, staying overnight for several weeks and coming often throughout the day to help with meals, provide basic care, and assist the staff in becoming aware of my unique needs.

As my strength returned, my articulate, convincing, “self-directing” nature began to return. I insisted on getting up and dressed every day, although this process exhausted me for hours. My behaviour was not that expected of an ill patient “on” a ventilator full time. I still needed constant suctioning, but I was absolutely convinced that if I got home, I would get better quicker. My chest was a wheezy mess and suctioning was becoming more difficult, but I did know about my PLV-100 ventilator. Although the respiratory and nursing staff were concerned, my attendants, who assisted me prior to the hospitalization, were willing to learn trache care and suctioning, and sicker people were waiting for my hospital bed. To go home, I had to accept 24-hour support – a combination of

30 hours of a home care RN per week, an insurance-paid RN overnight, and my usual three attendants. It was great to be home at first, but as I looked around and saw the transformation of my home into a “hospital,” it was not great at all. The overnight RN wanted to socialize; I wanted to sleep. The home care RN was an organizer, a tidy freak who could not sit still and seized every opportunity to organize for her convenience bathroom cupboards and drawers, putting things I use regularly out of my reach. She may have been an efficient nurse,

By now I learned that being articulate and self-directing about my disability needs could put me in jeopardy ...

but she did not understand the balance between nursing care and letting me be in charge of what I could. My attendants were excellent, comfortable with their roles and added functions. However, a problem of territory quickly developed, with the RNs having little respect for the attendants and not hesitating to embroil me in their unrest.

Five people around-the-clock whose schedules I had to coordinate, the lack of privacy, a geriatric cat whose vomiting on the carpet only seemed to increase, my 87-year-old, unsteady, deaf mum, who naturally expected me to again support her communication and daily living needs, not to mention my increasing suctioning difficulty and bronchospasm – it was all too much. I returned to emergency: an obstructing granuloma (soft tissue growth) was discovered below the trache tube and required my readmission.

Once the granuloma was removed by laser surgery at another downtown hospital, the news was bad – the back of my trachea had been eroded almost through to the esophagus by the tracheostomy tube. The surgeon put in a temporary soft-sponge cuffed tube, a Bivona, that he said he would replace in a week or so with a Montgomery T-Tube that would enable me to return to my previous mode of ventilation, a night-time mask and mouthpiece.

This was great news – except that my respirologist and respiratory therapists were not familiar with such a tube, and the otolaryngologist at my hospital felt that it was inappropriate: it was too soft and could fold on itself and suffocate me. It was not made to connect to a ventilator and could be pulled out by weight of the trache tubing. An anesthetic would be required for its insertion.

I felt like a pawn between respirology, otolaryngology, thoracic surgery, and two different hospitals. The waiting for consultation and coordination was endless. Although I could have negotiated a discharge and put myself in a stronger position of decision making and control, I was afraid to because I did not know enough and was worried that “out-of-sight” would mean “out-of-mind.”

By now I had learned that being articulate, knowledgeable, and self-directing about my disability needs could put me in jeopardy in situations of illness that are unfamiliar. Moreover, questioning and conversation that reveals my knowledge can be intimidating and confusing to skilled health care professionals who are used to taking the lead. They may decide that I know more than I really do. They may not understand that “independence” makes me ask

CONTINUED ON PAGE 10

for as little help as possible and be reluctant to bring a problem to staff attention because I am sure that I can surmount it or that it will simply go away.

I have been home for several months now. I have not used the tracheostomy for weeks and have returned to mask and mouthpiece. My new wheelchair has power and zip in spite of the weight and bulk of the PLV-100 on the back. My latest goal is to get the new Pulmonetic Systems' LTV1000™, the size of a laptop computer, that weighs only 12.5 pounds, thus reducing the weight and dimensions of my chair considerably.

I am willing to try a button to keep the stoma in my throat open for a while, but I simply have to get this trache tube out of my throat. It is just sitting there, not being used, taking up valuable throat space.

Disability and acute illness are two distinct experiences that often get confused. Finding and keeping the balance between independence and dependence in situations of severe illness and hospitalization is a challenge for those of us with significant disability. ■

Coming Home Again! is an edited version of Audrey's presentation via videotape to the 7th International Conference on Noninvasive Ventilation: Across the Spectrum from Critical Care to Home Care in Orlando, Florida, March 1999.

To purchase a copy of *From the ICU to Home Care: A Patient's Perspective*, the videotape featuring Audrey's presentation and her conversation with Dr. Allen Goldberg, contact Marilyn Lederer, The CHEST Foundation, 3300 Dundee Road, Northbrook, IL (Illinois) 60062 (847-498-8370, 847-498-5460 fax, mlederer@chestnet.org). The cost of the videotape is \$25.00.

