



CONNECTIONS



First Coast Post Polio Support Group

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The Post-Polio Patient: Psychological Issues

by Margaret E. Backman, Ph. D.

Abstract

Of the 200,000 to 300,000 persons who have survived polio, a significant number are now, after many years, beginning to experience a deterioration in strength, sometimes accompanied by pain and respiratory difficulties. The recurrence of symptoms reminiscent of the earlier illness can trigger emotional problems and regressive behaviors that are often misunderstood and interfere with treatment.

Psychological Issues

Most of the available published material has concentrated on the physical and demographic aspects of the post-polio syndrome, but little has been written about the emotional repercussions (Frick & Bruno, 1986). The present article focuses on the psychological concomitants of this syndrome.

Psychological Resistance

Compounding the emerging physical symptoms is that patients are now being told that the very treatment used years ago (i.e., to exercise as much as possible) may have exacerbated the present condition. Today, these same patients are being told to take it easy and to rest, not to exert themselves, to accept their lessening of strength and stamina.

Logically this advice may make sense, but emotionally such changes in life style are difficult to achieve, particularly when former patients have spent a lifetime believing what they were doing was good for them. Resistance to change is a natural reaction but, in this situation, even more resistance occurs since individuals are advised to curtail many pleasures and become more dependent on others. In addition, hope may be shattered and trust in authority shaken.

Patients become aware that recent prescriptions are based on new untested theory, as were many of the prescriptions that were given years ago with such authority, but are now being questioned. Thus, health care providers find patients avoiding treatment, minimizing their conditions, and disregarding advice - in effect, not wanting to become less active and more dependent, particularly when, in their mind, no one is really sure. Just treating the medical symptoms and expecting the patient to accept these new limitations without a struggle only compounds the problem. The effects of the recommendations need to be thoroughly recognized and understood. A reduction of activity can profoundly affect the person's role (cont. p. 6)

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Our next two meetings are celebrations! Get your checks in early to ensure a place for you and your guest (s) See pages 4 & 5. 8

From the President

Just Jim's thoughts.....

Dear Polio Survivors,

This is my report after having an appointment with Dr. Allen Berger, Neurology Department Chair at Shands/UF Hospital in Jacksonville. As expected I found Dr. Berger to be very personable and capable of addressing all of my medical issues, including Post-Polio.

I had seen Dr. Berger in 2001 for an issue that wasn't related to polio or post-polio syndrome. This time I was asking for his medical opinion and any treatment options for my PPS symptoms that have worsened over the years. Dr. Berger did a very thorough manual muscle strength testing of my arms and legs and compiled a very detailed amount of information regarding my symptoms and how they affect my daily life.

My main goal was to seek his input on my disability

application for Social Security and my company disability plan, both of which have denied me benefits as is their common practice.

I just received notice of my appointment with the Social Security Administrative Law Judge and I have also retained an attorney that specializes in suing the insurance companies that offer the workplace disability plan.



Jim Powell

Dr. Berger will write a report using his background of treating PPS patients, both here in Jacksonville and also in his previous practice in New York state, detailing my PPS fatigue, pain and weakness and how it affects my ability to hold down a meaningful occupation.

I would highly recommend Dr. Berger for all of us polio survivors. He is a competent Neurologist who is very knowledgeable in the area of PPS, having been part of a PPS clinic in New York during the 1980's when the diagnosis of PPS first emerged. Dr. Berger takes a wide range of insurance benefits making him an affordable, competent option for all of us PPS'ers. This is a doctor that deserves a place in First Coast Post Polio Support Group's list of local physicians that are knowledgeable sources for healthcare here on the First Coast; physicians that are ready and able to treat us polio survivors.

All the best to you and yours

Jim

Jim Powell, President
P.S. Dr. Berger will be a scheduled speaker for our group next spring.

Minutes for the August 21, 2010 Meeting

(Due to an illness, I was not able to attend this meeting but Janice, our 1st vice president, sent me these notes on the meeting.)

