

polio network news

Wellness: The Role of the Primary Care Physician

Marny Eulberg, MD, Saint Anthony's Hospital, Denver, Colorado

Wellness is being the best that you can be — physically, mentally, emotionally, and spiritually. The steps to attaining wellness may sometimes seem overwhelming and almost impossible to achieve. We may be hesitant to begin, but we must remember that we do not have to achieve perfection. This does not have to be an all or nothing situation. It is worthwhile and useful to work towards wellness, just as we may try to work towards perfection.

Most of the concepts of wellness are the same for all people whether they have a disability or are non-disabled. We are all ordinary, everyday people, and I would like to think that we are ordinary, everyday people first, and polio survivors second. That certainly does not negate the impact polio has had on your lives.

When you consult with a primary care physician about a personal wellness program, it is important that you both have the same goals. You need to clearly define your values and your definition of wellness. If your physician regularly runs in marathons, his or her ideas about wellness may be different than your definition and may not fit with your goals. A wellness program should be customized; one size does not fit all.

Look at what are you willing and ready to change, and equally important, what you are not willing to change. Remember that any and every step towards a

healthier life is progress. Do not forget to congratulate yourself for those areas in which you have already made changes.

Your primary care physician can give you advice about several aspects of wellness. Look at the items in the sidebar on page 2. Place a star beside items which you don't feel apply to you or you are already doing. Check the boxes next to items about which you would like more information and discuss them with your primary care physician.

Exercise is important for maintaining strength, to prevent osteoporosis, to burn calories, and to decrease insulin resistance. Decreasing insulin resistance is particularly important if you have a family history of diabetes, are overweight, or have other risk factors for adult onset diabetes. Exercising and maintaining ideal body weight can prevent or delay the onset of Type 2 diabetes.

Exercise is definitely an area that should require input from a polio specialist, so you do not overuse or overstress extremities that have already been weakened by polio. However, you may have unaffected or stronger muscles that can be safely used for exercise. (See *Non-Fatiguing General Conditioning Exercise Program: The 20% Rule*, on page 7.)

Not paying attention to safety issues can cause more suffering than many diseases. Issues to consider are: Do you always use a

seat belt? Do you have working smoke detectors in your home? If there is a gun in the home, is it stored safely? Are there bars and other safety devices in your bathroom? (Or, are you using a towel bar that is just attached to the wallboard?) Are there handrails on all the stairs in your home?

Preventive care includes age and sex specific considerations, such as testing for colorectal cancer if you are age 50 or older. For men, it is advisable to have prostate tests and possibly the blood test PSA (prostate specific antigen) done. Women are advised to have breast exams, mammograms, pelvic exams, Pap smears, and discussion of the pros and cons of hormone replacement therapy. Also, there are a number of new vaccines – chicken pox, Hepatitis B, and Hepatitis A. If you never had chicken pox (varicella), and you are going to be around children who might be exposed, you might consider getting the chicken pox vaccine. Chicken pox in adults can be a serious, even fatal, illness. If you are traveling outside the United States, there may be certain vaccines that are recommended to decrease the likelihood that you will get sick.

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Staying Well: What I Can Do

- Do not use any form of tobacco.
- Eat a healthy diet.
- Exercise regularly – must be individualized and may need consultation with a post-polio knowledgeable health professional.
- Drink alcohol in moderation, if at all.
- Do not use illegal drugs.
- Practice safe sex.
- Use seat belts (and car seats for children) when riding in a car or truck.
- See your doctor regularly for preventive care:
 - measurement of height, weight, cholesterol, blood pressure
 - other tests based on family history and certain risk factors such as screening for colorectal cancer, prostate cancer, breast cancer, etc.
 - immunizations for adults – diphtheria/tetanus once every 10 years
 - evaluation of need for vaccines for special circumstances, such as travel, and for persons with respiratory conditions, and/or age 65 or over
 - pneumonia vaccine – one shot good for at least 6 to 10 years
 - yearly flu vaccine

Osteoporosis is a common problem that may affect all people age 50 and older.

Many Americans will experience osteoporosis fracture – usually of the wrist, spine (vertebrae), or hip. A way to understand the magnitude of the problem is this: An average Caucasian 50-year-old woman has an estimated 16% to 54% risk of suffering a broken bone during her remaining lifetime. The estimated risk for a Caucasian 50-year-old male is 6%. At age 65, one fourth of the Caucasian females in the United States will have had one or more vertebral fractures. Many of these will go undetected unless an x-ray is taken.

Up to 20% of those who suffer a hip fracture will die within one year. Of equal concern is that many persons with a fractured hip never regain their pre-fracture level of activity and independence. Almost 20% of the general population with a hip fracture will require nursing home care and will not be able to return to living independently.

Osteoporosis is an important issue for polio survivors because many of us are either age 50 or older. The polio-affected areas have less bone mass and weaker bones because of the lack of normal weight bearing. Many of us will fall more often than persons with normal neuromuscular function. If we break our “good” hip or fracture an arm that we depend on to assist in walking with canes, crutches, or to propel a wheelchair, or for transferring, it makes a tremendous impact on our lives and our independence.

