To Reap the Rewards of Post-Polio Exercise

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In this year, 2002, we know more about exercise for persons who had polio than we did fifteen years ago. There have been a variety of studies conducted by superb and caring scientists, along with numerous personal accounts from polio survivors, themselves, which warrant a new way of thinking about exercise.

Exercise is different than physical activity. For the purposes of this article on exercise, it may be helpful to define these two terms. Exercise is generally defined as planned, structured and repetitive bodily movement, whereas physical activity is the movement you do throughout the day. Physical activity does increase the amount of calories you burn, but unlike exercise, is not necessarily planned, structured or repetitive motion. One benefit of exercise can be an improved ability to take part in ongoing daily physical activity.

Whether you have a planned exercise program or simply rely on day to day physical activity to stay fit, the message to polio survivors today is "beware of inactivity!" In the 1980s polio survivors across the nation heard and heeded a strong medical warning about the dangers of doing exercise, especially too much exercise and/or physical activity, but now post-polio scientists have qualified their advice. New knowledge tells us that no matter what our level of disability is, we should be encouraged to value exercise, enterprising enough to come up with a highly customized plan and enduring enough to reap the rewards. When it comes to exercise, we need to be smart, not scared! One woman in our University of Michigan wellness study told us that in the late 1980s she quit exercising completely out of fear of muscle loss, and gained 35 pounds. Dismayed, she joined the 1996 wellness study to find out what she could do to feel better and it worked! Exercise was put back on her list. She was guided to be selective and conservative as she designed her weekly plan for "working out." She found out that polio survivors need to:

- 1. First, gather the best medical literature from post-polio researchers, educators and clinicians such as Grimby, Agre, Perry, Halstead, Headley, Maynard, Birk, and Yarnell. They will all say that we must each have a custom-tailored plan since we were all affected a little differently by the capricious poliovirus. (See Selected References on Post-Polio Exercise at the end of this paper.)
- 2. Next, find professionals to work with. A well-selected physician and a physical therapist or exercise physiologist who each know or are willing to learn about post-polio issues would be most appropriate. There are no specific formulas for any individual that can be written in an overview article such as this. You must have one-on-one, in-person evaluation and testing to see what works and what does not work for you.
- 3. Then, together, literature in hand, establish a plan for exercise.
- 4. Start slowly, recognize limitations along the way, make adjustments in the weekly activity plan and keep going. Thomas Birk, Ph.D. (1997), recommends a two-month start up period in which your response to exercise is supervised and monitored by the professionals you have chosen to work with.

Gather Literature

The best place to start a literature search on post-polio exercise is to tap the International Polio Network's resources. They have a variety of the latest articles from the best researchers in the world on this very specialized topic. They can be reached by calling 314-534-0475 or connecting with their website at www.post-polio.org. You may also want to do a literature search of the medical journals at your local library. Librarians can help you do a "Medline search" for pertinent medical publications or you can do one on your own by tapping into the internet, going to www.medscape.com, then clicking on Medline.

Find Professionals

You need to establish an exercise coaching team. This can include you, your physician, and a therapist. If you have a post-polio physician that you trust, he or she is the best person to start with. This physician can then recommend a physical therapist or exercise physiologist to work with as part of your new "exercise coaching team." If you need to first find these professionals,

the journey will be longer since knowledgeable post-polio helping professionals can be difficult to find or cultivate. Be encouraged to begin your search however. Remember, if you sense that a professional is not interested in post-polio issues, move quickly on to find someone who will work with you and is willing to learn and help. Once again, the International Polio Network in St. Louis, Missouri can provide you with leads in this search. They publish a national/international directory of self-identified post-polio health professionals and support groups whose members know about the best helping professionals in their geographic area.

Establish a Plan of Action

The experts now agree, when it comes to exercise, a polio survivor doesn't have to do a lot, but one is highly encouraged to do *something*! Once you have gathered your exercise team, decide together what type of exercise is best for you and whether you want to join a group or exercise independently--or both! The amount of physical activity you do will also need to be addressed as you develop this action plan.

Maynard and Headley (1999) emphasize that the main focus of a new exercise program should be on stretching and general aerobic or cardiovascular conditioning exercises to improve endurance. Strengthening exercise, also called resistance training, needs to be approached much more cautiously, however, with a focus on very gradually building up functionally important muscles to a modest degree.

