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 upperextremity and/or bulbar weakness. We have tried it on seven patients: five continue without side effects and feel an improvement in their fatiguability (susceptibility to fatigue).

## **HEALTH INDICATORS:**

Level of relaxation 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 Fatique 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

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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.

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## 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