



I found this article in the old archives and thought it might be of interest to some of our new people who have joined us this last year. Stay healthy with love in your heart and a smile on your lips. -Janice..

PSYCHOLOGICAL ISSUES AND FAMILY RELATIONS IN POST-POLIO SURVIVORS

How does post polio syndrome affect survivors and their families emotionally and interpersonally? It was our hope that by talking about these things, you will be better able to understand yourself, what you want and need, why you feel what you feel, and how you can better understand your partner's feelings.

Our focus was on communication. How polio survivors can better communicate to their partners and family what the polio experience is like for them, and so partners and family can communicate to the polio survivor what their own experience is like. We all know very well that in human interaction misunderstandings are common. We misread each other, assume things erroneously, fail to listen, and fail to put our thoughts into words.

Many things stand in the way of communication, but when we are successful and do communicate, we naturally feel a great sense of relief at being understood, and this feels good. But more than just making us feel good, we now know, from the results of years of medical research, that expressing feelings and tending to your close personal relationships is good for your health. It helps those with cancer live longer, it diminishes the effects of heart disease, controls hypertension and strengthens the immune system.

The late effects of polio are threatening and upsetting because they change the things people can do and how they do them. Polio survivors who had learned to adjust to the impairments caused by their first illness often quite satisfactorily, are then decades later, unexpectedly faced with new deterioration in functioning. These changes are emotionally upsetting, affect self-image, challenge a person's idea of who he or she is, and push a person into new roles in relation to others, roles not necessarily wanted or sought.

Most importantly, you can't do what you used to do. Or, what used to be easy, you now have to work hard to do. Or, what you used to do independently, you now have to have help to do. Or, what you used to do without an adaptive device, can only be done with one. Or, what used to be comfortable to do, you now do only with significant pain. Or, what you used to accomplish in two hours now takes half a day and then you're too tired to do anything else.

In the initial stage of post-polio syndrome there is commonly a period of confusion; new symptoms may be dismissed, minimized, or attributed to something else. Once the true explanation is found, it is common to have a great deal of fear and anger: fear of possible progression of symptoms, fear of the unpredictable nature of the syndrome, and fear of how helpless you may become.

And there's anger at being forced to drastically and unexpectedly alter one's lifestyle. People ask, "Why me, or why us?" There is a feeling of being cheated, having already faced the effects of polio and have managed to live with it, now the polio tricked you, robbing you again, forcing more changes.

The old coping strategies of minimizing overachieving and over-compensating cannot be used in the same way as in the past. Because the physical condition has changed, denial and minimization can be hurtful because now more than ever you need to pay attention to your fatigue level or pain to avoid exhaustion and worsening the condition. It is a major change to let go of this refusal to give in, of pushing oneself to one's limit.

It is natural to feel a deep sense of loss - of one's identity and of abilities. You are forced to accept a new identity, perhaps one you don't like very much. For example, you may feel like a wet blanket who holds everyone back because you can't keep up on excursions, hiking, golf with your buddies. Perhaps, in the past you had no physical handicaps or disabilities, that was for other people -- but now, to your dismay, you find you've joined the club.

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Yoga Benefits Polio Survivor

Alan Fiala, PhD, Falls Church, Virginia (fialaalan@earthlink.net)

Alan Fiala, PhD, is an astronomer, who retired from the Naval Observatory in June 2000, after 38 years of service, specializing in eclipses and navigational almanacs. Fiala had polio in 1952 and began to experience the late effects of polio in 1984, when he started using the PLV®-100 while sleeping. He is also now using the Pulmonetics LTV800®. Although he has one fused ankle and a partially fused spine, he is ambulatory, but uses a scooter to conserve energy.



Yoga has provided benefits to me in improving breathing, maintaining flexibility, improving balance, and reducing stress. I have post-polio syndrome with loss of muscle strength, and I do not seek to gain strength from yoga. I do have pulmonary problems, and the development of good breathing habits from yoga practice has noticeably improved my performance on pulmonary function tests. A stretching routine works off "morning stiffness" more rapidly and keeps lower back pain and sciatica away. Habits developed from both yoga and Alexander Technique make me much more aware of my body and how it is functioning.

