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Polio survivors should be aware that some amount of exercise is usually beneficial, but caution should be taken in ensuring that each individual has a program that is tailored to fit their unique needs. Following is an excerpt from our *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors* (reprinted 1999) and past articles from *Polio Network News* (now *Post-Polio Health*) that address exercise issues and which remains applicable and pertinent today.

While the *Handbook* provides a broad selection of basic information about the late effects of polio, the quarterly *Post-Polio Health* builds on that foundation. In addition to these publications, Post-Polio Health International publishes an annual *Post-Polio Directory* that lists clinics, health professionals and support groups with experience in post-polio concerns.

**Excerpt from the *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors, Revised Edition* (1999, ISBN-0-931301-04-1 pbk.)**

## Exercise

Muscle stretching and joint range-of-motion exercises are important whenever there is muscle weakness. Preventing tightness, where muscles are weak, is important to maximize function and is particularly important in the chest wall and abdominal musculature if there is a limitation of breathing capacity. Preventing tightness in the hip and knee is important to maximize walking ability when there is significant weakness of the hip and thigh musculature.

General conditioning exercises or aerobic exercises, specifically to maintain or improve cardiovascular endurance, are good for many polio survivors and have been shown to be effective (Owen & Jones, 1985; Kriz et al., 1992). The best endurance exercise is swimming, because it minimizes mechanical stress on tendons and joints, but beneficially stresses the cardiovascular system.

Conditioning exercises or any repetitive activity, including walking, which causes pain or a sense of excessive muscle fatigue and increased weakness should be discontinued. The primary focus of any exercise program should be on building endurance, not strength (Agre et al., 1997; Ernstaff et al., 1996).

In general, muscles that are significantly weakened by previous polio respond poorly to vigorous strengthening exercise programs. Very gradual strengthening exercises which are guided in intensity and duration by the individual's level of fatigue and/or pain can lead to modest but significant improvements in strength (Agre et al., 1996). Exercise should be focused on functionally important muscles.

An appropriate exercise program will help to maintain the strength of previously involved muscles, and also avoid overloading those muscles which previously were not recognized as having been affected. An adequate exercise program will help to minimize loss in strength and endurance associated with the aging process. Professional advice may be needed to design a feasible and effective personalized exercise program. ■

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## A Statement about Exercise for Survivors of Polio

### Advising all polio survivors not to exercise is as irresponsible as advising all polio survivors to exercise.

Current evidence suggests that exercises are often beneficial for many polio survivors provided that the exercise program is designed for the individual following a thorough assessment and is supervised initially by knowledgeable health professionals. Polio survivors and their health professionals who are knowledgeable about the complete health status of the individual survivor should make the ultimate decision on the advisability of exercise and the protocol of the exercise program.

Clinical research studies support exercise programs that are prescribed and supervised by a professional for many polio survivors, including those with the symptoms of post-polio syndrome.\* (See References, pg 3.)

Acute paralytic polio can result in permanent muscular weakness when the viral infection leads to death of anterior horn cells (AHCs) in the spinal cord. Recovery from paralysis is thought to be due to the resprouting of nerve endings to orphaned muscle fibers creating enlarged motor units. Recovery is also attributed to exercise that facilitates the enlargement of innervated muscle fibers. For example, some polio survivors regained the use of their arms and have walked for years with crutches. Others regained the ability to walk without the aid of braces, crutches, etc., and have continued to walk for decades.

The increased muscle weakness recognized in those with post-polio syndrome is believed to occur from the degeneration of the sprouts of the enlarged motor units. The pre-

mature death of some of the AHCs affected by the poliovirus is speculated to also cause new weakness, and some new weakness is caused by disuse, or a decline in activity or exercise.

There is agreement that repetitive overuse can cause damage to joints and muscles, but can repeated overuse and excessive physical activity accelerate nerve degeneration or nerve death? This is the crux of the physical activity/exercise debate.

Physical activity is movement occurring during daily activities. Exercise is defined as planned, structured and repetitive body movement.

Therapeutic exercise is conducted for a health benefit, generally to reduce pain, to increase strength, to increase endurance and/or to increase the capacity for physical activity.

Polio survivors who over-exercise their muscles experience excessive fatigue that is best understood as depletion of the supply of muscle energy. But, some polio survivors'

weakness can be explained by the lack of exercise and physical activity that clearly leads to muscle fiber wasting and cardiovascular de-conditioning.