The meeting was held at the Golden Corral on Southside Blvd. We had 10 members present and 5 guests with two of the members being new. Jim Powell our president opened the meeting with greetings and a special welcome to our new members, Gene Lewis and Brenda Bronson and to Andy Sabel, a first time attendee member. He informed the group of a \$200 donation received from the March of Dimes and noted that this would help with the ex-

penses of our website and newsletter. Phyllis Moss was introduced as our new treasurer and she followed up with a treasurer's report. Next the group heard a personal story and encouraging testimony from Rosemary Lane, one of our members now battling cancer. Jim reiterated that this is the 40th anniversary of the Saulk vaccine. Jim mentioned one of the symptoms of PPS that he is now dealing with; heat intolerance, which some of us have not experienced yet. He suggested some of his methods for relief are: a cooling vest and a cooling strip that ties around the

(Cont. next column on p 3)

Helen's Story

By Don Guttinger



Hellen Guttinger had polio in Tallahassee in 1954, when a whole bunch of folks got a bad dose of the new vaccine.

Minutes (cont. from p 2)

neck. The meeting then went to a time of open discussion between the newer members and the older members sharing their knowledge and experiences and answering questions. *The meeting closed. (Janice, thank your for taking these notes in my absence.)*

Respectfully submitted,

Sheila Kilgore, Secretary

Helen Guttinger completed high school in a neck brace, but spent no time in an iron lung. The PPS was diagnosed at Mayo Clinic about 1988.

She had had no disability in the time I've known her, until early day fatigue, leg pain, etc. set in at that time.

Her knee replacement last August has not gone well. She now has had 8 months of round-the-clock bed. She has gained a lot of weight and has many gastric problems in addition to leg and back pain.

She had an active career in education and raising three children. She completed her doctorate in 1974 and taught at every level from second grade through graduate school. She spearheaded the organization of the Florida Writing Project and was a national teacher trainer with IBM's Writing to Read program. She moved from the University of Florida to Gwinnett County, Georgia, where she was county Director

of Computer Education. From there, she went on to Assistant Superintendent but had to ask for a no-nighttime meeting job when our daughter was diagnosed with brain cancer. She stepped down to principalship of an elementary school in Conyers, Georgia but had to take a disability retirement in 1994.



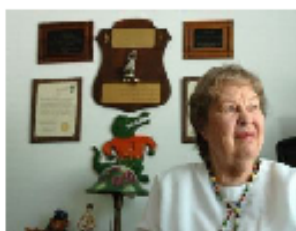
First Coast Post Polio Post Polio Support Group



Our 20th year REUNION PARTY

IT'S A PARTY! BRING A FRIEND

We are celebrating our 20 years together on **Nov. 13, 2010**



FOUNDER OF FCPPSG
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When was the last time you came to one of our parties?

We need your support for our next two parties. They are now charging us for the rooms and the cost of food has gone up. We will still try to help you with the cost of the food but we need you to support these events so the room cost will remain down.

I need you to **R.S.V.P** on this party as soon as possible. Call me at **333-3457** to reserve your seating. We can only get approximately 30 -40 people in the room.

Your Cost for November meal is **\$9.95**

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First Coast Post Polio Support Group
13119 Blackhawk Trail Ct
Jacksonville, FL 32225



Place: **RAMADA INN CONFERENCE CENTER** 3130 Hartley Road
Jacksonville, FL 32257
Phone: 904-268-8080

Games, Door Prizes, Surprises on every table.
Will you be the lucky one?

Time: 11:30 am —2:00 pm



Bring your pictures and stories to share of your time with our group...



MERRY CHRISTMAS TO ALL!!!

Join us at our annual Christmas Party on December 18, 2010

You are invited to HIDDEN HILLS COUNTRY CLUB

3901 Monument Road, Jacksonville, FL 32225

333-3457

Time: 11.30 am—2:00 pm

Price: \$16. 50 per person



Entertainment: Surprise Guests!!