Yoga is very popular these days, and it has developed many forms. The yoga I practice is the so-called gentle version of hatha yoga. I discovered it by accident about six years ago (1996).

To my great good fortune, my first instructor had studied some anatomy and physiology as part of her yoga training, and she had a great interest in helping those with disabilities to find alternate ways to perform poses made difficult by the disability. (Explore her website at www.yoga4u2.com for more on her style of practice.)

As you are taking classes, you should strive to develop your own daily practice at home with advice from the instructor. Some may offer an individual development session for a fee. While the cost of yoga classes (in the Washington, DC, area) typically run \$13-17 per session, an individual session can run \$50 or more. If you have severe disability, a few private sessions to find adaptations for your particular body may be of more benefit than a group session that tries to help all and hurt none.

The typical yoga class lasts 60-90 minutes. Within this time, you may do some warm-ups, some breathing exercises, some meditation, some eye exercises. You mostly do ?poses,? aimed at flexing and stretching all parts of the body. Emphasis is on flexing the spine in all directions – forward, backwards, and sideways. Poses are done lying down, sitting on the floor (or a chair), on hands and knees, and standing.

Balance poses involve standing on one leg at a time. There may also be inverted poses. In a gentle class, inverted poses are limited to lying down and having your legs up on the wall or a chair. The class always ends with 10-15 minutes of complete relaxation.

Is it for you? The first requirement for most yoga classes is the ability to get down onto the floor and get up by yourself. Occasionally a class is offered for people who cannot do this, but can sit in a chair. Such classes are perhaps offered in assisted-living homes, hospitals, etc. Otherwise look in recreational centers, adult education programs, YMCAs, yoga studios, and, maybe, health clubs.

In all instances, if the class is called "gentle yoga," interview the instructor for certification by a yoga organization, and experience in working with individuals with disabilities. Does the instructor know what each pose is meant to do for your body, and know alternative poses that might be easier for you? An unqualified or inexperienced instructor can lead you to hurt yourself.

You might also check with your physician or other health care professional for advice. In my experience, health professionals who do not have firsthand knowledge of yoga may tend to be negative. If so, ask for specifics, as it applies to you, and take that advice with you to class.

There are also books and videos on yoga, and even a few aimed at rehabilitation. There may be some on "gentle" yoga, but I have not seen them. I personally doubt that you could develop a practice for yourself this way, without personal instruction, and suspect that you might hurt yourself, if not be outright discouraged.

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PSYCHOLOGICAL ISSUES AND FAMILY RELATIONS IN POST-POLIO SURVIVORS (CONTINUED)

A common aspect of post-polio is chronic pain which affect us in many ways. It affects our thoughts, our mood and our relationships. People become more internally focused. Often people feel bad about themselves, inadequate in their usual roles. For example, one may wish to make a dress for a granddaughter, or a gourmet dinner for friends but be hurting too much to do it. This can lead to feelings of guilt and of self-punishment.

Some may feel depressed and discouraged because they can't do the things they used to do. Pain creates internal stress. Stress in turn affects our perception of pain. When you are feeling down or unhappy, your ability to distract yourself from your pain is decreased. Since the mind and body interact, these emotional reactions lead to increased muscle tension and anxiety, causing physiological changes within the body incompatible with relaxation. You need to learn ways to relax, to regenerate emotionally and physically. Family members may have several styles of coping when dealing with someone with chronic pain. Denial and avoidance is common. You may avoid talking with your partner, pretending not to notice the distress. Others may avoid by taking over their partner's responsibilities. These coping strategies are not necessarily bad unless you are unaware of your own feelings regarding the change in your partner's status.

Why do people hold back from expressing their feelings? Sometimes they are afraid to talk about the current changes as they don't want to draw attention to the fact that the partner is changing.

Many also feel protective of their partner, believing that talking about their own feelings and worries will make their partner feel worse since the partner may already be afraid and demoralized.

Some don't feel they have the right to complain, or resent having to make sacrifices, work harder, do more than the spouse, and give up activities, but they may feel too guilty to express any of these feelings.

Many partners feel frustration at not being able to do more to help, or are frustrated at seeing the polio survivor make mistakes in pushing too hard and not pacing themselves and being unable to stop them.

Loss of control is at the heart of all disabling conditions, and often this loss of control is felt almost as strongly, although differently by the families and friends of the disabled.