Bone loss normally begins at age 30 or 35. After that age, you cannot increase bone mass. If you break a bone, you are able to remodel and generally heal that bone, but you can't add density.

If the usual bone loss that would naturally occur has not been slowed, statistics show that 90% of women and 50% of men at age 80 will have osteoporosis.

Bone loss can be prevented or slowed. Calcium in the diet is important. Most Americans get about 700 or 800 milligrams (mgm) of calcium per day (recommended is 1,000 to 1,500 mgm). To increase calcium in your diet, include at least four servings of dairy products per day. Adequate amounts of Vitamin D (between 400 and 800 units per day) are also needed. One glass of milk is fortified with 100 units of Vitamin D. If you drank four 8-ounce glasses of milk, you'd get the recommended daily amounts of calcium and Vitamin D. (You can get enough Vitamin D by a daily 15-minute exposure to sunlight, which is possible even in winter-time when you are fully clothed because your hands or face are exposed.) In one study, calcium and Vitamin D were given to a group of nursing home patients and the fracture rate was decreased by 40%, compared to the control group.

Hormone replacement for women (estrogen with or without progesterone) and sometimes testosterone replacement for men can slow bone loss, preserve bone strength, and decrease fractures by approximately 50%. Estrogen alone can be used for women who have had a hysterectomy. Estrogen also has some other advantages; it has been shown to cut coronary artery disease by approximately one-half and it may decrease the

MARY EULBERG, MD is a polio survivor, a family practice physician educator, and a post-polio specialist, who has advised polio survivors since 1985.

risk of Alzheimer's disease. There may be a slight increased risk of breast cancer in women who take estrogen for more than ten years; studies show mixed findings about whether estrogen replacement does increase breast cancer risk or not. Estrogen can increase bone mass even if it is begun after age 65. For it to be most effective, it must be taken for many years, perhaps a lifetime. A new drug, raloxifene (Evista), can be used in women who have had breast or uterine cancer or those at high risk for these forms of cancer.

Two drugs released in the last couple of years to prevent and treat osteoporosis are calcitonin (Miacalcin, Calcimar, etc.) and alendronate (Fosamax). It is interesting that these new drugs have only been approved by the FDA for treatment of osteoporosis in women, but not officially approved for use in men.

Calcitonin is administered by injection or as a nasal spray. One should take calcium with calcitonin. It increases bone density and prevents further mineral loss for at least one or two years, but the studies to date have not shown a decrease in fractures.

Alendronate (Fosamax) is in a class of drugs called biphosphonates and is new; another called etidronate (Didronel) has been available for at least five years. Fosamax is taken orally every day; Didronel is taken orally for seven days once every three months. The biphosphonates have been shown to decrease fractures by 50% and are recommended for women who cannot take estrogen. Supplemental calcium should be taken with the biphosphonates. All of the biphosphonates can cause gastro-intestinal distress and therefore should be taken upon arising with tap water, before food or beverages. One

should not eat before and should remain upright for 30 minutes after taking these medicines.

Other drugs are being used such as parathyroid and various growth factors, but these are still experimental and should be taken only after consultation with a metabolic bone specialist.

Testing is available for osteoporosis. It is not usually recommended for the general public, but you may want to discuss your particular situation with your primary care physician or your polio specialist. The testing that is generally done is a special x-ray called dual photon energy absorption. Another method that measures the bone density in one's heel bone also has been approved. I would recommend caution about the interpretation of the heel bone density test in a polio survivor who has weakness around one or both feet or ankles. If you have one polio-weakened leg and one apparently unaffected leg, I would expect the scan of the polio-affected heel to show fairly significant osteoporosis and the unaffected heel to show little or no osteoporosis or even super good bone.

Armed with all this information, what are you going to do to start a journey toward being a healthier person? ■

To receive more information about osteoporosis ...

contact the National Osteoporosis Foundation, 1150 17th Street NW, Suite 500, Washington, DC (District of Columbia) 20036-4603 (202/223-2226).

For your information, the following benefits were added by Medicare in 1998 ...

For women ...

Yearly mammograms:

Started January 1, 1998
(No Part B deductible)

Pap smear, including pelvic and breast examination:

Started January 1, 1998
(No Part B deductible)

For everyone ...

Colorectal cancer screening:

Started January 1, 1998

Bone mass measurement:

Starts July 1, 1998

Flu & pneumococcal

pneumonia shots:

Medicare pays 100 percent.

international polio network

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Wellness for Polio Survivors

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Once they have seen appropriate rehabilitation professionals to alleviate and manage the late effects of polio, or as they simply grow older, what can polio survivors do to take charge and promote good health? It is hoped that findings from this study, by demonstrating how a wellness program can help, will encourage and activate survivors to stay as healthy and functional as possible.

Halfway to completion, *Wellness for Women with Polio: A Holistic Program Model*, a study funded by the National Institutes of Health, is proceeding at the University of Michigan Medical Center. Two hundred women who have various levels of disability from polio are participating in this investigation, which is directed by Denise G. Tate, PhD, and James A. Leonard, MD.