Ann Swartz, Ph.D. (personal communication, February 28, 2002), exercise physiologist at the University of Michigan Health System, describes each of these three types of exercise:

Stretching and Range of Motion Exercise: Why is it important?

Stretching or muscles and joints is important to maximize and maintain function. For instance, arm circles can help maintain the function of your shoulders, making it easier for you to reach for something, or move something out of your way. Preventing tightness in your hips, knees, and ankles will help maximize your walking ability.

What types of exercises are considered stretching or range of motion?

These include arm circles, wrist circles, shoulder shrugs, calf stretches, lifting your knee up towards your chest, bending and extending your knee, knee to chest stretches, back stretches and ankle circles. Many people also enjoy the movements that are part of Yoga or Tai Chi. The following Yoga stretching exercise was part of the University of Michigan Wellness for Women with Polio Workshop and was particularly well received:

The Breathing Tree

Stand or sit erect. Feet apart, body balanced over hips. Arms at sides, palms forward.

As you inhale raise your arms slowly up. Stretch up, up.

Exhale arms to starting position

Inhale arms to starting position

Inhale arms slowly up. Stretch up, up

Exhale arms out at shoulder level. Turn head to look at fingertips

Exhale twisting from the waist toward the direction you are looking

Inhale forward. Turn head to look at other fingertips

Exhale twisting from the waist toward the direction you are looking

Inhale head forward and arms down to starting position.

Cardiovascular Exercise: Why is it important?

Cardiovascular exercise is also known as aerobic exercise. It is exercise that increases your heart rate and blood flow, and makes you breathe a little more heavily than you would when performing your daily tasks. There are numerous benefits, some you may notice, and some you may not. The benefits you may notice include increased ease of accomplishing your activities of daily living and such things as getting in and out of the car, or going from place to place, and an improved mood. Benefits you may not notice include lower blood pressure levels, improved blood cholesterol levels, and lower blood sugar levels to name a few.

Swimming, biking, and walking are examples of cardiovascular exercise. Machines such as the elliptical machines (low impact equipment that combines the movements of walking and stair climbing), stair climbing machines, rowing machines and a machine called the NuStep are also useful for cardiovascular or aerobic exercises. Swimming may be the best exercise for polio survivors because it minimizes mechanical stress on the body. However, you may not have access to a pool, or may not enjoy swimming. So, do what you enjoy, what feels good, and what is accessible.

At what intensity should aerobic exercise be performed?

Health professionals will usually recommend a moderate or low intensity. This means that you should be exercising at a level where your heart rate increases and you are breathing heavier than you would normally (when you are performing your daily tasks.) If you cannot easily carry on a conversation, slow it down!

Strength (Resistance) Training: Why is it important?

Strength training, also known as resistance training, improves muscle strength. When your muscles are stronger, it is easier to carry in your groceries, take out the garbage, and other tasks of your daily routine.

What types of exercises are considered resistance or strength?

Any exercises that involve hand-held weights, weight machines, stretch bands, or even balls are usually strength exercises. These types of exercises, like the stretching exercises, can involve any muscle of your body-- from your head to your toes.

You may choose to exercise alone or with an "exercise buddy." Often, sharing the experience with a friend can be more fun, a chance to learn from each other and stay motivated. Joining or starting a wellness program with other polio survivors may also help. Our 1996-1999 study at the University of Michigan (Tate & Leonard, 2001) of a holistic wellness program for women who had polio found that the biggest change was in participants' exercise routines and resultant physical activity. Program participants changed dramatically in their reported regular participation in vigorous exercise. While prior to their participation 57% never regularly exercised vigorously and 23% did so often or routinely, after their participation, only 26% never did and 41% reported exercising regularly often or routinely. Similarly, program participants demonstrated a marked improvement in terms of the regularity with which they exercised with moderate exertion. Prior to the program's onset, 63% stated that they did so three or more times per week. Following the program's conclusion, 78% of program participants reported conducting moderate exercise with this regularity. Also, while prior to the program's onset 42% of participants said they never engaged in stretching exercises and 23% said that they did routinely, following program participation only 11% said that they never did stretching exercises; 35% of participants said that they did them routinely. Six months following the conclusion of the program, 61% of participants said that they had increased their level of physical activity during the last six months. We also found that exercising vigorously at least three times per week was associated with improved assessments of depression and distress.