At the Workshop: What polio survivors had to say, what families had to say.

The group was divided into polio survivors and family members. Each group was asked one question, with discussion lasting 45 minutes. They then reconvened to summarize and discuss what the two groups said. The question posed to each group was:

"What part of the experience of the post-polio syndrome is most difficult to communicate to your spouse/family?"

The Polio Survivors: by all accounts this turned out to be an intense discussion. Strong feelings were stirred up. Many were moved, some cried. It was clear that the process of confronting the emotions surrounding the experience of post-polio is difficult and painful. Similarly communicating about these feelings to family and even to other polio survivors can sometimes feel overwhelming.

Paraphrased, here are some of the areas of concern:

- We are afraid of what the future holds. In fact, sometimes the future seems so scary we can't allow ourselves to even think about it, let alone talk about it.
- We are afraid that our physical needs will place such demands on our families that they will grow weary and resentful and withdraw support. We wish we had reassurance that we will not become so burdensome that others will leave us.
- We want family and friends to not judge us by our appearance. Appearances can be deceiving. More often than not, we look much better than we are. Weakness, fatigue and pain are less visible than braces and wheelchairs, but no less real.
- When we are tired, we mean it. In fact, it usually means we're exhausted, and it may not be remedied by a short rest. Don't over estimate how much we can do. We struggle enough as it is, to figure out our own limitations.

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PSYCHOLOGICAL ISSUES AND FAMILY RELATIONS IN POST-POLIO SURVIVORS
(CONTINUED)

- Sometimes we need to put ourselves first, which is difficult for most of us to do, as this is a major shift for us. We would like you to help us do this by cooperating when we say there is something we need. We know the difference between a need and a whim. It is hard for us to ask for help, it doesn't come easily.

Conflict within the group emerged when some participants expressed fear and frustration and others reacted with anger. It seemed that both fear and anger were central and universal experiences, but that people cope differently. The anger expressed seemed to grow out of a need to fight feelings of vulnerability and helplessness and instead maintain a sense of control and a positive attitude. Worried that their fears and sorrow will pull them down, and unwilling to let themselves stay down, some people use anger to protect against feeling fear. Other people are afraid of how intense their anger can become and so they inhibit and suppress it.

Partners and families: All expressed a deep commitment to their partner and a readiness to be a part of their lives, regardless of changes in physical status. This commitment was not naive or superficial, but seemed founded on genuine love and respect for the challenges their partner have faced and will continue to face. They acknowledged that coping with post-polio syndrome involves a series of compromises, but they adapt by remaining flexible and tolerant. Within this group there was much commonality, but when differences of experience emerged that group was quite respectful and compassionate.

Partner and family expressed the following concerns:

- It is difficult to see our partners in pain. We feel helpless to ease physical suffering. Therefore, we'd like our partners to listen to their bodies, slow down and not be so perfectionistic.
- It is hard to see our partners reject changes that would help them cope better (e.g. using a wheelchair or a scooter). We do not view use of an adaptive device as failure, but as an increase in functionality and freedom to enjoy life together.
- Sometimes our partner's anger is hard to deal with. When they are feeling tired and frustrated they get irritable. If we say the wrong thing, they get upset. We sometimes have to ignore what they're saying so that we don't take it too personally.
- The lack of predictability of the illness is frustrating and frightening. We don't know what our partners will be able to do in the future. Therefore, we feel an imperative to live for today and not postpone doing things that give us pleasure.
- Over time, our role in household responsibilities is getting larger. We accept this. Still, your comments of appreciation are very welcome.
- Some of us feel concern about our own physical ability to provide care for our partners as we, ourselves, age and contend with our own aches and pains. We worry about the possibility of not being able to give necessary help.
- It is difficult to know when to be the cheerleader, when to be comforting and soothing, and when to confront anger or passivity. We'd like to feel we have permission from our partners to express our feeling about this.

In conclusion, there was broad agreement that life is all about challenge and response, that amidst all the hardship, post-polio presents an opportunity for personal growth for both survivors and family if the challenge can be faced with flexibility, acceptance and openness.

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The following article has been submitted by Drs. Susan and David O'Grady, Ph.D. as a summary of their talk and the discussion that ensued.

