

PART II:

A Case for Re-evaluating Physical Therapy as a Viable Extended Treatment for Polio Individuals in the 1990's

Sandra Hughes Grinnell, Independent Medical Researcher

Continuing my research, I realized that I still needed to find a current article by a polio specialist actually advising the use of physical therapy specifically designed for tightness of muscles, so I could establish a pattern of advice going from the 1930's to the 1990's linking everything I had read together. That link appeared in the Fall (1990) issue of *Polio Network News*, in an article by **Dr. Thomas P. Anderson**, Spaulding Rehabilitation Hospital, Boston, entitled "Prescription For Pain" which states in part: "There are many people who feel that tightness plays a greater role in producing deformities after polio than weakness... Many people, including a lot of physicians, tend to overlook this. There is something that can be done about tightness and it is important not to forget that." He goes on to express disappointment that so few authors mentioned the recurrence of tightness. I share his disappointment especially because he goes on to say that many of us were told to do exercises in the early stages "not to get stronger, but to prevent the recurrence of tightness and that many of us were told to do these every day for the rest of our lives." Dr. Anderson, if you are reading this article, I think I can speak for many survivors when I say, "I wish you had been involved in my acute follow-up care, because I nor my parents were even given that advice, but thank you for restating it now."

I strongly suggest that you study his article along with the other materials I have suggested, and then, perhaps, you can begin to isolate your areas of tightness. After establishing your problem areas, you will be in a well-informed position to present a convincing case to your specialist for working with you to design a physical therapy program specifically for you with the goal being to achieve as much improvement as possible, and, then depending on your progress, have therapy treatments authorized to keep in reserve for "as needed maintenance." Ask your doctor to write to your insurance company citing recent articles like Dr. Thomas Anderson's.

In my case, even though I had my doctor's full support along with exceptional medical benefits, it still took additional effort on my part to convince them to cover my expenses which came to approximately \$5,000 for 80 treatments from April 1989 to May 1991. I kept forwarding copies to my insurance company of my physical therapist's notes documenting my steady

progress, along with names of medications I no longer needed and other related orthopaedic complications that I was actually reversing. I have been able to establish, so far, that my physical therapy has actually been a preventative form of medicine. To date, my insurance has paid 90% of my expenses for those treatments.

Barring unforeseen problems, I do not anticipate needing much help in the future. I feel so much more in control of my physical health again — needing less than an hour of exercise a day to maintain what initially took three to four hours a day, for months, to achieve. However, my doctor and I believe that my insurance carrier should continue to cover any treatments I may need now and in the future. If the insurance company is willing to certify future treatments on an "as needed" basis as a form of "extended maintenance care," thereby acknowledging that physical therapy has indeed been well-documented, in my case, to be the most useful and cost effective form of ongoing treatment for the late effects of acute polio; it may increase the chances that additional insurance companies will do the same for others. I will keep you posted through IPN of my status on this important issue.

4. COMBINING ADVICE AND CREATING A NEW STRATEGY — In the Winter (1991) edition of *Polio Network News*, **Dr. Jacquelin Perry** writes in an article entitled "Prescription For Weakness"; "An important point about muscle action is the fact that speed reduces muscle strength. ...so we recommend that polio survivors slow down... Give muscles time for repair and refueling in order to create force again... Polio individuals need to know their muscle strengths so they can plan safe levels of activity." Reading those words made me think back to 1984 when Dr. Perry examined me at the Polio Clinic in Downey, CA. It was shortly after that visit to the clinic that I came up with what I called my "swiss cheese" analogy with reference to finding the "invisible holes in our muscle strength" (see *Polio Network News*, Vol. 4, No. 4). I have expanded that analogy to include the importance of locating "invisible areas of muscle tightness." My doctor has documentation going back several years, in which he suggested a variety of traditional exercise programs, which consistently resulted in increased muscle tightness and painful spasms. In short, an