The research supports the fact that many survivors can enhance their optimal health, their range of motion and their capacity for activity by embarking on a judicious exercise program that is distinct from the typical day-to-day physical activities. These same polio survivors need not fear "killing off" nerve cells, but do need to acknowledge that the deterioration and possible death of some nerve cells may be a part of normal post-polio aging.

Exercise programs should be designed and supervised by physicians, physical therapists, and/or other health care professionals who are familiar with the unique pathophysiology of post-polio syndrome and the risks of excessive exercise. Professionals typically create a custom-tailored individualized exercise program that is supervised for two-four months.

### \*Criteria for diagnosis of post-polio syndrome

- ◆ Prior paralytic poliomyelitis with evidence of motor neuron loss, as confirmed by history of the acute paralytic illness, signs of residual weakness and atrophy of muscles on neurologic examination, and signs of denervation on electromyography (EMG).
- ◆ A period of partial or complete functional recovery after acute paralytic poliomyelitis, followed by an interval (usually 15 years or more) of stable neurologic function.
- ◆ Gradual or sudden onset of progressive and persistent new muscle weakness or abnormal muscle fatigability (decreased endurance), with or without generalized fatigue, muscle atrophy or muscle and joint pain. (Sudden onset may follow a period of inactivity, or trauma or surgery.) Less commonly, symptoms attributed to post-polio syndrome include new problems with breathing or swallowing.
- ◆ Symptoms persist for at least a year.
- ◆ Exclusion of other neurologic, medical and orthopedic problems as causes of symptoms.

SOURCE: *Post-Polio Syndrome: Identifying Best Practices in Diagnosis & Care*. March of Dimes, 2001.

During this period, they will monitor an individual's pain, fatigue and weakness and make adjustments to the protocol, as needed, to determine an exercise program that a polio survivor can follow independent of a professional.

When designing a program, these general principles are followed to achieve specific goals and/or maintenance levels.

- ◆ The intensity of the exercise is low to moderate.
- ◆ The progression of the exercise is slow, particularly in muscles that have not been exercised for a period of time and/or have obvious chronic weakness from acute poliomyelitis.
- ◆ Pacing is incorporated into the detailed program.
- ◆ The plan should include a rotation of exercise types, such as stretching, general (aerobic) conditioning, strengthening, endurance or joint range of motion exercises.

Polio survivors who experience marked pain or fatigue following any exercise should hold that exercise until contacting their health professional.

Researchers and clinicians cannot make a more definite statement until additional studies on the long-term effects of exercise and the effects of exercise on function and quality of life are undertaken. ■

Visit [www.ncpad.org](http://www.ncpad.org) and review "To Reap the Rewards of Post-Polio Exercise"

by Sunny Roller, MA, University of Michigan Health System, Ann Arbor, Michigan, and Frederick M. Maynard, MD, U.P. Rehabilitation Medicine Associates, PC, Marquette, Michigan.

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## **Yoga Benefits Polio Survivor**

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

Yoga is very popular these days, and it has developed many forms. The yoga I practice is the so-called gentle version of hatha yoga. I discovered it by accident about six years ago (1996). To my great good fortune, my first instructor had studied some anatomy and physiology as part of her yoga training, and she had a great interest in helping those with disabilities to find alternate ways to perform poses made difficult by the disability. (Explore her website at [www.yoga4u2.com](http://www.yoga4u2.com) for more on her style of practice.)

As you are taking classes, you should strive to develop your own daily practice at home with advice from the instructor. Some may offer an individual development

session for a fee. While the cost of yoga classes (in the Washington, DC, area) typically run \$13-17 per session, an individual session can run \$50 or more. If you have severe disability, a few private sessions to find adaptations for your particular body may be of more benefit than a group session that tries to help all and hurt none.

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

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

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

centers, adult education programs, YMCAs, yoga studios and, maybe, health clubs.

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

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

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

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

## Polio Myths and Half-Truths

Julie K. Silver, MD, Medical Director, International Rehabilitation Center for Polio, Spaulding Rehabilitation Hospital, Framingham, Massachusetts

### Myth #1: Some medications are bad for polio survivors and should be avoided at all costs.

Many polio survivors have read that some medication classes are bad for them – the most common I am asked about is probably the “statins” (e.g., fluvastatin, simvastatin, etc.) These are medications that end in *statin* and are used to lower cholesterol levels. The fear is that these drugs will cause muscle pain or weakness (a known side effect) and compound the weakness that a polio survivor is already experiencing.