Whether with a group or on your own, exercise programs can occur on land or in the water. It is important to do whatever works best for you. If swimming is not possible, you may want to exercise in your house, at a health club or gym, or outdoors. Pick an exercise you enjoy, whether it is walking, stretching, or any other exercise, and begin with small bouts. It is not necessary for you to perform only one activity. You can combine all your favorites. Also, you do not have to do the activity all at once. For instance, Tom enjoys biking, stretching and walking, so his exercise program was as follows:

Morning:

2 minutes stretching 2-5 minute break 2 minutes walking 2-5 minute break 2 minutes stretching 2-5 minute break 2 minutes biking Afternoon:

2 minutes stretching 2-5 minute break 2 minutes walking 2-5 minute break 2 minute stretching 2-5 minute break 2 minutes biking

This is how he began his exercise program, and slowly, over the course of months, he began to increase the bouts of exercise and decrease the length of his breaks. It is very important to rest between exercise sessions. Make sure you rest long enough to fully recover after the exercise; otherwise you may remain in a constant state of overload, which has negative effects on function. Incorporating regular rest periods into an exercise routine is called "interval training." Exercising in a warm pool is another way to work out. According to Lauro Halstead, M.D., water therapy was the exercise of choice for many persons during their recovery from the original polio. It is still excellent therapy. Because of the buoyancy of water, it allows people to do things they can't perform on land. For especially weak limbs, inflatable cuffs can be used to float an extremity. For other limbs, water resistance provides a workout that can be fine-tuned to each person's strength. The principal disadvantages of hydrotherapy are that the temperature may not suit one's body and it may be difficult to find pools that have lifts (if needed). Also, the surfaces around pools tend to be slippery and dangerous for anyone with a tendency to fall.

Aquatic programs for exercise have been recognized as morale boosting and physically beneficial. An early study by Hoffman and Maynard (1992) describes a swimming program for polio survivors as having a "therapeutic effect." Emphasizing the added benefit of group exercise, the authors go on to say: " it is of great importance to recognize that perhaps one of the greatest benefits of a program that brings together individuals who share a common concern is the emotional support they receive from knowing they are not alone in their efforts to confront the late effects of polio." In a more recent Swedish study by Willen and Sunnerhagen (2001), 15 persons with polio's late effects worked out in a pool for 40 minutes twice a week for 5 months. At the end of the study, participants reported an increased sense of well being, pain relief and increased physical fitness. Additionally, at the end of the 5-month period, their heart rates during exercise were down. The study's investigators recommend this program of pool exercises in heated water.

In his 1998 book, *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome*, Halstead additionally provides general guidelines for customized exercise based on his personal and clinical experience with the effects of polio:

Individualized and supervised program. Exercise programs should be supervised initially by a physician or physical therapist experienced in neuromuscular diseases, if not polio. Each program should be customized to your personal needs and residual strengths. Given these constraints, research studies have shown that some polio survivors (but not all) can improve muscle strength (as a result of new muscle hypertrophy, or enlargement) and enhance cardiovascular endurance with a closely monitored training program. In fact, some studies have reported an increase in strength in muscles both with and without new weakness.

Type of exercise. There are numerous kinds of exercise. Finding the one that is right for you and each of your limbs often takes trial and error. Usually, it is a good idea to find two or more exercises that can be varied, exercising different muscles on alternate days. For example, walking or exercising the lower extremities one day and then performing an upper extremity exercise the next. This kind of schedule provides a period of rest for each muscle group and variation that keeps the overall exercise program challenging and enjoyable. As a general rule, muscles that have a grade of 3 or less (using the muscle examination scale: 0 = no contraction and 5 = normal strength) should be protected and not exercised; grade 3+ muscles can be exercised with

caution; grade 4 and 4+ muscles can be exercised moderately; and grade 5 muscles can be exercised vigorously.

Start Slowly; Make Adjustments; Keep Going It will be important to gradually begin your personalized exercise routine-only do little bits at first. One approach might be to apply the "20% Rule." If you have chosen to do a conditioning program, Stanley Yarnell, M.D. (1991), post-polio specialist, suggests a general conditioning exercise program to restore stamina or endurance using this "20% Rule." You establish your maximum capacity (the point at which you begin to tire) for any one exercise. Then you begin your program by working at 20% of that maximum exercise capacity. Do that 3-4 times per week for one month and then increase the rate (time) of exercise by another 10%. Each new month, increase the time exercising by another 10% until maximum capacity is reached. Yarnell clearly warns polio survivors to stop if they become fatigued during their exercise program, or if they experience pain or aches in their muscles. Most survivors, he says, "are able to continue increasing their exercise program to nearly the maximum capacity. " Rests are to be taken every few minutes. This 20% Rule can also be applied to home stretching and flexibility programs too.