overall regression of stamina instead of progression. It was only in retrospect, after being diagnosed with post-polio syndrome, that those poor results year after year made any sense to him. In contrast, after two years of extended physical therapy, my doctor views the current improvement in my muscle strength, tone and alignment, as quite dramatic. We both agree that my overall physical fitness and flexibility is better than it was when I became his patient in 1975. We are therefore convinced that stretching of tight muscles, if done slowly, consistently and frequently — initially with the supervision and assistance of a well-trained physical therapist — is, in fact, in and of itself an incredibly productive form of exercise. For this reasons, I felt it was appropriate to expand my "swiss cheese" analogy for the benefit of other survivors and their doctors to include in their evaluation procedures. *(Remember — usually wherever you locate weak, stretched, lengthened muscle groups, there will be an opposing group of tight, strong, shortened muscles).*

I believe that if polio specialists were to combine Dr. Jacquelin Perry's advice on conserving muscle strength with Dr. Thomas Anderson's on stretching tight muscles, hopefully drawing on Florence Kendall's physical therapy work that I have cited in this article, they could together formulate a very balanced and conservative approach to physical therapy that is highly adaptable to individual needs and abilities of post-polio individuals. One possible strategy may be to have new post-polio physical therapy guidelines not unlike acute care guidelines with well-outlined charts and illustrations on muscle stretching protocol — preferably presented on video tape by polio specialists and therapists. These formal physical therapy guidelines would be an overview which any reputable family physician could prescribe and any well-trained physical therapist could implement right in the communities where the patients live. I, myself, did not have to go to a polio clinic for my treatments. Many, if not most, post-polio survivors do not live near polio specialists and/or clinics, so to be cost-effective to insurance companies, the more that can be implemented close to home, the better.

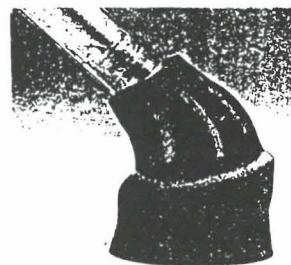
In cases where physical therapy is not available and/or affordable, much progress could be made right at home by beginning to initiate simple but effective physical and mental behavioral changes. In my case, for example, correcting my 1/4" leg length discrepancy was of equal importance to stretching tight muscles. These discrepancies have often been overlooked and/or minimized by the medical profession. After being evaluated by a physician, any reputable orthopaedic shoe store can make a quality shoe lift insert and/or alter the heels on existing shoes. In addition, they can custom fit you with shock absorbing heel pads to

cushion your spine when you walk. The deep breathing techniques referred to later in this article, for example, require no outside assistance and will improve your stamina. Perhaps, a video strictly for at home use which would make it possible for family members or friends to learn to safely assist a survivor with selected stretches. For example, stretching the pectoral minor muscles, per Florence Kendall's work, to improve breathing.

In retrospect, in my own case, after establishing my areas of tightness and corresponding weakness and

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A Case for Re-evaluating Physical Therapy *(continued from page 7)*

implementing a physical therapy plan of action, which included the use of a 1/4" heel lift, the next step, and the most important one, was to develop a long-term plan for conditioning my muscles to prevent further recurrence of tight muscles, thereby making changes permanent. The most efficient way for others to do this, if you have a professional therapist, is to take a very active role, on a mental level, in the physical therapy sessions that your doctor authorizes.

Often, your therapy is a "passive" experience for you physically, but think of each session as a class or seminar where you are going to *learn as much as you can about your body and how and why things work or do not work*. On your own, develop a heightened mental awareness of physical behaviors you do or not do throughout the day, which either increase or decrease your levels of pain. Then ask your therapist for suggestions to help you correct these behaviors. Finally, ask questions of your therapist as to what you need to do at home on an ongoing basis to make newly developed physical behavior patterns permanent. In my experience, highly skilled therapists spend more time and energy on a well-motivated patient, because it is more challenging to them and you reap the benefits. (Note: It is critical to a successful outcome, in the first two months at least, to relax and get plenty of rest in the 24 hours after treatments — making time to repeat your stretches. Trying to schedule a quick treatment on your lunch hour the way you perhaps used to schedule a tennis game, would be a waste of time and would probably do more harm than good. If you work full time, some kind of flexibility in your schedule will be needed. If necessary, use some vacation time to devote to your initial therapy treatments. If you are in a position to negotiate for a short medical leave of absence, do it!)