The purpose is to test the effectiveness of a holistic wellness program. One hundred women are participating in a wellness workshop; 100 others are the control group. The major question to be answered is: "does attending a ten-week workshop on nutrition, exercise, and stress management lead to greater physical fitness, improved nutrition, and reduced stress for polio survivors?" Further, "as polio survivors grow older with their disability, would focusing on health promotion activities lead to optimal health (i.e., a higher state of wellness) and improved quality of life, as well as inhibit the development of secondary conditions such as osteoporosis or carpal tunnel syndrome?"

The specific intervention in this study is a comprehensive and integrated (holistic) wellness workshop. The holistic approach was developed on the premise that mind and body work together as one, and that sound nutrition,

appropriate exercise, and stress management are interrelated and contribute to a woman's overall state of wellness.

In this study, the three-hour workshop covering each key health topic convenes every other week for eight weeks. Approximately twenty participants with similar disability levels come together to learn about the interrelationship of good nutrition, safe exercise, and stress reduction from four different facilitators. Polio and its late effects is also woven in as part of the course content. There are lectures, group discussion, literature-sharing, deep breathing to soft music, with practice in stretching and strengthening exercises.

The wellness workshop's content and activities are individualized for each participant. Regular at-home health promotion activity and positive buddy-system support outside of class are encouraged. Two weeks after the workshop has ended, each participant meets individually for a coaching session with each facilitator to discuss and create a personalized plan for wellness activities. Goals are not grandiose; the activities laid out must be safe and achievable, including small but regularly-practiced improvements in daily health-promoting activities.

Participants in the study are clinically examined before, after

(for short-term effects), and six months following the finish of the wellness workshop (for longer-lasting effects). Self-report questionnaires are also completed at each point to register change during the study's entire nine-month duration.

As of this writing, 112 of the total 200 women have started participation in the study. By June 6th, two-fifths of the study sample will have completed their participation requirements. Anecdotally, several women expressed extreme relief to learn that intelligently-planned exercise is an option for them, alleviating fears that polio survivors could never exercise without dangerous risk attached.

Companions and spouses attending clinics or workshops have also expressed appreciation at the feeling of support from others who have had similar experiences and for the opportunity to learn more about polio's late effects.

This study is slated for completion by October of 1999. Investigators will continue to provide regular updates to *Polio Network News* regarding the study's progress and data trends. ■

Polio survivor SUNNY ROLLER has been a post-polio educator and researcher for fifteen years and has authored professional and consumer literature on the late effects of polio and wellness programs for polio survivors. Roller is the project manager for *Wellness for Women with Polio: A Holistic Program Model* and is currently serving on the federal subcommittee to write "Healthy People 2010," which will outline our new national guidelines for health and health promotion for all American citizens, including those with disabilities.

Wellness from Within: The First Step

"According to the World Health Organization, 'health is more than the absence of disease. Health is a state of optimal well-being.' Optimal well-being is a concept of health that goes beyond the curing of ILLNESS to one of achieving WELLNESS. Achieving wellness requires balancing the various aspects of the whole person. These aspects are physical, emotional, mental, and spiritual. This broader, (w)holistic approach to health involves the integration of all of these aspects and is an ongoing process."

"Many of us have been brought up to believe that our health depends solely on the quality of the healthcare we receive. The truth is, your health is YOUR responsibility. You are the only person who can make the lifestyle decisions that contribute to your well-being. You are the one who must take the steps to preserve your health and promote your wellness. Only you have the power to create wellness for yourself."

"Your power lies in the choices you make every day on your own behalf. If you react out of habit or fixed attitudes, you may not be using your choices wisely to create wellness in your life. To create wellness, you must expand your focus beyond mere physical health and:

- ◆ strive to balance and integrate your physical, emotional, mental, and spiritual aspects;
- ◆ establish respectful, cooperative relationships with your family, friends, community, and the environment;
- ◆ gather information and make informed wellness-oriented lifestyle choices;
- ◆ actively participate in your health decisions and healing process."

Copyright 1995, 1997 American Holistic Health Association

The American Holistic Health Association (AHHA) has developed a 25-page booklet to help achieve wellness. Contact them at P.O. Box 17400, Anaheim, CA (California) 92817-7400 (714/779-6152, ahha@healthy.net, or www.ahha.org) for a copy (free within the US, \$1 in North America, and \$2 outside of North America). The American Holistic Health Association (AHHA) is a national clearinghouse for self-help resources promoting health and well-being.

Sleep-disordered breathing

defined: Signs and symptoms of underventilation (hypoventilation) include fatigue, daytime sleepiness, morning headaches, need to sleep sitting up, sleep disturbances (dreams of being smothered, nightmares, restless sleep), poor concentration and impaired intellectual function, shortness of breath on exertion, claustrophobia, anxiety, difficulty in speaking for more than a short time, quiet speech with fewer words per breath, use of accessory muscles to breathe, and a weak cough with increased susceptibility to respiratory infections and pneumonias.

Polio survivors experiencing more than one of the above signs and symptoms should seek a pulmonologist, preferably one experienced in neuromuscular disorders, for pulmonary function testing. Pulmonary function tests should include at least: forced vital capacity (FVC), forced expiratory volume in one second (FEV1), FEV1/FVC ratio, and arterial blood gas analysis.