Heart disease is the leading cause of death in men and women as they age. Stroke is a leading cause of further disability. Both conditions are directly linked with high cholesterol levels and “statin” drugs that reduce cholesterol are critical for many people in order to lower their risk of stroke and heart attack. *But, why give a drug to a polio survivor that may cause him or her to become weaker?* The answer is because it may save a life.

It is important to understand what the actual risk may be of developing musculoskeletal problems if you take a particular medication. For example, the drug Zocor (simvastatin) underwent fairly vigorous testing prior to it being approved

by the Federal Drug Administration (FDA). More than 2400 people were tested on the medication.<sup>1</sup> No one in the study knew if they were actually taking the drug (it was blinded), and the results showed that more people complained of muscular side effects when taking a sugar pill (1.3%) than when taking the actual medication (1.2%). The point here is that even if you do take simvastatin, there is nearly a 99% chance that you won’t develop muscular side effects.

So, my advice always goes like this: *talk to your doctor* – the one who prescribed the medication in the first place. *Ask him or her whether it would be okay* for you to stop the medication for a period of time to see whether it is indeed causing you to feel weaker or more pain or whatever you are concerned about. A “drug holiday” is a good way to see whether you are actually experiencing side effects from a medication.

When you go off the medication, pay attention to whether you feel any different. If you do not, that medication is probably fine for you. Keep in mind that every drug has a huge list of *potential* side effects. This does not mean that you will experience them – it just means that in studies that were done on the drug, some people had these side effects.

At the same time, ask your doctor whether there are other alternatives that you can try – including medications and life-style changes. For example, exercise, smoking cessation, and weight loss have all been associated with reducing cholesterol levels. Although I used the example of the *statin* class of medications, this advice applies to any medication that concerns you.

### Myth #2: Polio survivors should rest, rest, rest!

This is another myth that has some truth to it, but taken to an extreme is dangerous. All bodies become extremely deconditioned without the constant use of the muscles. Even polio-weakened muscles can become weaker from disuse. Not using muscles results in weakness, and diminished endurance and cardiac fitness. If you are at complete bedrest, your muscles will lose 10-15% of their strength per week.<sup>2</sup> If you stay in bed for a month, you will have lost about half your strength. Muscles need to be contracted regularly in order for them to maintain their size and strength.

On the other hand, it is important to note that the opposite of disuse – overuse – can also cause further weakness in polio survivors. So, the trick is to balance your daily activities with rest and also do an appropriate exercise program.

This sounds easier than it is, and I always recommend that people talk to healthcare professionals who are experienced in prescribing exercise programs for polio survivors. But some simple suggestions are as follows:

- ◆ Nearly everyone, including polio survivors, should exercise regularly.

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## Polio Myths and Half-Truths

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◆ Exercise is not what you do in your daily activities, but rather is a set program that has a time limit and a certain number of exercises with a particular amount of weight or resistance that is used.

◆ Doing the same exercises over and over may lead to further weakness. Instead, exercises should be alternated regularly so all of the muscle groups are used and no one muscle group is overused. The concept of cross-training that is widely accepted in sports medicine is what we promote at our center.

◆ Include some strengthening, range-of-motion and aerobic exercises to be sure you maintain optimal fitness.

◆ If you experience pain or undue fatigue, check with your doctor. This generally means that what you are doing needs to be modified or even stopped altogether.

### Myth #3: Swimming is good for you.

If you love to swim, do it regularly, and have easy and safe access to a pool, then swimming probably is good for you and you should continue to do it. However, if you do not swim for exercise and you feel guilty about it, then let me relieve you of your guilt – because swimming can be dangerous for your health.

Famous polio survivor, Franklin Delano Roosevelt, loved the buoyancy of water and the freedom it gave him to move his paralyzed body. The fact that much of his swimming was done in the beautiful Warm Springs, Georgia, only added to the benefits he received from this exercise. But swimming is not for everyone and there are some good reasons why you might not want to swim.

