

# ***THE POLIO SOCIETY***

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## **Background:**

### ***The Problem***

With the introduction of the Salk and Sabin vaccines over thirty years ago, the frightening polio epidemics were successfully eradicated almost overnight. Today the National Center for Health Statistics has estimated that there are over 650,000 survivors of paralytic polio in the United States today. Over half of these polio survivors are experiencing new difficulties that are related to their old polio.

There are various theories about the cause(s) of this new deterioration. The most widely accepted explanation is that nerve cells damaged by the polio virus decades earlier, and the neighboring nerve cells that took over for those killed by the virus, are now wearing out. Although the severity and nature of the new post-polio symptoms are diverse, generally they include new muscle weakness, severe fatigue, pain, difficulties with swallowing, breathing and sleeping, and for an intolerance to cold.

### **How do I determine if my health problems may be related to polio?**

Although not all of the following symptoms will apply to every individual, this list is a useful guide for you to begin to assess your own situation:

- new and/or increased muscle weakness in areas of your body originally affected by the polio virus and in areas not believed to be affected during the original paralysis;
- marked fatigue following usual level of activities;
- new and/or increased joint or muscle

- generalized pain or aching;
- sleep disturbances often related to muscle or joint pain;
- new and/or swallowing problems;
- new and/or difficulties breathing;
- increased sensitivity to cold especially in polio-affected limbs.

## Where can I get help?

The first step is to seek a medical evaluation by health care professionals experienced in post-polio management. Testing in neuromuscular, circulatory and respiratory areas will provide a baseline for assessing your health problems and determining the likelihood of their being the late effects of polio.

Many nationally recognized clinics deal exclusively with the late effects of polio and most individuals can find a post-polio clinic and support group within their local area. The Polio Society publishes a quarterly newsletter, provides access to inexpensive reprints of state-of-the-art information, sponsors national conference, and offers information about clinics and support groups across the country. **Post-Polio Health** provides a state-by-state directory of post-polio clinics, health professionals and support groups, a quarterly newsletter, and national conferences. In addition, ask your librarian how to conduct a literature search of articles on current post-polio research studies and disability-related issues. There have been over 2000 articles and books published on post-polio problems since 1984.

## What treatment options are available?

Treatment is highly individualized because of differences in severity of the original polio, variability in one's retained functions, and type(s) of new problems. Many individuals are finding relief from pain through a variety of options. These therapies do not prevent the onset of the late effects of polio, but they can help to mitigate the severity of the symptoms and even slow the progression of symptoms. Therapeutic strategies include:

- changes in activity patterns that reduce demands on weakened muscles;
- modifications of work-sites and homes to increase accessibility and allow

- for more comfortable sitting, sleeping, eating, and working positions;
- changes in exercise routines;
  - use of assistive devices and adaptive equipment, such as canes, braces, wheelchairs, electric scooters, and stair glides.
  - use of new health management techniques, such as weight loss, stress management, personal counseling and participating in post-polio support groups;
  - medications such as Mestinon, Flaviil and Amantadine. have been found to be effective in some individuals;
  - massage and other body-movement therapies (e.g. The Alexander Technique) have been effective for some individuals.

## **Post-Polio Common Sense**

With the onset of post-polio symptoms, a new and different kind of common sense thinking is in order:

- Do not assume that every physician fully understands post-polio problems; educate yourself and never hesitate to ask questions;
- Seek interested and knowledgeable health care professionals to work with you as you learn how to solve post-polio problems. Occupational therapists can help you determine how you can change your daily activities to reduce pain and fatigue. Physical therapists can help you determine your need for assistive devices, such as canes, braces, wheelchairs and scooters. Both therapists should be supervised by a physician knowledgeable about the late effects of polio;
- If you are experiencing increased muscle weakness, exercise only under the supervision of a physician and physical therapist knowledgeable about the late effects of polio. Discontinue any exercise that causes pain, weakness or muscle fatigue;
- Pay attention to your body's signals, especially pain. Think about what you can do to modify activities that preceded the onset of pain: Pacing yourself is one way to manage many post-polio symptoms;

Plan your daily and weekly activities. Consider when the best time of day is for each activity;

- Prioritize your activities in order of their importance to you- You might begin by making two lists: 'Ten Things I Love to Do, and Ten Things i must DO.' Then, take a hard look at both lists and try to prioritize your activities so that items on both lists receive a fair share of your time and energy.
- Take time to rest; it is the best known treatment for aching, tired muscles. You will probably do better to rest systematically at a certain time each day before you become tired;
- Proper body positioning saves energy, How you position your body while you sit and sleep is especially important for people with muscle weakness and\or joint Physical therapists are good consultants to help you manage body position problems;
- Avoid gaining weight, lose weight if necessary; losing weight decreases and relieves the everyday stress on overworked muscles.
- Remember that asking for help is not a sign of giving in, but part of choosing how to budget your resources of time and energy.