You don't want to miss this one!

Make your reservation today with Janice at

904-333-3457 R.S.V. P. only.

I need 30 to 40 people on this one. Please call a friend or family member to come with you...

If you have family visiting for Christmas bring them along. They will love the show and the food.

Directions: from North or South. Take 9A get off on Monument Road East.

Approximately 3 miles. Club house is on the Right. When you park in the lot a golf cart will be there to bring you to the doors. If you have a scooter or wheelchair please have your family or friend let you off at the door then park in circle drive or parking lot. This is a steep incline. Do not try to walk it. Thank you..

(cont. from p 1)

in the family and society. A patient may have to take early retirement; a mother or housewife may be forced to have others do her work for her; roles may become reversed between husband and wife, parent and child; social involvement with friends and family may have to be curtailed. And with what do they fill the void in their lives? How does the person regain psychological equilibrium?

After years of not thinking of themselves as disabled, the new weakness and pain shakes their sense of self. The unknown course of the disease makes it further difficult to adjust, as these individuals do not know what they will be expected to adjust to.

The Reemergence of the Repressed

Although many of the psychological problems of post-polio patients are similar to those of other physically disabled groups, there is one major difference: the patient now experiences, both physically and emotionally, a recurrence of the disabling disease. The weakness, the pain, and the fear of never being able to walk are reminiscent of the earlier episode, causing the patient to relive much of the overwhelming emotional feelings that had been repressed (Frick & Bruno, 1986).

Weakened defenses

For years, these repressed feelings and associated memories had been kept in check by the psychological defenses of denial, avoidance, and isolation. For many, these defenses worked well, helping the individual cope with his or her disability. Yet many of these repressed memories and fears from childhood remained unexpressed and distorted in the unconscious.

Now, however, under stress, the defenses begin to break down and the repressed feelings rise to the surface, overwhelming the individual. The fact that someone has gone through this before is no reason to assume that it will be easier the second time, or that the person will have a better understanding of the situation.

On the contrary, having to relive the experience - an experience that the individual thought had been put to rest - reawakens anxieties and conflicts that he or she had been able to ignore for many years. As one patient exclaimed, "I thought I had all this behind me; I don't know if I can go through it again."

Understanding regressive behavior

As most post-polio patients were children or adolescents when they struggled with the disease and its aftermath, clinical observation suggests that many of the needs and behaviors that appear under the new

stressful situation are reflective of childhood issues - a reliving of the earlier event. The emerging regressive behavior is often treated as an irritation by the busy physician, yet such behavior is not unexpected, and may be an attempt to regain equilibrium. Not only are the defenses not working, but many of the psychological issues are those that the patient had not been able to work through as a child.

What the family, physicians, and rehabilitation personnel see are behaviors and ideation that, on the surface, appear excessive or unrealistic, but are in effect symptoms of the underlying emotional concerns, which cannot find appropriate release.

Returning to the use of a brace or wheelchair after having struggled to overcome the need for such aids 25 to 30 years before may activate long-standing emotional conflicts. Many of these conflicts center around issues of dependency, sometimes revealing themselves as angry outbursts at those the patient is closest to and whose help is now most needed. Fears of being restricted and trapped, of being abandoned, emanating from the previous experience in hospitals and convalescent homes re-emerge.

Patients' complaints about not being able to swim, bicycle, or walk for any length of time may seem self-

indulgent or unrealistic to others. "After all," some say, "it is little to ask, if such restricted activity will result in a slowing down of the deteriorating process."

But what needs to be understood is that these desires are expressions of fears of what is to come: fears of not being able to walk or breathe. Complaints about not being able to drive, for example, may be expressions of anxiety related to dependency and lack of control in one's life.

Resistance to being put in a brace may on the surface appear unrealistic if such support is needed, but this resistance may be an expression of the person's fear of impending lack of mobility. Cosmetic complaints may be brushed aside by others as pure vanity, but vanity is often an expression of self-esteem - an important element for successful outcomes, both physical and mental.