First, getting ready to go swimming is a lot of work. For most people swimming involves many or all of the following steps:

1. Locate your bathing suit and towel.
2. Go from your house to your car.
3. Drive to the pool.
4. Go from the parking lot to the locker room.
5. Change into your bathing suit.
6. Go from the locker room to the pool.
7. Swim.
8. Go from the pool to the locker room.
9. Change out of your bathing suit.
10. Go from the locker room to your car.
11. Drive your car home.
12. Go from your car to your house.
13. Hang your bathing suit and towel up to dry.

Of the 13 steps I listed, only one of them involves the “exercise” of swimming. But, in order to get that exercise, you must do at least 12 other things that may just serve to wear you out. So, although I am a huge advocate of exercise that promotes cardiovascular fitness for polio survivors (keep in mind that post-polio syndrome is *disabling*, but cardiovascular disease *kills* more middle-aged and older people than any other condition), swimming is a lot of work.

Second, you may be at risk to fall as you do these 13 steps. In one study, 46% of polio survivors noted that walking outdoors was difficult.<sup>3</sup> In another study, 82% of polio survivors reported increasing difficulty with walking.<sup>4</sup> Yet another study revealed that 64% of survivors reported falling at least once within the previous year and of this same group, 35% reported they had a history of at least one fracture due to a fall.<sup>5</sup> Given these statistics, the number of steps it requires to go swimming (often both literally and figuratively) and the likelihood that there may be some slippery surfaces in the locker room or

around the pool, it is easy to see how someone might fall and sustain a serious injury while going swimming.

I think it is really important to not discourage anyone from exercising in a safe manner and swimming can be a great exercise for polio survivors. But, it is not a great exercise for ALL polio survivors. If you love to swim and you can do it safely, then definitely continue. But, if you find yourself overly fatigued after swimming, or if you think you are at risk to fall and have a serious injury then consider other exercise options. ■

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## **General Information Letter for Polio Survivors**

# **Why are “old polios” who were stable for years now losing function? What should they do about it?**

Jacquelin Perry, MD, DSc (Hon), Rancho Los Amigos National Rehabilitation Center, Downey, California

The basic problem is that polio destroyed some of the nerve cells that activate the muscles. To the extent possible, the neurological system responded by having the remaining nerves adopt the muscle fibers that had lost their original nerve supply. This meant that nerve cells now had a demand much greater than normal. While this was an effective solution initially, the passage of time (30+ years, usually) has taught us that overuse can be destructive. As a result, these secondary nerves are wearing out with resulting muscle loss, i.e., post-polio syndrome.

Post-polio muscle strength is commonly over-estimated as the usual test depends on manual resistance by the examiner. In addition, polio survivors mask their disability by clever use of their normal control and normal position sense to substitute for missing musculature. The post-polio muscle graded “normal” (5) averages 25% less than “true” normal (only 50% normal for the quadriceps). Similarly, the muscle graded “good” (4) is only 40% of normal strength. These strengths are adequate for a person to carry on customary activities in a typical manner, but at a demand that is 2-2½ times the usual inten-

sity; hence, the muscle nerves have been experiencing strain for years.

The apparent abrupt loss in function relates to two functions. One is the buffer zone present in all of our physiological systems which enables them to accept strain for a considerable time, but once the buffer limits are exceeded, the loss is very prominent. Secondly, activities such as walking or lifting objects present fixed mechanical demands. As long as the person's muscle strength exceeds that demand, he/she can continue to perform as usual but with earlier fatigue. When the strength goes below the essential limit, suddenly that function is lost.

The answer is redesigning your lifestyle to avoid those activities that cause muscle strain, cramping, persistent fatigue and, consequently, weakening. This means to very carefully look at how you are using your arms, legs and back, and to avoid those tasks that cause the symptoms of persistent fatigue, muscle soreness and/or a sense of weakness after use. At times, this requires the employment of special devices to take the load off of the arms. If the changes are made early, strength can be recovered. It will not be sufficient to prepare the

muscles for excessive strain again, but it does bring the muscles up to a more useful level. Other ways of reducing strain is by using self-care devices, walking aids, braces and corrective surgery to lessen the stress.

Once the strain has been reduced, then cautious exercise may be of value. We have been using short duration (5 repetitions) or moderate intensity (50-70% of one's maximum capability). Let me caution you not to take on the exercises, however, until you have worked out a lifestyle that avoids the strain. Also, if the exercises cause any pain, persistent fatigue or increased weakness, STOP! This means just the mechanics/activities of daily living (ADL) are sufficient exercise for your muscles.

