

Reprinted with permission of: ACCENT ON LIVING http://www.blvd.com/accent/

New Drugs & Treatments For Post-Polios by Julie K. Silver, M.D. Accent On Living-Summer 1996

Julie K. Silver, M.D., is a graduate of the Georgetown University School of Medicne. While training in Washington, D.C., Dr. Silver worked with Dr. Lauro Halstead who is one of hte nation's leading authorities on the diagnosis and management of polio-related health problems. Dr. Silver approaches the late effects of polio from both a professional and personal level. Her mother, her mother's father and mother's brother had polio. Dr. Silver also wrote *THE BUSINESS OF MEDICINE*, book for acquainting physicians and medical students with the many business aspects of medicine and is now on the faculty of <u>Harvard Medical School/Spaulding Rehabilitation Hospital</u>

For polio survivors it came as something of a shock - these new symptoms of weakness, fatigue, pain and difficulty with breathing and swallowing. How could it be that after all these years, polio could come back to haunt them again?

Indeed, the late effects of polio, or Post-Polio Syndrome as it is often called, can be more devastating than the original disease. The most likely explanation for the new symptoms is that muscles which were weakened by the original polio virus have had to work excessively hard for many years. This has lead to overuse of these muscles and a faster than normal aging process. For many people, this seems "all of a sudden." In reality, it is a process that takes many years before any new symptoms are noticeable.

In fact, the diagnosis of Post-Polio syndrome requires at least four things:

- 1) A History of paralytic poliomyelitis
- 2) At least some neurological recovery from the paralysis
- 3) A stable period for many years, and,
- 4) new symptoms which can be traced to the original polio.

As we become more knowledgeable about the mechanisms which cause the symptoms, we are able to offer more appropriate treatment options for polio survivors. Our understanding of Post-Polio Syndrome is rapidly evolving and currently there are treatment options which were not available even as recently as one year ago. Scientists and clinicians are hard at work with some exciting prospects for the future as well.

Therapeutic exercise

Initial studies done to evaluate the effect of exercise on people with new weakness from their old polio gave conflicting results. Some people got stronger and others got weaker with prescribed exercise protocols. Recent studies, however, suggest that most people with the late effects of polio do benefit from non-fatiguing exercise programs.

The first step in prescribing any exercise program for someone who had polio is to determine which extremities are involved. This is important because someone who only has their legs involved can do very vigorous exercises with their arms, while limiting their legs to non-fatiguing exercises. In contrast, if someone has both their arms and legs affected, then all exercises must be non-fatiguing. Determining which extremities have evidence of old polio is done with electrodiagnostic studies (EMG and never conduction studies) which are ordered by a doctor. These studies are important in guiding he therapeutic exercise prescription.

In most cases, an appropriate exercise program will help strengthen muscles as well as improve heart condition. ON the other hand, a program which is too strenuous can accelerate muscle weakness, and a program which is too easy may not help at all. Therefore, it is important to exercise under the guidance of a health care professional who is knowledgeable about the late effects of polio.

Medications

While there are too many medications to adequately describe in this article which are used to treat post-polio symptoms, there is one exciting drug which recently had very favorable results during a trial at the Sister Kenny Institute in Minnesota. This drug is called pydirdostigmine or Mestinon. Pyridostigmine was shown to significantly improve strength, endurance and reduce fatigue in-patients who were studied. In addition, side effects noted in the study were minimal. While not appropriate for everyone, pyridostigmine is currently gaining favor among doctors who treat Post-Polio Syndrome.

Assistive devices and braces

There are many new styles of braces which can be used to stabilize weak legs. Braces should be used to stabilize weak legs. Braces should be made of lightweight materials and should be updated regularly Old, heavy braces which don't fit well can make post-polio symptoms worse.

Appropriate assistive devices (e.g., crutches, canes, etc.) should be prescribed by a health care professional who is skilled in treating patients with Post-Polio Syndrome. For example, many people who have new leg symptoms may start using a cane to walk. This puts a new stress on the arm which is holding the cane. If the arm also has evidence of old polio on electrodiagnostic studies, this can promote symptoms of weakness, fatigue and even pain in the arm. Even if the arm is not involved, an assistive device which is used improperly can cause other injuries like tendinitis, never compression, etc.

Appropriate braces and assistive devices certainly can make walking easier and can help to prevent unnecessary falls; however, they may cause further weakness or other complications and should be prescribed with this in mind.

Prevention of falls

Because weakness and balance are so intimately linked, any new weakness can cause falls. Unfortunately, bones surrounding weakened muscles are tin or osteopenic, and

therefore more likely to fracture when a fall occurs.

A fall which results in a fracture can be a devastating setback for someone who has had paralytic polio. People who have had polio are often maximally using their muscles to move about and any disruption, such as a fracture, which may take weeks or months to heal, can be devastating. Therefore, preventing falls if of great importance to a person who has had polio.

A prime time for falls is during poor weather conditions. Thus, an attempt should be made to limit time spent outdoors during bad weather. Appropriate assistive devices (e.g., canes, crutches, etc.) and braces should be used to increase safety -- especially during the winter when weather conditions can be precarious. Slippery bathrooms are also the site of many unnecessary falls. Simple modifications such as a tub bench or shower seat, grab rails and a non-slip mat can greatly reduce the risk of falling in the bathroom.

Keeping a record of how often, where and why falls are occurring can help our doctor troubleshoot for you. It is extremely important to prevent as many falls as possible. When patients ask me how many times is too many, I reply that I want to do everything possible to eliminate all falls.

Respiratory treatment options

Because breathing is something we do continuously, it is very difficult to rest the respiratory muscles. People who are experiencing late respiratory complications due to polio are sometimes candidates for CPAP or Continuous Positive Airway Pressure. What may even be more comfortable and effective is BiPAP or Bi-level Positive Airway Pressure. There are several commercially available masks which can be tried for maximal comfort.

Some respiratory conditions are reversible, so any symptoms should be carefully reviewed with your doctor in order to make the correct diagnosis.

In the future

Each year brings new treatment options, and it is important for people who have had paralytic poliomyelitis to be ware of these exciting new advances. The future is certain to bring more options, and although we all wait impatiently, we can anticipate them with renewed hope.

Pyridostigmine

Pyridostigmine (Mestinon) was recently given to patients with Post-Polio Syndrome in a double-blind crossover study at the Sister Kenny Institute in Minnesota. Dr. Barbara Seizert and colleagues reported that patients in the study had significant improvement in strength, endurance and reduction of fatigue. In addition, there were minimal side effects. Pyridostigmine has also been used to treat other disorders such as Myashenia Gravis and Parkinson's. Pyridostigmine must be prescribed by a doctor and although the dose can vary, a typical maintenance dose is 60 milligrams, three times a day.

Additional resourses from the net:

- A Dogma Upended: Sister Kenny Post-Polio Treatment
 Healthtouch® Drug & Pharm. Information
- Sister Kenny Institute-Minnesota

© Copyright 1996 ACCENT ON LIVING

Post-Polio Syndrom Central Post-Polio-Med Email List