Halstead also lays out the following guidelines as you begin your exercise program:

Expect improvement. Exercise should make you feel better physically, and even, mentally. If the activity is not strenuous enough to improve your strength, much less your cardiovascular system (e.g., stretching or yoga exercises), it still should give you a psychological lift just to be doing a special activity for yourself on a regular basis.

Listen to your body. Avoid pain, fatigue, and weakness. These symptoms are signals that your muscles have overworked. A brief period of fatigue and minor muscle pain for 15 minutes to 30 minutes after exercise is usually normal. Symptoms that last longer than 30 minutes to 60 minutes reflect muscle overwork and possible injury. If this occurs, the exercise should be reduced or stopped. Any exercise that causes additional weakness should be discontinued immediately.

Pacing. Pacing [i.e., not going too fast and methodically taking breaks] has been shown to be safe and effective in increasing strength in some individuals. The intervals of exercising can be as short as 2 minutes to 5 minutes alternating with equal intervals of rest. The evidence also shows that secondary symptoms, such as generalized fatigue, can be reduced as individuals become conditioned and are able to perform more work with less expenditure of effort.

Use your best muscles. Polio is often a focal, asymmetric disease with variable amounts of weakness in different limbs. Exercise the limbs least affected or those completely unaffected by polio, while avoiding the more affected extremities. For instance, if only the legs were affected, then the arms can be used in a fairly strenuous program that includes swimming or using an upper extremity arm bicycle; meanwhile, the legs will usually get adequate exercise in the course of doing daily activities.

Warm up and cool-down. As with other exercise programs, a warm up [very light movements such as walking slowly, arm circles or leg lifts that are done for about 5 minutes to get your muscles warm, and to get the blood flowing through your body] followed by gentle stretching should be done to improve flexibility and reduce the possibility of injury. After exercising, a cooldown period [very light movements like the warm ups that will slowly decrease heart rate and prevent any feeling of light-headedness that can occur if exercise is stopped abruptly] should take place. Finally, the type of activity should be one that the participant enjoys to minimize the potential for dropping out because of lack of interest.

Having the tenacity to stick with the program and make the proper adjustments is a real challenge, but polio survivors are good at setting goals and achieving them. Across the country men and women who had polio are beginning to apply these principles of exercise and are experiencing much success. The real reason to get into motion is that exercising can make you feel better! Joan Headley (personal communication, February 26, 2002), high profile polio survivor with a mild disability attests to that in her personal account:

"In 1994, seven years after I had switched jobs from teaching school (and being on my feet most of the day) to working at the International Polio Network where I consciously stayed off of my feet, several observations caused me to rethink my approach to activity.

The pain in my 'good' leg was gone, but was replaced by a pain in the hip of my 'polio' leg. Shopping trips and other family outings were cut short because I did not have the stamina to be on my feet for more than a couple of hours. Each year it became more difficult to climb the stairs to reach my symphony seat because my legs were weak. Then one night, while walking up those stairs and "listening to my body," I also realized I was panting and "out of shape."

One day an elderly polio physician suggested that the pain in my 'polio' leg was not from muscle weakness, but from connective tissue tightness and perhaps I should 'stretch it.' It was at that point I decided to make a change. I visited Bally's with my brother and sister-in-law and we made the circuit trying each machine identifying my weakest muscles. So, I began an 'exercise' program using Dr. Stanley Yarnell's (St. Mary's Hospital, San Francisco) 20 % Rule. I did a select exercise to the greatest extent I could, and then cut it back to 20% and slowly added repetitions and distance carefully observing if there were any consequences.

Today, eight years later, I have eliminated the pain in my leg by doing 30-35 repetitions at least five times a week, as well as two exercises for my arms. I also walk one mile an average of four times a week and do about an hour of stretching exercises once a month in the pool.

For a few years, I walked in the neighborhood park and an added benefit was that I left all of my daily work problems there. I now walk at the YMCA on an official track with no worry about bumps in sidewalks or my safety when I walk in the evenings. I still leave my problems behind, however-the happily embraced extra benefit of a good exercise program.

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Call Gazette International Networking Institute at 314-534-0475 or visit their website at www.post-polio.org to order:

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