Sleep apnea (temporary cessation of breathing) may also be experienced by polio survivors, especially those with a history of snoring. A sleep study (overnight oximetry or polysomnography) should be performed to rule out sleep apnea. Some polio survivors may have both sleep apnea and under-ventilation.

Post-Polio Bibliography

Hsu, A. and Staats, B. (1998). "Postpolio" sequelae and sleep-related disordered breathing. *Mayo Clinic Proceedings*, 73, 216-224.

The medical records of patients seen at Mayo Clinic Rochester with the diagnosis of post-polio syndrome and sleep apnea or hypoventilation over the period 1984 through 1994 were reviewed. Adequate data was obtained in 35/108 patients. We found that a broad spectrum of sleep-disordered breathing was represented from those with obstructive sleep apnea (19), to hypoventilation (7), and

including both diagnosis (9). Patients with hypoventilation tended to have a history of neurologic deficits involving the trunk during acute polio, and scoliosis and restricted lung function at later presentation. Our group was selected and not representative of all patients with post-polio syndrome. We suggest that patients with a history of breathing difficulties during sleep and/or excessive sleepiness should undergo sleep disorders consultation.

BRUCE STAATS, MD,
ROCHESTER, MINNESOTA

7th International Conference on Home Ventilation

"Noninvasive Ventilation: Across the Spectrum from Critical Care to Home Care"

**March 14-17, 1999
Caribe Royale Resort Suites,
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Sponsored by the American College of Chest Physicians and the American Association for Respiratory Care, in conjunction with the International Ventilator Users Network and National Jewish Medical and Research Center.

What Works: Results and Implications of Post-Polio Clinic Survey

Stanley K. Yarnell, MD, Saint Mary's Medical Center, San Francisco, California

Polio survivors who were evaluated and treated in the post-polio clinic at Saint Mary's Medical Center in San Francisco were surveyed in order to answer four critical questions.

We wanted to know if our advice was useful. Most importantly, we wanted to know how polio survivors felt months or years after visiting the clinic. We also wanted to know why polio survivors thought they felt the way they did. And, we wanted to know what things polio survivors thought helped them to feel better.

STANLEY K. YARNELL, MD, has been involved with the disability community professionally and personally for 20 years. He founded the first post-polio clinic in northern California in 1981 in Saint Mary's Medical Center and promoted the establishment of post-polio self-help groups throughout the area. He is a well-known presenter at post-polio conferences throughout the world and continues to be involved with the early care and management of spinal cord injured patients in his private practice.

Dr. Yarnell's contact with the disability community is not limited to his role as treating physician. He has been legally blind due to recurrent optic neuritis since 1978 and serves on several disability-related boards.

We sent out 239 surveys, of which 137 were returned (57 percent). Six were incomplete and excluded from analysis.

Of those who saw the consulting physiatrist, 80 percent felt that the advice was useful; sixteen percent felt it was somewhat useful; and four percent felt the advice was not helpful.

We asked the polio survivors who had been seen by the full complement of the post-polio treatment team how they felt, and 130 responded. Of these, 59 percent felt better, 18 percent felt worse, while 23 percent felt the same.

Patients who felt better:

Polio survivors who stated that they were feeling better following their clinic visit were on average 54.5 years old. Twenty-five respondents were male; 52 were female. The average time lapse since the last clinic visit was 1.7 years. Ninety-five percent of the people who felt better attributed it directly to their clinic visit. Five percent stated they felt better, though they did not attribute it to their clinic visit. Those who felt better were asked whether they felt better, worse, or the same in 22 health indicators. (See sidebar on page 7.) This group felt improvement in ten of the parameters — better coping skills, more relaxed, more self confidence, fewer numbers of falls, less pain, less irritability, better sleep, better mobility, less anxiety, greater efficiency, less depression, and better general health.

Polio survivors who felt better were asked to choose from twenty treatment options offered by the clinic. (See sidebar on page 7.) Selected as being *most useful* were: energy conservation techniques (79 percent), non-fatiguing general-conditioning exercise programs (74 percent), early retirement/work cutbacks (59 percent), emotional reassurance (55 percent), power wheelchairs/electric scooters (40 percent), back conservation techniques (31 percent), adaptive equipment (30 percent), and finally, medication recommendations (26 percent). Other options ranked were not statistically significant.

Patients who felt the same:

Polio survivors who indicated that they felt the same after their clinic visit were on average 56.2 years old. Thirteen respondents were male; 17 were female. The average time lapse since their last clinic visit was 1.6 years. Those who felt the same were asked to rank the 22 health indicators, and all of the respondents indicated that they felt the same in each of the health indicators. Asked why they felt the same, many (43 percent) indicated that if they had not visited the clinic, they thought they would have felt worse. Twenty-three percent felt they had learned that they were already doing the right things as a result of their clinic visit.

Patients who felt worse:

Those respondents who indicated that they felt worse were on average 64.1 years old. Seven respondents were male; 16 were female.

It had been, on average, 2.0 years since their last clinic visit. Those who felt worse indicated that they felt worse in nine and the same in 13 of the 22 health indicators. They characterized themselves as feeling worse because of decreased energy, increased weakness, poor mobility, increasing fatigue, more pain, less stamina, worse sleep, poorer concentration, and greater anxiety. It was the perception of these polio survivors that they felt worse because their disease or condition had progressed (76 percent), felt older (48 percent), felt more stress (28 percent), and developed other illnesses (24 percent). No one blamed the clinic visit for the fact that they felt worse.