Recent research on the course of muscle strength over time in persons over age 50 years showed a normal average decline of 1% per year, but for post-polio survivors the rate was 2% per year. The rate of change is so subtle that a four-year study was needed for a measurable change. Also, the weaker “polios” experienced greater functional loss. This latter fact *appeared* to indicate strength training by exercise would deter the process. However, retesting this group of polio survivors at eight years and adding muscle analysis told a different story. The muscle fibers were hypertrophied, twice normal size, not atrophic. The person with the greatest strength loss also had the greatest hypertrophy. MRI recordings showed areas of muscle loss and fatty replacement. The source of the visible muscle atrophy is muscle fiber loss secondary to

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Dr. Perry has been involved in the management of the problems of polio survivors since that time. She is Professor Emeritus Orthopaedics, University of Southern California.

## Why are “old polios” who were stable for years now losing function?

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nerve fiber overuse failure. These findings confirm the need for a saving program rather than challenging exercise.

The advantage of having had polio rather than another disability is that it allowed one to resume a very active and profitable life for many years. Now it is necessary to recognize that excessive strain was being experienced and that lifestyles must be changed to accommodate this situation.

Be an “Intelligent Hypochondriac” – Listen to your body and adopt a program that avoids the strain. ■

\* “Several histologic studies have shown that the myofibers of polio survivors can be twice the size of those found in other persons. A few studies have provided indirect evidence for a possible transformation of some of the surviving type II (fast-twitch fibers) to type I (slow-twitch fibers). The few studies performed have shown a preponderance of type I muscle fibers in very weak muscles that were constantly

being used in daily activities. It has been postulated that a person would have to utilize all motor units in these very weak muscles to perform all daily activities and that, over time, the type II fibers are transformed to type I fibers.”

SOURCE: Agre, J.C., Sliwa, J.A. (2000). Neuromuscular rehabilitation and electro-diagnosis. *Archives of Physical Medicine & Rehabilitation* 81(3), Suppl S27-31.

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## Aspects of Muscle Compensatory Processes and Physical Activity in the Survivors of Polio

Gunnar Grimby, MD, PhD, Professor of Rehabilitation Medicine, Sahlgrenska University Hospital, Göteborg, Sweden

With the increasing understanding of the factors causing new symptoms in polio survivors comes an increasing awareness of the benefits and risks of physical exercise and training. Some training studies have been reported lately in the literature that can be of help in recommending appropriate training regimes. An important aspect is that different muscles in different persons can be very differently affected by polio: some may be atrophied to the point where no exercise or training is possible; some may be moderately weak but in an unstable state showing progressive weakness and a risk for overuse; others may be moderately weak but stable to where some training might be of value; and in some muscles, compensation by reinnervation has resulted in “nearly normal” or “normal” muscle function, but there might be risk for disuse. It is, thus, important to individualize the training advice, not only among individuals but also for different muscle groups of a particular individual.

In practice, this is a great challenge to the physiotherapist, and other

professionals who design the training programs, and requires a detailed analysis of the muscle function both with clinical testing and laboratory investigation using dynamometer measurements and electromyography. Our experience is that by having detailed information, the polio survivor has a better opportunity to adopt a daily physical activity pattern that provides the appropriate amount and type of exercise but without overuse and fatigue.

### Does too much daily physical activity and exercise training cause acute and/or persistent damage of polio-affected muscles?

To answer this question, detailed knowledge about the compensatory processes in the polio-affected muscles is necessary. Compensation occurs through reinnervation by adjacent nerve fibers to muscle fibers (muscle cells), which have lost their innervation by the death of nerve cells in the acute polio phase as well as later on. The polio-affected muscles otherwise would have atrophied. This compensatory mechanism seems to be

very powerful: a nerve cell can reinnervate 4-5 times the normal number of muscle fibers and, in extreme cases, even more than 10 times. The other compensatory mechanism is hypertrophy of the muscle fibers, most likely caused by extreme use of the weak muscle that is still strong enough to be used in daily activities. Even to rise from a chair or walk on a flat surface may give a near maximal load and by that be a stimulus for increase in size of muscle fibers, but not in number, just as in very heavy resistance training. Muscle fibers may then reach a size double or three times the normal size. Thus, whereas physical activity does not seem to be a prerequisite for reinnervation, it is for the increase of muscle fiber size.