5. RE-MASTERING THE ART OF DEEP BREATHING — WE ALL CAN IMPROVE.

Since breathing capacity seems to be a great concern for many, there is a detailed outline including illustrations on page 30 of ***Muscles: Testing and Function***, 1983, emphasizing the stretching of the pectoral muscles. It helps if you visualize these muscles as a thin membrane or sheath deep down in your chest cavity. They play an important role in breathing efficiency and more often than not, they are tightened by polio. With my physical therapist's assistance, I followed Florence Kendall's outlines on page 301 to the letter. Over time, emphasizing slowness and repetition, I experienced elimination of cramping in my chest, greatly increased breathing capacity, and an expanded level of physical endurance.

After you have increased your breathing capacity, you need to be further motivated to maintain it. The book, ***Unlimited Power*** has a terrific chapter which makes breathing correctly an art form you will want to master. If you do it correctly and routinely, it will change the biochemistry of your body as well as your mind. Finally, an excellent deep breathing, muscle stretching and conditioning video tape, entitled ***Say Goodbye To Back Pain***, may help you. It was recommended to me in 1988 by a urologist and medical author by the name of Dr. Larrian Gillespie in Beverly Hills, CA. Normally one would expect to get a video like this from an orthopaedic specialist, but *Dr. Gillespie believes in the important inter-relationship of medical specialties*. She fervently believes that if a patient is motivated enough to use the video every day, as the exercises begin to improve abdominal muscle tone and stimulates increased blood circulation into the abdominal area, bladder function (as well as intestinal) will improve. (Many people with a history of polio have bladder and intestinal muscle tone problems in addition to orthopaedic problems all of their lives.) The video format is designed to help you to slow down when you stretch your muscles. By doing that, your mind will be able to focus on helping you to better isolate your areas of muscle tightness and opposing areas of weakness. Do not make the mistake of trying to do the routines from memory. I can tell you from experience you will tend to do each repetition much too fast, undermining the whole purpose. While it is true that some of you may not be able to do much more than the breathing exercises (which can be done sitting or lying on a bed), doing something is better than nothing. The video comes with a money back guarantee and is also available on audio tape. For more details you can call 800/826-8864 or write: Westwood Productions, 12121 Wilshire Blvd., Los Angeles, CA 90025. I am hopeful that perhaps one of you is in the video business and might consider using the ***Say Goodbye To Back Pain*** video format to create a tape exclusively made for post-polio individuals.

6. THE EMPOWERING STRENGTH IN BELIEVING THAT EVERYTHING HAPPENS FOR A REASON —

If you think everything has a reason, it will keep your mind open to ask "why?" and motivated to find the right answer. Always ask "why?" not so much as a patient with a limitation, but as a medical investigator with a challenge. A great illustration is a book by Meir Schneider, PhD, LMT, called ***Self Healing, My Life and Vision***, Penguin Books, 1987. Born in Russia and raised in Israel, his book is available in four languages worldwide and has inspired countless numbers of people, including me, to realize that much of our healing ability has to come