However, this group was troubling. Pain was high on the list of health indicators. In my experience of collecting statistics in the polio clinic since 1981, musculoskeletal pain has become the most common complaint (79 percent of all polio survivors).

Conclusions: The importance of this study is that it is based on the perceptions of polio survivors themselves. What did we conclude? We felt gratified that we were doing a good job, helping most of the polio survivors who came to the polio clinic to feel better, or at least not lose ground. We will continue to emphasize energy conservation, teach exercise parameters, advocate early retirement or work simplification, provide emotional reassurance, encourage use of power wheelchairs and motorized scooters and adaptive equipment, emphasize joint conservation, and recommend medications.

In addition, we are trying to better individualize pain management. And, as a result of the complaints of weakness, increased frequency

of falls, fatigue, loss of stamina, and decreased energy, we have reexamined the use of Mestinon (pyridostigmine) for polio survivors with profound fatigue and upper-extremity and/or bulbar weakness. We have tried it on seven patients; five continue without side effects and feel an improvement in their fatigability (susceptibility to fatigue). ■

HEALTH INDICATORS:

- Level of relaxation
- Pain
- Shortness of breath
- Number of medicines
- Mobility
- Family relations
- Work relations
- Weakness
- Irritability
- Coping skills
- Energy level
- Sleep
- Frequency of falls
- Self-confidence
- Efficiency
- Stamina
- Concentration
- Fatigue
- Anxiety
- Depression
- Average weight
- General health

TREATMENT OPTIONS:

- Emotional reassurance
- Medication recommendations
- Energy conservation techniques
- Myofascial release
- Massage
- Seating changes
- TNS (transcut. nerve stimulation)
- Family education
- Heat/ice
- Change or start ventilator
- Adaptive equipment
- Bracing
- Wheelchair/scooter
- Injection
- Retirement/work cutback
- Biofeedback
- Back/joint conservation
- Swimming
- Oxygen
- Traction
- Non-fatiguing general conditioning exercise (20% rule)

Non-Fatiguing General Conditioning Exercise Program (The 20% Rule)

*Stanley K. Yarnell, MD,
Saint Mary's Medical Center,
San Francisco, California*

The non-fatiguing general conditioning exercise program using the 20% rule was designed to help restore stamina or endurance for those individuals who have continued to be bothered by profound fatigue following surgery, illness, or trauma.

The program begins by determining the polio survivor's maximum exercise capability with the help of the clinic physical therapist. The type of exercise can be in a pool or on dry land, using an arm ergometer or an exercise bicycle, depending on the individual's abilities and preferences. If one prefers swimming, the maximum number of laps that the patient can swim is used as the maximum exercise capability. If the survivor has considerable residual weakness and is only able to swim one lap in half an hour, then the amount of time actively swimming can be used as the maximum exercise capability rather than the number of laps.

Having established the maximum exercise capability, the polio survivor is instructed to begin his aerobic swimming program at 20% of the determined maximum exercise capability. He can swim three to four times per week at that level for one month, and then he is instructed to increase by 10%. For example, if an individual is able to actively swim in a pool for

CONTINUED ON PAGE 8

half an hour, then one-half hour would be his maximum exercise capability. He would begin swimming just six minutes per session three to four times per week for a month before increasing the amount of time actively swimming to nine minutes three to four times per week for another month. Then he would increase by 10% once again so that he was actively swimming 12 minutes per session three to four times per week for another month, and so on. After three to four months, our patients have reported that they feel an increase in their general stamina or endurance.

Alternatively, if an arm ergometer or exercise bicycle is used, the same basic principle can be utilized, calculating distance pedaled or time spent actively pedaling. The individual begins his aerobic or non-fatiguing general conditioning exercise program at 20% of maximum exercise capability three to four times per week for one month before increasing the distance by 10%. He continues with that level of activity for another month before increasing

by another 10%, so that he is exercising at 40% of maximum exercise capability.

For example, if an individual is able to pedal an exercise bicycle for one mile or is able to actively pedal the bicycle for up to 20 minutes, then that is his maximum exercise capability. He is instructed to begin his exercise program at one-fifth of a mile (or, if time is used, then four minutes is the beginning exercise time). This is repeated three to four times per week for a month before increasing the distance to one-third of a mile or six minutes. Our patients are encouraged to maintain that for an additional month before increasing by another 10%, and so on.

Individuals are cautioned to stop if they become fatigued during their exercise program, or if they experience pain or aches in their muscles. Most polio survivors are able to continue increasing their exercise program to nearly the maximum exercise capability, though it clearly would take a full nine months if this program were

strictly followed. Conditioning or aerobic exercise at this submaximal level allows the individual to regain a healthier sense of stamina without damaging delicate old motor units.

It is imperative to incorporate the concept of pacing and spacing within the non-fatiguing general conditioning exercise program, meaning that rests are to be taken every few minutes.