### Is there a danger in having large motor units (that is, too many muscle fibers innervated from the same nerve cell) and too large muscle fibers?

Our recent followup studies over eight years (Grimby et al, 1998) indicate that very large motor units,

more than 20 times normal, with around 10 times the normal number of muscle fibers, may have problems. Either they may lose some of their muscle fibers and thin out due to defective neuromuscular connections, or they may just die easier. We have no systematic information available whether physical activity and overuse could bring about such a loss of muscle fibers or nerve cells. A defective neuromuscular transmission can be identified in some motor units, but we have not found in our studies an indication that this is a major factor for muscle weakness. Whether it can contribute to muscle fatigue is still under debate. The other compensatory mechanism — hypertrophy (increase in size) of muscle fibers — has a positive effect on the maintenance of strength, but it could be a negative for endurance, as capillarization and the aerobic metabolic system of the muscle cell (mitochondria) do not increase in response to the increase in size. Indeed, such large muscle fibers may be less resistant to overuse.

We know, in fact, very little about the risk of overuse causing persistent muscle damage. What we know now is the risk for long-lasting fatigue after too strenuous exercise in polio-affected muscles. They need a longer recovery period than "normal" muscles, which must be taken into account when designing training programs and adjusting daily activities. In training studies, we have the experience that with long enough rest periods, which could be days or weeks after a too strenuous bout of exercise (Agre et al, 1998), full recovery will occur. Thus, there is a risk for overuse

but, with proper attention to the fatiguing symptoms, the function will recover after the exertion. The risk occurs when the polio survivor does not rest enough, and his/her muscles remain in a constant condition of overload, with its negative effects on function. Although this is not easy to prove scientifically and experimental studies would be unethical, we must rely on a successive collection of data to understand the balance between the pros and cons of physical activity. My personal view is that an approach of trial and error under professional monitoring will yield in practical terms what is a beneficial level of physical activity and what could be deleterious for a specific individual.

#### **The literature now documents a number of training studies.**

Of prime importance is separating resistance from endurance training programs. A person with weak muscles may use them close to their maximum only for a short period of time, e.g., climbing stairs. Thus, there will be no time for adaptation to endurance. By reducing the intensity, such as walking slower and taking short breaks for other types of activity, both resistance and endurance training at an appropriate level may be achieved. Another way is to choose a medium where the load can be more individualized between muscle groups as in pool training. In a study with a control group at our polio clinic, increased general endurance and less pain in daily life was demonstrated in the group with pool training compared to the group that received advice about their physical activity. There was no

deterioration of function after the pool training (Willén et al, 1999).

Other training studies indicate the possibility of improving the general endurance of polio persons by using individual training programs, as on a bicycle ergometer, or group training on the floor with combined endurance and submaximal resistance training with music (Ernstoff et al, 1996). In general, it would be of value to encourage endurance types of programs with proper intensity and the possibility of individualizing the load as in pool training, giving proper time for rest between the exercises.

The role of resistance training for polio muscles is more controversial. However, short-term resistance training at high or maximal intensity has been demonstrated to give an increase of muscle strength in moderately affected muscles, measuring more than 3 on the manual muscle testing scale (Einarsson, 1991). Such an increase in strength seems to be maintained, probably by adaptation of the physical activity level in daily life, and could be beneficial and allow a broader type of exercises with relatively less effort. Such a program did not result in any negative effects or evidence of muscle damage when properly supervised. Also low intensity strength training can improve muscle performance and reduce the experience of fatigue. There was no change in serum creatine kinase after a 12-week muscle-strengthening program, which would have indicated muscle damage (Agre et al, 1997).

**To learn the appropriate level of physical activity to avoid unnecessary overload on the one hand and disuse on the other is important for maintaining optimal physical function in polio-affected muscles.**

As important, is to avoid pain, it being both a limiting factor for physical performance and an indi-

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Since 1983, Dr. Grimby has conducted numerous studies on muscle function in polio survivors.

