



1450 Scalp Avenue, Suite 120
Johnstown, PA 15904

Post-Polio Clinics Directors Network
November 16, 2004

Disclaimer: The following are unofficial notes which have not been read by or approved by the speaker.

Points of discussion:

- Post-Polio Syndrome is most commonly a life course event.
- If you look at the common reasons for people with polio having secondary conditions producing pain and fatigue, you don't have to look for every zebra under the sun. If you keep emphasizing with patients it encourages a lot of fear or some answer if they are expecting a cure.
- If you encourage polio survivors to view their typical symptoms of pain and fatigue as a life course, it helps them to get interested in secondary condition education.
- Post-Polio Syndrome is a diagnosis of exclusion. It is difficult to come up with a uniform set of criteria. Diagnosis depends on how wide and long and how far the physician looks and how smart he or she is at looking at the symptoms.
- Aging - as part of the Post-Polio clinic comprehensive evaluation - how do we set the stage for evaluations and how do we encourage them into health promotion and secondary education activities. People approach health promotion as how to accept it as they are getting weaker.
- Three major pillars of health promotion are: Nutrition, Exercise and Stress Management. The latter emphasizes holistic health on an individual, personal level.
- Nutrition emphasizes calories and weight control. There is a high percentage of overweight individuals and obesity in the Post-Polio population.
- Exercise - it is more accurate to describe it as physical activity - and it is very important. Physicians must always talk about exercise very carefully. Exercise including both stretching as well as strengthening and aerobic exercise. It can include skill activity including walking. All four exercises are extremely important in the Post-Polio population.
- The value of exercise and the potential damages of exercise, related to the intensity and strength of exercise, should be discussed. If a person is not physically active, they will be less healthy.

- There is a website out of the University of Illinois called the National Center for Physical Activity and Disability (www.ncpad.org) which will be streamlined and coordinated with the Center for Disease Control.
- Stress Management is psychosocial, emotional health. This is the one that drives the change in other areas such as exercise.
- Pilot project done by a nutritionist and a community-based therapist in Mount Pleasant involved eight women and one man and two women as "control". They had 16 weeks of group session that lasted two hours - one hour of warm water exercise with permission from their PCPs. Following the exercise session, they rested, had snacks, and had one hour of nutrition educational instruction.

Clinical measurements were taken before and after. They had an eight pound weight loss among the women. The three in the control over the 16 weeks gained 2-1/2 pounds. Participants lost inches in their waist and decreased their body fat. Eighty-one percent of them continued to lose weight in the following year. Cholesterol decreased, dietary intake improved. The project showed that it's possible to get some measurement changes in a 16-week period.

- "Wellness for Women With Polio: A Holistic Program Model" was done at the University of Michigan. There were 189 subjects selected. They participated in four, three-hour sessions held every other week for 12 months and a fifth session - an individual feedback session.
- Results of this study were disappointing. The nutrition changes were relatively modest. Those who participated in activities to decrease stress went up. Physical activity did increase. Weight, blood pressure and cholesterol did change significantly.
- It was a nice feasibility study and they are trying to get some longer-term measurements.
- Dr. Eulberg's article talks about wellness and the role of the PCP. It is an important article to remind us that polio survivors and health care will be enhanced if we help control secondary health problems such as hypertension, heart disease, osteoporosis, sleep apnea, anemia, etc.
- Most clinic directors have experience with polio survivors who had have a variety of symptoms and are willing and able to make changes in their nutrition, exercise and emotional health and did not see improvement in their overall well-being.
- There is a lot we can do for patients if we take it on as our Post-Polio Clinics assessment and management program.
- Dr. DeMayo encouraged everyone as they come across articles and endorse them to send them to Joan to post on the website for everyone to view.
- Spiritual health can be a subject that most physicians find difficult to bring up to their patients. However, some patients welcome the opportunity to talk about that part of their lives.
- Physicians need to be reminded there is help available. It might help people initiate the change that they need to make. It is part of the whole topic of promoting emotional health.
- Dr. DeMayo recently did a presentation at a Post-Polio Conference on exercise. He chose to try and share the insight or importance of focused exercise for focused problems. In the

hectic pace of a practice, physicians might refer a patient to therapy without specific guidance or recommendations.

- For people who have specific pain, a focused exercise program can be helpful. It is possible to overwhelm patients if you give them too much at once.
- Dr. DeMayo has his patients use a log book to help both the patient and physician keep track of the exercise program.
- Dr. DeMayo: When we did our formal pilot study on yoga and stress management using the Stanford self-management course, was surprised about the people who stayed on the program. Education is an important part of this and I found the Stanford program to be very helpful as far as people taking ownership and responsibility to set goals and some people did not have the skills for this.
- Jan Goodard: It is not just one thing but a group of things that lead to compliance and once they take ownership and set goals for themselves doing yoga, etc., was surprised at the number of people who kept setting goals and following criteria in the Stanford program from the retreat from over a year ago.
- Tai Chi is very modifiable for a person with a disability.
- Physicians need to increase their knowledge and ability to promote health and wellness.
- Detection and treatment of osteoporosis is more important for polio survivors than other patients.