The 20% rule is sometimes also applied to polio survivors when they are given instructions in a home flexibility and stretching program so they do not exercise too vigorously.

This exercise program can be modified with the supervision of a physical therapist, depending on the progress made by the polio survivor. This program may not eliminate fatigue, but we have found it effective for those who have a significant element of deconditioning contributing to their sense of fatigue. ■

(Reprinted from *Polio Network News*, Vol. 7, No. 3, Summer 1991)



The Sitter

A portable device for providing the equivalent of chair arms

All of us who live with the effects of polio have learned to adapt, substitute, and "make do" in order to survive in a world that has been slow in accommodating our particular needs. There is a significant difference between the prowess of a 30-year-old just coming to grips with polio and that same person two score and three years later.

As an engineer, I have developed a number of devices to help neu-

tralize the changes. One is the "sitter," a portable device with essentially the same structure as a "walker," but proportioned differently because its function is different. The sitter's function is to provide a reasonably unobtrusive, easily-portable set of arms for chairs and toilets not so equipped. I walk with forearm crutches and have only a trace of function in my quadriceps. The "sitter," which I have used at home, in restaurants, when visiting friends, and while traveling, has made a big difference in my life.

The accompanying photos show the "sitter" in place around a

My Experiences with Progressive Oropharyngeal Dysphagia

Peter C. Ellis, Nepean, Ontario, Canada

After an attack of acute bulbar polio in 1951 at age 15, the entire left side of my body and my right arm were affected. I could not swallow or talk, but was not placed in an iron lung. Following a 16-day hospitalization in Montreal, I received physiotherapy for six months, and then returned to high school. I made a good recovery, but have some residual effects in my left leg, both arms, speech and swallowing.

History of swallowing problems:

AGE 43, 1979: My swallowing started to deteriorate. Food stuck in my throat, and I began to use liquids to assist in swallowing solid foods. Barium swallow x-rays and esophagoscopy revealed a small hiatus hernia, subsequently treated with antacid medication (Pepcid, 20mg b.i.d.). I could eat most foods without difficulty, and my swallowing remained stable for the next 17 years.

AGE 60, LATE 1996: My swallowing deteriorated over a month's duration to the extent that I could not eat solids, especially later in the day. I dreaded coming to supper, and the effort required to swallow solids became too great for me. I lived on a liquid diet for three weeks, lost 25 pounds, became weak, and felt awful. After three weeks, I decided that it was imperative to get more nourishment and to risk choking. I started eating pureed foods (baby foods, Boost nutritional drinks, etc.) and other very moist soft foods (boiled eggs, cream of wheat, moist toast). I had to learn how to swallow all over again. My general practitioner referred me to a cardiothoracic surgeon for an esophageal motility study because of the symptoms of the hiatus hernia and because saliva was collecting in my throat that I could not swallow.

AGE 60, APRIL 1997: The cardio-thoracic surgeon performed a barium swallow x-ray, esophagoscopy, and esophageal manometry. The latter two tests were performed on the operating table because the upper sphincter in my esophagus was constricted, and they could not pass tubes through my throat when I was awake. Test results revealed a very weak pharynx (only 10 % of normal strength), no hiatus hernia, a very small (1 cm.) Zenker's diverticulum, weakness in the mid-esophagus, and confirmed that the upper sphincter at the entrance to the esophagus was constricted. The surgeon told me that he could cut the upper sphincter to provide more open area, but the contraction strength would decrease by 50%. He would not guarantee that the surgery would help me because of the inherent structural weakness in the pharynx and in the mid-esophagus. I decided not to have surgery. The surgeon was an expert in his field, but I was the

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chair and around a toilet. A "sitter" is made from a "walker" and requires widening all three elements (back and both sides), so it will fit around the backs of chairs and so the arms will be sufficiently long to make it easy to sit and arise. It is also necessary to shorten the entire structure to position the arms at a comfortable height with respect to the chair/toilet seat height.

I will be happy to share details of my "sitter" (and a "walker" to "sitter" conversion) with anyone who is interested. Contact me via International Polio Network.

HAROLD J. BENZULY



first patient he had seen with the late effects of polio. After studying medical articles on dysphagia, I asked my physician to refer me to a physiatrist and to a speech/language pathologist.

AGE 61, JULY 1997: The physiatrist immediately referred me to a speech/language pathologist for my swallowing and to the physiotherapy department of the Ottawa Rehabilitation Centre for a chronic lower back problem, my weak left leg, and arthritic knee. In the Communications Disorder Department at the Centre, I had a bedside assessment of my swallowing by the speech/language pathologist. The following recommendations were made:

- Drink eight glasses of water per day to loosen up my saliva.
- Do not drink carbonated beverages; they are difficult to swallow.
- Do not take muscle relaxants or alcohol; they tend to relax and inhibit coordination and muscle control.
- Do not swallow foods of different consistencies together.
- Continue diet of moist, soft foods.
- Turn my head to the left (the weaker side) when swallowing.
- Eat several small meals per day instead of three large ones in order to avoid symptoms of pressure buildup in the esophagus.
- Continue taking Pepcid.
- Continue multiple swallows.
- Alternate small sips of liquids to assist the swallowing of solids. Do not take large gulps of liquid.
- Do not eat when fatigued.