Distrust of authority

Much of the conflict in dealing with the medical establishment revolves around earlier experiences of hospitalization. Patients were often not dealt with directly, they were allowed to exist with their fantasies of what was happening, or about to happen to them.

A lack of trust developed, for example, when patients were told they would not be

in the hospital for long, and then found themselves "trapped" in the hospital or convalescent home for six months or a year.

Related to this distrust are reemerging feelings of guilt and anger at parents, spouses or other significant people, who were experienced as having abandoned them, as having abnegated control to the medical staff, or having neglected them, possibly exacerbating the disease. The early experiences of others being ineffectual reawakens insecurities in the postpolio patient now trying to gain control in areas where there are many unknowns.

Bereavement Process

Persons with disabilities often go through an adjustment process that has been compared to that of the dying, with the physical deterioration constituting a symbolic or actual death of a part of the body (Dembo, Leviton, & Wright, 1956; Fink, 1967; Kubler-Ross, 1969; Livneh, 1985; Parkes, 1975; Shontz, 1975).

For post-polio patients, the recurrence of symptoms may thrust them into the bereavement process once more, and this time the experience is intensified by the reemergence of memories and feelings long repressed.

Their feelings are not unlike those of stroke patients when dealing with crises in their illness (Bucher, Smith,

& Gillespie, 1984), or cancer patients who are experiencing a recurrence of the disease (Koocher, 1986; Koocher & O'Malley, 1981). Anger and guilt are common emotions that come to the fore during bereavement: now they may be experienced as confusing to patients who feel there should be no reason for them, since such feelings are from the past and should have been dealt with then (Lindemann 1981; Tucker 1984).

Anger may be directed at their own fate, at themselves for not having followed medical advice, at parents for not having helped them enough, at family for not understanding their plight or at friends, for the pressure their very presence imposes; guilt may emerge over the anger felt at loved ones or over feelings that their own children's problems may have resulted from the polio, either directly or indirectly.

Recognition of one's own vulnerability and mortality surfaces again, triggering fear and panic. Psychoanalytic theorists stress the importance of the ego's awareness of the possibility of its own vulnerability and mortality (Livneh, 1985). As part of the bereavement-adjustment process, the defense mechanisms of denial and repression mitigate against this painful awareness.

Social withdrawal

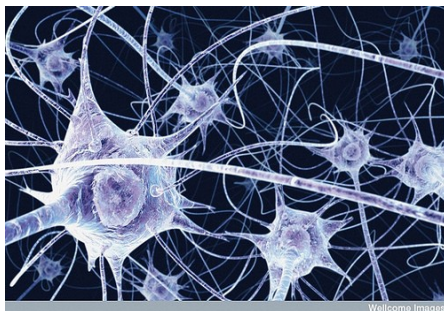
One stage in the bereavement process is social withdrawal, which may take the form of distancing from family and friends. Although going out and being with others may seem like a positive step in overcoming depression, for the post-polio patient, being with others may increase feelings of uncertainty, anxiety and self-consciousness.

Having been the focus of so much scrutiny during the first bout with polio, many of these individuals now feel panic when anticipating social situations. Having been self-sufficient before, help is difficult to accept. The many questions that people ask often do not have ready answers and serve to remind patients that they do not know what is to happen to them.

Thus, social interactions can be supportive, but can also be anxiety producing when the coping mechanisms, such as the defense of denial, are weakened. Friends, in turn, sensing the patient's mood are unsure of what to do or say. And in becoming more aware of the patient's disability they face their own feelings regarding vulnerability and mortality.

These feelings set up what Siller (1969) calls "interaction strain": an uneasiness in the presence of disabled persons and an uncertainty as to how to

deal with the patient's own discomfort and the discomfort of others feed upon each other, making the patient choose social isolation as a way of coping. Yet, in this isolation, the patient is prone to become obsessed with his or her present state, and thus sink further into depression.