within ourselves first. He is well known in holistic medical circles and has a Center for Self Healing, 1718 Taraval Rd., San Francisco, CA 94114 (415/665-9574). You can order the book directly from The Center, if you wish. Self healing for him appears to be a total commitment to highly personalized physical therapy programs based on the disability and/or illness. He was born blind in both eyes but by going through years of "physical therapy" for his eyes, he now has perfect vision. His book documents the details of his own case as well as patients with residuals of neuromuscular diseases, including polio. It is inspirational reading and made me realize that most of us could make significant progress which could indeed be maintained for the rest of our lives if we were totally committed! His book will help you set realistic and achievable goals. (I spoke with Dr. Schneider this summer. He told me he has a great interest in post-polio patients and has devoted a whole section of his soon to be released new book to the subject of treating post-polio syndrome.) Dr. Schneider recently forwarded copies of articles about himself, including interviews, which thoroughly document his accomplishments. Upon reading the articles, I realized that his total philosophy is a wonderful "mirrored" combination of all of the people I have cited in this article whose personal advice, articles, and books have shaped my remarkable progress to date. Video and audio tapes illustrating his therapy techniques for various illnesses are available at the address listed above. I hope that polio specialists worldwide will take a hard look at his impressive results and dedication to his work.

To get yourself in the right frame of mind, think back to how challenged and determined you felt during your acute care physical therapy program. Mentally put yourself there again and with the same spirit and enthusiasm you had then, *re-learn to pace yourself and re-educate yourself with new goals*. Carver Mead, a scientist at the California Institute of Technology in Pasadena, CA, was recently quoted to say, "The human brain is vastly more efficient than the best digital computer we have today." **Unlimited Power** will teach you how to access and use the full potential of your internal computer. You really can program yourself to make significant progress. Remember, also, that just as in weight reduction, you will reach plateaus and even though you are working very hard, nothing will happen. Then you will experience a seemingly sudden breakthrough which will be the encouragement you need. With enough breakthroughs you will never go back to your old behaviors, because you will know for a fact that your "sudden improvements" are no more "sudden" than your 30 year loss of strength was. You are simply now gradually replac-

ing old habits and behaviors that were dragging you down with ones that are quite literally lifting you up!

Maybe one of the reasons for post-polio syndrome in the grand scheme of things is, simply, that we still have an important contribution to make. After all, there are still children in other parts of the world facing life as a post-polio survivor someday. If we can convince the medical professionals and insurance companies that individualized physical therapy can be a preventative form of extended care, as well as being cost effective, think of all the individuals who will be able to conserve their energy much more efficiently than we have been able to do because of an expanded version of the acute care polio guidelines. (In order to be workable, these new guidelines would have to be flexible enough to allow for the medical variables which have accumulated over the past 30 years unique to each post-polio patient. I believe the results would be well worth the effort.)

In conclusion, whenever you start to procrastinate, think of the following — Life is not a dress rehearsal. Some of you may say, "Oh well, some people are just lucky." My answer to that is another quote from Anthony Robbins, "The meeting of preparation with opportunity generates the offspring we call luck." Based on that definition, I admit to being very lucky. So, why share my good luck with you now as I did in my first article in 1989, giving credit to all those who helped me along the way? Maybe another quote from Ben Johnson sums it up best when he says, "Everything that enlarges the sphere of human powers, that shows man he can do what he thought he could not do, is valuable."

NOTE: On July 12, 1991, my doctor made a formal, written request to my medical insurance company for "ongoing physical therapy on a maintenance basis." Even though I have not needed any treatments for several months, on July 31, 1991, my insurance carrier certified an additional six treatments "to be used on an 'as needed' basis for the next year subject to continued review" for certifying additional treatments in the future. The diagnosis reads *Late Effects Acute Polio*. Although it is a very limited number of treatments, it is certainly a breakthrough decision for an insurance company to make. Prior to this extension, they have approved and paid for approximately 80 treatments since April of 1989, so I am not complaining! I hope it gives others reading this article additional encouragement to try to get the help you need.

Sandra Hughes Grinnell, B.A., graduated from the University of California, Santa Barbara, with a major in sociology and a minor in psychology with emphasis on behavior modification. She and her husband, William, a senior environmental specialist for the Southern California Edison Co., have resided in Southern California for over 20 years. Medical professionals and survivors may write to Sandra with questions or comments c/o International Polio Network, 5100 Oakland Ave., #206, St. Louis, MO 63110.