AGE 61, SEPT 1997: The Rehabilitation Centre referred me to Ottawa Général Hospital for videofluoroscopy to further document my swallowing dysfunction. Results of this study revealed moderate oropharyngeal dysphagia, consistent with dysphagia associated with the late effects of polio.

AGE 61, OCT 1997: My wife and I viewed the videofluoroscopy film with two speech/language pathologists, which was very beneficial. Further recommendations to help me swallow were:

- Alternate liquids and pureed/minced consistencies to facilitate swallowing/pharyngeal clearing.
- Eat slowly and eat small quantities at a time.
- Swallow several times after each mouthful to facilitate pharyngeal clearing.
- Avoid foods that do not form a cohesive bolus, (i.e., rice, lettuce).
- Eat minced, moist food.
- Use the Mendelsohn maneuver when swallowing to improve bolus flow through the pharynx. (Swallow and attempt to feel the elevation of the larynx and the feeling of the throat closing/holding one's breath. Swallow again, prolonging the elevation of the larynx during the swallow.)

AGE 61, MARCH 1998: I was discharged from the outpatient department at the Rehabilitation Centre after six months of physiotherapy. I also saw a pulmunologist there to determine if the function of my lungs had deteriorated as well, but it had not.

Today I am able to eat most foods (both liquids and solids) using the new strategies learned from the speech/language pathologists. I have to be careful, and am unable to socialize (talk) when eating. I avoid alcohol. I have regained all the weight I lost. I am grateful for the medical care and advice given to me over the past year and a half, and especially to fellow polio survivor, Bonnie Hatfield. ■

The Winter 1996 issue of *Polio Network News* (Vol. 12, No. 1), featured swallowing problems in aging polio survivors. For a copy, send \$3 to International Polio Network.

Calendar

International Polio Network (IPN) invites all post-polio related groups to submit details of upcoming meetings. Send the name of the event, dates, location, and contact information to Sheryl R. Prater at GINI, 4207 Lindell Boulevard, #110, Saint Louis, MO (Missouri) 63108-2915, 314/534-5070 fax, or gini_intl@msn.com.

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Solutions for the Future: Post-Polio Syndrome, JULY 10-12, International Plaza Hotel, Toronto, Ontario, Canada. Contact: Ontario March of Dimes, 10 Overlea Boulevard, Toronto, Ontario, Canada M4H 1A4 (800/263-3463 toll-free Ontario only, 416/425-3463 ext. 213, 416/425-1920 fax, omod@inforamp.net).

Future Approaches for Polio Survivors, AUGUST 28-29, Holiday Inn/Northglenn (a suburb of Denver). Contact: Mary Ann Hamilton, 1185 S. Williams Street, Denver, CO (Colorado) 80210 (303/722-6945, 303/722-7386 fax, or hamil1185@aol.com).

Post-Polio Conference, OCTOBER 2-3, Ramada Inn, Anderson, IN (Indiana). Sponsored by the Central Indiana Post-Polio Support Group. Contact: 765/649-0431.

Seminar for Polio Survivors and Caregivers, OCTOBER 10, Las Vegas, Nevada. Contact: Caroleanne Green, National Polio Care Advocates, 741 Gullwing Lane, North Las Vegas, NV (Nevada) 89031 (702/649-9361, 702/649-6824 fax, or send LSASE for packet (no registration fee).

International Polio Congress and Industrial Exhibition, OCTOBER 30-31, Jena/Thuringia, Germany. Contact: Bundesverband Poliomyelitis e.V. c/o Hendrich, Thaestr. 27, D-35392 Giessen, Germany (+49/30/805-3593; +49/30/8060-2251 fax, www.members.aol.com/poliomed/ or WEFMurach@aol.com).

"A remarkable thing happened in Chambersburg, Pennsylvania..."

Phyllis Bailey, Chambersburg, Pennsylvania

This is a story about the development of a post-polio support group in a small Pennsylvania town. Composed of well-educated consumers and thus empowered to educate their personal physicians and to become partners in their medical care, the group was recognized as a health advocacy model at a national conference sponsored by the Alliance for Continuing Medical Education headquartered at the University of Alabama, Birmingham, Alabama.

I had polio at age seven and was given the whole gamut of treatments including the iron lung, years of physical therapy, bracing, and orthopedic surgeries. During the early '80s I discovered a post-polio support group in Bethesda, Maryland, where I was then living and working as a special education instructional assistant. There I learned about the late effects of polio, although I was not at that time experiencing symptoms.

In 1990, I retired and moved with my husband, Walt, and our dog, Ginger, to Chambersburg, Pennsylvania. I started to experience some symptoms and began searching for a local support group to have as a resource for future information and treatment options. One was not to be found.

As a result of my search, our local Easter Seal Society asked me to determine if there was sufficient interest in forming a post-polio support group.

After some local publicity, we held our first meeting in May of 1994. There were thirty attendees, some in wheelchairs or scooters, some using walkers or crutches, making

it necessary for us to move from the conference room to the larger entrance hallway.

At our second meeting, the representative from our local hospital education department observed our cramped quarters and volunteered their hospital lecture facility, a recent addition, which is "handicapped accessible." The Easter Seal Society has continued to make available their administrative staff to aid us in the printing and distribution of our monthly newsletter.