Dear Friends,

I was talking with a friend about not being able to do the exercises she did and the next thing I knew she had me in her car and took me to the WMCY on Merrill Road. This facility used to be Gold's Gym and is now the WMCY.

She took me to a yoga class. Boy was I surprised to find I could actually do these mild therapy exercise. I started to relax and enjoy the freedom of movement in my joints. It made a big difference for me. There was some positions I could not do so I spoke with the instructor after our session and she was kind enough to give me a few websites which has helped me a lot.

I now have found I can do my yoga at home on my bed which is much easier for me.

Every night I do my yoga exercises before going to sleep from the privacy of my own home. I put on my headphones and listen to the soothing music as my mind and body begin a journey of healing. It has helped me by making it easier to get up in the mornings without stiffness in my joints.

Give it a try. It's mild stretching. However ask your doctor first if this is right for you. I have found after 54 years of dealing with polio I know my bodies limitation better than most. Therapy is good for us so treat yourself to an hour of getting in touch with your body and mind.

Check it out:

http://www.yogajournal.com/health/844_1.cfm

<http://www.themessenger.info/archive/April2002/Ratziel.html>

Your President, Janice Askwith



LAUGHTER FREES THE HEART!

An 82-year-old man went to the doctor to get a physical. The doctor cautioned him about his age and sent him home with a lecture on the proper lifestyle. A few days later, the doctor saw the man walking down the street with a gorgeous young lady on his arm.

At his follow up visit, the doctor said to the man, "You must really be doing great!"

The man replied, "Just doing what you said Doctor: 'Get a hot mamma and be cheerful.'"

The Doctor said, "I didn't say that. I said you've got a heart murmur. Be careful!"

WHATS NEW IN THE BOOK WORLD?

Margaret Backman, Ph.D., a Clinical Psychologist who has written numerous articles and given presentations on the psychological aspects of post-polio, has just published:

The Post-Polio Experience:

Psychological Insights and Coping Strategies for Polio Survivors and Their Families.

The book is based on her more than 25 years of experience working with those who have had polio.

Today many polio survivors find themselves with new symptoms reminiscent of the earlier days when they first had polio- these new symptoms trigger frightening memories that had long been repressed, along with anxieties about what the future holds.

In ***The Post-Polio Experience*** Dr. Backman, examines polio survivors' psychological reactions to their earlier experiences and to their current struggles with the late effects of polio.

The book also includes practical guidelines for polio survivors on:

- o Coping with the emotional and interpersonal aspects of Post-Polio Syndrome
- o Managing stress and depression
- o Negotiating relationships with family and friends
- o Developing a positive self-concept
- o Improving doctor-patient communication

Family and friends will also find the **The Post-Polio Experience** of interest, as they learn to deal with the changing roles that they and the survivor now face and gain insight into their own needs, which interact and sometimes conflict with the polio survivor's needs.

Mental health providers and physicians will find insights that help them gain a better understanding of their patients' psychological reactions to Post-Polio Syndrome-paving the way for more effective treatment.

The Post-Polio Experience can be purchased online through the publisher: www.iuniverse.com, or it can be ordered at Barnes & Noble bookstores. You can also place your order by telephone through the publisher at: 1-800-288-4677, Ext. 501. The cost is \$18.95, plus shipping and sales tax, where applicable.

Dr. Backman, who specializes in Health Psychology, is also the author of *The Psychology of the Physically Ill Patient: A Clinician's Guide* (Plenum Press/Kluwer) and is in private practice in New York City.



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thank the "March of Dimes" for providing the mailing of this news letter for First Coast Post Polio.

"Saving Babies, together!"

We would like to



Our Goal is to Serve and Support You!

We need your help!

Please take a moment to share your story with us. It may seem small to you but to someone else you could be touching a need in them. We all have Post Polio Syndrome and if your wondering what you could add to the information that is already out there? Then just let me inform you that not everyone's story is the same and we would love to have the opportunity to hear yours as it could improve the quality of others.

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Our Meeting Place!!!!
 Courtyard Marriott by
 Mayo Clinic
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 12:00 pm
 San Pablo Road

Welcome to our new
 members!
 Pamela Pattee
 Virginia McClain
 Anne McClellan

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