Depression

Depression and sadness are normal reactions when a person's level of functioning is decreasing. Poor concentration, sleep disturbance, and decreased interest in activities may be symptomatic of the depressed state.

Suicidal ideation may also be a reflection of the person's despair, growing out of the helplessness over the uncertainty of the future. Psychological treatment of the depression may decrease suffering even if many of the physical symptoms still persist. The patient may have developed coping mechanisms that are no longer suitable; avoidance and denial may now serve to exacerbate problems that need attention.

The patient may be ambivalent about psychological intervention, however, as the

earlier experiences that will need to be discussed in therapy will themselves be experienced as painful.

Combining psychotherapy with physical or occupational therapy is useful for developing better coping mechanisms (Laurie et al., 1984). A therapist or rehabilitation counselor can play an important role, acting as a liaison to the medical personnel: helping them to understand the patient's behavior and helping the patient understand medical explanations, which are often misunderstood initially because of anxiety.

Most patients see this professional interaction as positive, experiencing a certain amount of comfort that they are being taken care of. Protecting confidentiality is still of utmost importance, and patients should be involved in decisions about what may be shared with others.

Family therapy or couples therapy is often indicated. Group therapy with others who have had polio is often recommended as a way for the patient to learn about others' coping strategies and keep aware of new techniques and specialists (Laurie & Raymond, 1985).

For some, being in a group and learning that the same problems are experienced by others can be reassuring.

However, for others a support group or group therapy may actually increase their anxiety. Those who previously had milder cases of polio often avoid the group experience, particularly if those in the group have obviously more severe disabilities.

Many of these persons have difficulty identifying themselves as "handicapped" or "disabled" and, in some cases, seeing persons with more complications makes them anxious about their own eventual prognosis

Summary & Conclusions

As more and more former polio patients enter middle age, what is now a newly recognized problem (i.e., progressive weakness and

pain) is expected to become increasingly common.

The physical and emotional needs of these patients are only beginning to be understood. Memories, conscious and unconscious, from the initial confrontation with the disease influence their current functioning. Having adjusted to whatever limitation that polio may have imposed on them, many of these patients now feel overwhelmed with the prospects of going through the process again.

Compounding this feeling is the unknown course of the disease. Psychotherapists and rehabilitation counselors have a role to play in helping these patients deal with unresolved issues related to

their earlier bout with polio and with their present condition, as well as serving as a liaison to medial personnel and the family.

*The author of this article, **Margaret E. Backman, Ph.D.** is a clinical psychologist working in the area of health psychology. She has a private psychotherapy practice in New York City and holds an adjunct clinical faculty appointment at the New York University Medical School. Dr. Backman specializes in helping individuals and families cope with medical illnesses and physical disabilities. She has been working with people who have had polio for over 15 years and has written articles and given presentations about the psychosocial aspects of the late effects of polio. Reprinted with permission.*



2011 Update of Members and Dues

Name: _____

Address: _____

City _____ State _____ zip code _____

Phone: _____ Email: _____

Name of Emergency Contact* _____ Phone _____

Join our Birthday Club: Month: _____ Day: _____ Year: _____ (optional)

Dues: \$20.00 payable to *First Coast Post Polio*.

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 Jacksonville, FL 32225

Your dues pay for mailing this newsletter as well as to maintain our website. This money also supports our door prize and gifts throughout the year.

* *Name and contact information for your closest relative or a friend who will always know where you are in case of emergency or a change in residence.*

Due by January 1, 2011



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Blind and Handicapped
Postal manual Part 138**

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20th Anniversary**

11:30 am—2:00 pm

RAMADA INN CONFERENCE CENTER
3130 Hartley Road Jacksonville

**SATURDAY Dec 18 is our
HOLIDAY PARTY!**

11.30 am—2:00 pm

HIDDEN HILLS COUNTRY CLUB
3901 Monument Road, Jacksonville

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