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cation of overload that could be on muscles as well as joints and other tissue structures. The experience of pain is evidently closely related to physical activity. Individuals who spontaneously chose a walking speed close to their maximum speed were more prone to experience pain in their daily life (Willén et al, 1998). The results of that study indicated also that those who were less affected by muscle weakness experienced more pain than individuals with weaker muscles, and they might, thus, have a pattern of daily activity that was too strenuous. Advice and adaptation

of the daily physical activity to avoid pain is an important feature in the post-polio management. ■

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## The Role of Activity

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"To exercise or not to exercise, that is not the question for polio survivors. Rather, the questions are these: what amount of exercise is enough? what amount is too much?"

There is no easy answer for all polio survivors, but we can make some general observations about inactivity and exercise.

### Adverse Effects of Inactivity

Limitation in physical activity results in progressive deterioration of cardiovascular performance and efficiency; metabolic disturbances; difficulty in maintaining normal body weight; disturbed sympathetic nervous system activity; reduction in muscular strength and endurance; and possibly emotional disturbances.

### Beneficial Effects of Regular Exercise

In contrast, beneficial physiologic adaptations to regular exercise include reduction in heart rate and blood pressure; morphologic changes in skeletal and cardiac

muscle resulting in improved physical work capacity and an enhancement of cardiovascular efficiency in delivering oxygen and nutrients to the tissues; increased muscular endurance; increased myocardial vascularity; reduced blood coagulability; reduction in adiposity and increased lean body mass; increased cellular sensitivity to insulin; and favorable changes in blood lipids and cholesterol.

Beneficial psychological changes from regular exercise include reduction in muscular tension; improved sleep; and possible increased motivation for improving other health habits such as changes in diet (reduction in saturated fat consumption, for example) and cessation of cigarette smoking.

### Evidence for Beneficial Effects of Exercise in Post-Polio Individuals

Studies have shown strengthening exercise, aerobic conditioning exercise and ambulatory exercise to be beneficial.

**Strengthening Exercise** – In Feldman and Soskolne's study of six post-polio patients, the subjects performed non-fatiguing exercise three times per week for 24 weeks or longer. Strength either increased or remained the same in all muscles in all subjects except for one muscle in one subject that became weaker. The authors concluded that the strengthening exercise was, in general, very beneficial.

Einarsson and Grimby studied 12 subjects who exercised three times per week for six weeks. The subjects performed intervals of strengthening exercise interspersed with rest breaks. All subjects became significantly stronger in the six-week period.

Fillyaw and colleagues studied 17 subjects who exercised every other day for up to two years. The exercise intervals were interspersed with rest breaks. Over this period of time, all subjects gained significant strength.

When I was at the University of Wisconsin, we conducted a 12-week study of muscle-strengthening exercise in seven post-polio subjects. Subjects exercised four times per week for 12 weeks at home. Exercise intervals were interspersed with rest breaks. After the 12-week program, the average increase in strength was 36%; also work capacity and endurance increased by 15% or more.

#### **Aerobic and General Conditioning**

**Exercise** – Four such studies have been performed. Jones and colleagues studied 37 post-polio subjects: 16 volunteered for the exercise program while 21 served as control subjects. The exercise subjects performed stationary bicycle exercise three times per week for 16 weeks. They began with bouts of exercise of 2-5 minutes on the bicycle with 1-minute rest breaks, progressing up to 15-30 minutes of exercise per session. After the program, the exercise subjects were found to have significant improvements in their aerobic power and their capacity to exercise. The control subjects did not change in this same time interval.

Kriz and colleagues performed a similar study in 20 post-polio subjects (with 10 exercise and 10 control subjects); however, the exercise was upper-limb cycle ergometry (rather than lower-limb cycle ergometry). In this study, too, exercise subjects significantly increased their aerobic power and exercise capacity.

Grimby and Einarsson studied 12 post-polio subjects who performed

submaximal endurance and strength training twice weekly for six months. Activity was interspersed with rest breaks. Except for one, all subjects were significantly improved from the training program. The exception reported excessive fatigue with the training program. Grimby and Einarsson concluded that combined endurance training and submaximal strengthening exercise can be generally positive in post-polio individuals, but that overtraining can occur.

Prins and colleagues studied 13 post-polio subjects. Nine performed a swimming and aquatic strengthening exercise program and four were controls. Intervals of exercise were interspersed with intervals of rest. The authors reported significant improvements in strength and flexibility in the exercise subjects and no change in the control subjects.