New Publications

A Nearly Normal Life (ISBN 0-316-55852-4) is a memoir by polio survivor Charles L. Mee. 6x9, hardcover, 227 pages. \$24 USA; \$32 Canada. Contact Andrew Fleishman, Time Warner Trade Publishing, Time & Life Building, 1271 Avenue of the Americas, New York, NY (New York) 10020 (212-522-8112).

Polio and Me in Nigeria and Malawi, Belgium, England, and Other Places, 1955-1998 (ISBN 0-9534567-0-6) by Ken Barnes. 6x9 paperback, 55 pages. £5.99. Checks payable to the British Polio Fellowship, Ground Floor, The Runway, South Ruislip, HA4 6SE (k.j.barnes@btinternet.com).

My Last Days as Roy Rogers (ISBN 0-446-52388-7) by Pat Cunningham Devoto is a novel set in the 1950s during the polio epidemics. 6x9 hardcover, 358 pages. \$20. Contact Andrew Fleishman, Time Warner Trade Publishing, Time & Life Building, 1271 Avenue of the Americas, New York, NY (New York) 10020 (212-522-8112). ■

Post-polio Bibliography

Ivanyi, B., Nollet, F., Redekop, W.K., de Haan, R., Wohlgemuh, M., van Wijngaarden, J., & de Visser, M. (1999). Late onset polio sequelae: Disabilities and handicaps in a population-based cohort of the 1956 poliomyelitis outbreak in The Netherlands. *Archives of Physical Medicine & Rehabilitation*, 80, 687-690.

In The Netherlands, every suspected case of polio must be reported. Even though most of the records were destroyed, the researchers found 564 individuals reported as having paralytic poliomyelitis between May and December 1956. The addresses of 191 could not be traced; 23 people had died. The remaining 350 were contacted and 74% responded, 27 of whom denied or did not recall having had paralytic poliomyelitis. Other interesting data, in part, include that 70 individuals (30%) did not answer the question regarding new muscle atrophy and that com-

plaints of increased muscle weakness were associated with increasing age and the presence of disabilities and neuromuscular complaints during the stable period.

Wilson, D. (1998). Crippled manhood: Infantile paralysis and the construction of masculinity. *Medical Humanistic Review*, 12(2), 9-28.

Another in a series of articles by polio survivor and professor at Muhlenberg College in Allentown, Pennsylvania, Dan Wilson, who is writing a book about the social history of polio. ■

Incidence of Polio Worldwide

As of May, 1999, 6227 polio cases with onset during 1998 were reported worldwide. This number exceeds the 5185 cases reported in 1997 by 20% and can be explained by improvement in surveillance and reporting techniques. Poliovirus transmission now is confined largely to southern Asia, western Africa, central Africa, and the Horn of Africa. At the end of 1998, poliovirus was suspected or known to circulate in 50 countries, including seven major reservoir countries (Bangladesh, DR Congo, Ethiopia, India, Nepal, Nigeria, and Pakistan), and eight countries in conflict (Afghanistan, Angola, DR Congo, Liberia, Sierra Leone, Somalia, Sudan, and Tajikistan). The southern Asia reservoir countries reported $\geq 80\%$ of all polio cases globally in 1998. ■

Revised Vaccine Policy

The Advisory Committee on Immunization Practices (ACIP) has recommended that the United States change to an IPV-only immunization schedule for the polio vaccine. If approved by the Centers for Disease Control and Prevention (CDC), the recommendation will take effect January 1, 2000. The IPV is the inactivated poliovirus vaccine and is given by injection. ■

1999

Mobile Area Post-Polio Support Group Meeting, AUGUST 28. Guest speaker will be Joan L. Headley. For more information, contact Vera Moore, 6650 Cottage Hill Road, Apt. 701, Mobile, AL (Alabama) 36695 (334-639-2189, 888-248-1680 fax, vmoore4474@aol.com).

Post-Polio Conference, SEPTEMBER 17, Embassy Suites Hotel, 555 South 10th Street, Omaha, Nebraska. Speakers include Burk Jubelt, MD, Syracuse, New York. Contact Marian Barnett, Nebraska Polio Survivors Association, P.O. Box 45139, Omaha, NE (Nebraska) 68145-0139 (402-341-0710, mjbarnett@worldnet.att.net).

Living Well in a New Century, SEPTEMBER 17-19, Bethesda Marriott Hotel, Bethesda, MD (Maryland). Featured speakers include Lauro Halstead, MD, William Anthony, PhD, Grace Young, OT, and Jane Wootton, MD. Contact Polio Society, 4200 Wisconsin Avenue NW, PMB #106-273, Washington, DC 20016-2143 (301-897-8180, 202-466-1911 fax).

First Annual Indiana Polio Survivors Association (IPSA) Post-Polio Conference, SEPTEMBER 18, Methodist Hospital of Indiana, Indianapolis. Contact Rebecca Balsley, IPSA, P.O. Box 441226, Indianapolis, IN (Indiana) 46244 (765-759-9094, ipsa1@juno.com).