At these early meetings I heard amazing stories. One member, who had polio at age five and wore long leg braces with a pelvic band, had to be hospitalized for a fracture. During her rehabilitation, the physician demanded that she try to stand without her braces, a rather ridiculous request since she had needed such support since childhood.

As members talked and shared their experiences, there were tales of being misunderstood, misdiagnosed, patronized by their physicians, and referred to psychiatric facilities.

One morning while I was volunteering, I cornered the hospital CEO and explained that it had become evident that there was a need to educate area physicians about the late effects of polio. He referred me to Robert Pyatt, MD, who was the physician in charge of scheduling weekly staff Continuing Medical Education seminars.

After many attempts, I finally met Dr. Pyatt. His first words to me were, "How many people are we talking about anyway?" I was

armed with a video, printed material, and our membership list of seventy-five-plus people.

Together, we organized a program to educate our physicians on post-polio issues. Invitations were sent from the hospital to our personal physicians. Also, all group members encouraged their physicians to attend. I recommended three speakers and Richard Bruno, PhD, now at Englewood Medical Center in New Jersey, agreed to lecture to the group of over fifty physicians. Also in attendance were retired physicians, physical therapists, occupational therapists, anesthesia specialists, and nurses.

Overall reaction to the seminar was favorable. (The expenses of the seminar were paid by the hospital.) Our health professionals now recognize post-polio problems and the need for pacing and not over-exercising and have a clearer picture of treatment options.

Our support group is not unique and, for our part, we avoid non-productive gripe sessions. We focus on educating ourselves and have become well-educated.

Members of our group are learning how to talk with their physicians and thus be active participants in their own health care. We feel it is up to us to keep abreast of information and often prepare copies of information with highlighted areas applicable to our individual needs for our physicians, who now welcome this information. One member, who has been intimidated by physicians, has now learned that doctors are approachable and is taking initiative and becoming more assertive in working with her physician.

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Halstead, L. (1998). Post-Polio Syndrome. *Scientific American*, 42-47.

Trojan, D. (1997). *NeuroRehabilitation: An Interdisciplinary Journal*, 8(2).

The whole journal, edited by Daria A. Trojan, Montreal Neurological Institute and Hospital, Quebec, Canada, features post-polio syndrome. Major articles include:

Post-polio syndrome: historical perspective, epidemiology, and clinical presentation by A.C. Gawne and L.S. Halstead;

Pathophysiology and diagnosis of post-polio syndrome by D.A. Trojan and N.R. Cashman;

Management of post-polio syndrome by D.A. Trojan and L. Finch;

Muscular function in late polio and the role of exercise in post-polio patients by J.C. Agre and A.A. Rodriguez;

Biomechanical abnormalities of post-polio patients and the implications for orthotic management by J. Perry and D. Clark;

Pulmonary dysfunction and its management in post-polio patients by J.R. Bach and M. Tilton.

Contact: Elsevier Science (USA -- 212/633-3730, 888-4ES-INFO toll free in North America, 212/633-3680 fax, or usinfo-f@elsevier.com; Europe -- +31/20-4853757, +31/20-4853432 fax, or nlinfo-f@elsevier.nl; Asia -- +81/3-5561-5033, +81/3-5561-5047 fax, or kyf04035@niftyserve.or.jp).

We have expanded our educational activities at our local college campus. Two of us speak with a class of physical therapy assistant students each semester, describing when we first were taken ill as well as all the adjustments that we have had to make over the years. This, in effect, becomes our story of living with polio. We have found these classes of 40 to 45 students very interested, attentive, and full of good questions.

Dr. Pyatt, now Medical Director of the Cumberland County Health Network, continues to monitor our group's assessment of their improved medical care. He asked for my participation in the annual Continuing Medical Education Conference in San Diego to highlight our accomplishments, offering it as a model for other groups, i.e., diabetes, arthritis, multiple sclerosis, stroke victims, and to encourage other medical educators to seek input from patient groups.

Our session entitled "Patient-Centered CE: Improving Quality and Outcome," was followed by a workshop with the focus on "Patient-Centered CE." Joan Headley, Executive Director of the International Polio Network in Saint Louis, Missouri, also participated. We emphasized how patients and their advocacy groups can play a critical role in CE.

Self-help philosophy states that people who are part of the problem can also be part of the solution. Our group would add — that an educated patient is their own best resource. ■

"A Paralyzing Fear: The Story of Polio in America,"

a 90-minute film, has been scheduled for national air on PBS on October 5 at 9:00 pm. (Local stations may air at anytime. Check your local listings.)

Following the airing of the film, PBS has scheduled a 30-minute studio show which will feature experts in post-polio syndrome, the worldwide eradication of polio, and the future of vaccination for children.

REMINDER:

The film is being made available to groups wishing to show it prior to its running on PBS. For more information, contact: Nina Gilden Seavey, Center for History in the Media, George Washington University, 801 22nd Street, NW, Washington, DC 20052 (202/994-6787, 202/994-6231 fax, or seavey@gwu.edu). ■

Gazette International Networking Institute

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