**Ambulatory Efficiency** – Dean and Ross studied 20 post-polio subjects. Thirteen were control subjects and seven performed treadmill walking exercise three times weekly for six weeks. The exercise was low-level, non-fatiguing and not painful. After the six-week program, the exercise subjects walked more efficiently, while the control subjects showed no change. The study concluded that regular exercise could improve movement economy.

Exercise studies have shown that judicious exercise can improve muscle strength, range of motion, cardiorespiratory fitness and efficiency of movement in some post-polio individuals. These benefits appear to occur when they keep

their activity and exercise within reasonable limits to avoid excessive muscular fatigue or joint or muscle pain. Post-polio individuals should avoid activities that cause increasing muscle or joint pain or excessive fatigue, either during or after their exercise program because the performance of activity at too high a level may lead to overuse/over-work problems. ■

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Dr. Agre has written many articles on the results of his research on post-polio syndrome (published in the referred literature) and has presented at many conferences. He is a firm believer, both professionally and personally, in regular exercise.

## 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.

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 next page). 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 (see next page) offered by the clinic. 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 (see next page), 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 conser-

vation, 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). ■

**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.

**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)

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

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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 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

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## Non-Fatiguing General Conditioning Exercise Program

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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. ■

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## Gait and Post-Polio

Marianne Weiss, MS, PT, University of Findlay, Findlay, Ohio

Falls are a chief cause of death and increased disability in this country. Among the physical problems leading to falls are loss of balance, overall fatigue, repetitive motion leading to individual muscle fatigue, weak muscles and abnormalities in gait.<sup>1</sup> Many polio survivors exhibit one or more of these problems. Using assistive devices for walking can reduce the severity of these abnormalities or reduce the effect that they have on the lives of polio survivors.

Some survivors have used assistive gait devices for many years. Others used them only in the acute stage of recovery after polio, while others never used them. How do you know if you need an assistive device for walking or if you need to change the one you have?

Some signs that can help you answer those questions are these:

lessening endurance for walking due to muscle fatigue, worsening of a limp, pain in the legs during walking, a history of falls or the recent occurrence of new falls.<sup>2</sup> If you suspect that you need an assistive device in walking or a new type, discuss the matter with your doctor, who will probably refer you to a physical therapist for an evaluation.

The therapist will then assess: how your strength and flexibility affect your ability to walk and to get up and down from a seated position; whether you have enough upper body strength and flexibility to safely and effectively use an assistive device; how good your balance is,<sup>3</sup> and how your heart and lungs react to walking. In many cases, the use of an assistive device reduces the strain on the heart and lungs because the device uses less energy than, for example,

the limp it corrects. However, in some cases, using an assistive device may be more taxing on the heart and lungs than walking without a device.<sup>4</sup> If this is the case, the assistive device that the therapist recommends may be an electric scooter or motorized wheelchair.

Finding an appropriate assistive device for walking for polio survivors can be a challenge. If a person has a one-sided problem in the legs, usually a one-sided device, such as a cane or a single crutch, is indicated (most often used in the hand opposite the affected leg). However, abnormalities of strength, pain or flexibility in the arms may make using a one-sided device impossible.

Similarly, problems in the arms may make using two-sided devices such as walkers, two crutches or two canes difficult, if not impossible.

The trick is to find the device that provides enough assistance to compensate for the physical abnormality without causing other physical problems.

Sometimes the evaluation reveals too much disability for the survivor to benefit from an assistive gait device. This finding can free the survivor to make the decision to walk only in the home and to use motorized conveyances to move about in the community. Many who become motorized are pleasantly surprised to find how easily they can participate in community activities again and how much more energy they have after they make the decision to ride rather than walk outside their homes.

If the evaluation reveals that an assistive device would improve your gait, the therapist will recommend a specific device, assist you in obtaining it, fit it to you, teach you how to use it, and assess its

effectiveness in meeting the goal for which it was recommended. Frequently the therapist may also recommend a gentle exercise program of strengthening and stretching to further assist your walking efforts. Certain types of braces or splints may also be recommended.<sup>5,6</sup>

In working with polio survivors for the last 15 years, I have seen many of them helped significantly by their using appropriate assistive devices for walking. The devices can help reduce pain and fatigue, and reduce limping. And, of course, all of this leads to a reduction in the incidence of falls – resulting in less chance of more serious disability or even premature death.

So, what are you waiting for? If you think an assistive device might make your life easier, start the process described above by obtaining your physician's opinion. ■

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