Post-Polio Seminar, NOVEMBER 13, Marietta Conference Center, Marietta, Georgia. Speakers include Richard Bruno, PhD, and Nancy Frick, MDiv, LhD. Contact Atlanta Post-Polio Association, P.O. Box 250566, Atlanta, GA (Georgia) 30325 (404-350-7631, bgbonham@mindspring.com).

61st Annual Assembly and Technical Exhibition of the American Academy of Physical Medicine and Rehabilitation (AAPM&R), in conjunction with 13th World Congress of the International Federation of Physical Medicine and Rehabilitation, will be held NOVEMBER 11-14, 1999 at the Hilton Washington & Towers, Washington, DC. Contact AAPM&R, 1 IBM Plaza, Suite 2500, Chicago, IL (Illinois) 60611-3604 (312-464-9700, 312-464-0227, info@aapmr.org, www.aapmr.org).

2000

Polio: Options, Links, Issues, Outcomes, JANUARY 19-22, Edmund Barton Centre, Moorabbin, Victoria, Australia. Featured speakers include Mary Ann Keenan, MD, Alberto Esquenazi, MD, and Jerry Zimmerman, MD. Contact Australian Polio Network (Victoria), PR Conference Consultants Pty Ltd., P.O. Box 2954, Fitzroy Delivery Centre, Victoria 3065, Australia (+61 3 9419 6400 fax, prcc@labyrinth.net.au).

Living with PPS - How Can I Help Myself?, MARCH 2-5, Executive Inn Hotel and Suites, Richmond, British Columbia (Vancouver suburb), Canada. Contact the Post Polio Awareness and Support Society of British Columbia (PPASS), 205 - 3994 Shelbourne Street, Victoria, BC V8N 3E2, Canada (250-477-8244, 250-477-8287 fax, ppass@pacificcoast.net).

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Program and registration details
will be published in the Winter
(January, 2000) *Rehabilitation*
Gazette.

"Rendezvous with Destiny" Campaign is a project of the National Organization on Disability to complete the Franklin Delano Roosevelt Memorial by adding a statue of him in his wheelchair.

The legislation, signed by President Clinton in July of 1997 calling for the addition, requires that the funds be raised in the private sector. For more details, contact "Rendezvous with Destiny" Campaign, National Organization on Disability, Department 0571, Washington, DC 20073 (202-293-5960, 202-293-5968 TDD, 202-293-7999 fax, www.nod.org). ■

A Recent Subscriber?

International Polio Network is offering (while the supply lasts) 12 back issues of *Polio Network News* for \$8. The issues are Volume 11 (1995), Nos. 1-4; Volume 12 (1996), Nos. 1-4; and Volume 13 (1997), Nos. 1-4. Articles include *Defining Post-Polio Problems*, *Coordinating Post-Polio Treatment: You, Your Primary Physician, and Your Expectations*, *The Battle with Bracing*, *Post-Polio Corrective Surgery: Then & Now*, *Post-Polio Corrective Spinal Surgery*, *New Breathing Problems in Aging Polio Survivors*, *New Swallowing Problems in Aging Polio Survivors*, *Recognizing the Effects of Non-Polio Health Problems on Post-Polio Symptoms*, *Responding to Loss: A Practical Framework*, *Disability as a Life Cause: Implications of Early Experiences for Later Coping*, *Managing Your Need in Relationships*, *Pain in Post-Polio Syndrome*, *Anesthesia Concerns for the Polio Survivor*, *Lessons Learned - Future Challenges*, *EMG: What, Why, and Why Not*.

Please send your check, made payable to GINI, to International Polio Network, 4207 Lindell Boulevard, #110, Saint Louis, MO 63108-2915. (International readers should add \$4.00 shipping and handling. USD only.) ■

The Revised Edition of the Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors

ISBN 0-931301-04-1 pbk. (1999)

The 120-page book in dictionary format contains 90 entries, a compilation of the research and experience of more than 40 experts.

Edited by Frederick M. Maynard, MD and Joan L. Headley, MS



International Polio Network has just completed the revised edition of its popular *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*, which was first published in 1984.

The revised edition, edited by Frederick M. Maynard, MD, currently in private practice of

physiatry in Marquette, Michigan, and Joan L. Headley, polio survivor and Executive Director of GINI, retains the easy-to-use dictionary format in presenting information appropriate for polio survivors and the health professionals who treat them. The 90 topics, from A to W, are diverse and include: Adaptive Equipment,

Anesthesia, Communication, Coughing, Diagnosis, Epidemiology, Evaluation, Independent Living, Orthotics, Pain, Pulmonary Function Tests, Swallowing, Vaccines, Weakness, and Wellness. The sections are cross referenced to related topics, and the paperback book contains over 200 references.

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