

90

THE LATE EFFECTS OF POLIO

An Overview

INTERNATIONAL POLIO NETWORK

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As the first step in prevention and management ...

- Polio survivors should undergo a complete general medical evaluation by a primary care physician and a specialized neuromuscular evaluation by a knowledgeable and experienced polio specialist to establish a baseline from which to judge future changes and to develop an appropriate treatment plan. International Polio Network annually publishes a listing of self-identified post-polio clinics and polio knowledgeable health professionals.
- Polio survivors should first and foremost take care of their health by seeking periodic, basic medical attention. Be nutrition-wise, avoid or reverse excessive weight gain, and stop smoking or overindulging in alcohol.
- Polio survivors should listen to their bodies. Avoid activities that cause pain — pain is a warning signal. Avoid unrestrained use of pain killers, especially narcotics. Do not overuse muscles but do continue activity that does not worsen the symptoms. In particular, do not overexercise or continue to exercise through pain. Avoid activity that causes fatigue lasting more than 10 minutes.
- Polio survivors experiencing symptoms should pace themselves in their daily activities, resting when tired. Stop for a 15- to 30-minute rest when needed, perhaps several times a day. Management may include the increased use of assistive devices. A change of equipment or new bracing may be recommended.
- Polio survivors should educate themselves. International Polio Network, through its conferences and publications, *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*, and *Polio Network News*, provides accurate and updated information. Polio survivors can benefit from the support and knowledge of other polio survivors. The *Post-Polio Directory* lists over 300 independent support groups worldwide.

INTERNATIONAL POLIO NETWORK is a consumer-based, non-profit network coordinated by Gazette International Networking Institute (G.I.N.I.) whose principal goal is to provide accurate and updated information about the late effects of polio. G.I.N.I., founded by Gini Laurie, has a history of networking which can be traced back to 1958 and has earned it the moniker of the "glue that holds the polio survivors of the world together." G.I.N.I. also publishes *I.V.U.N. News* for ventilator users and *Rehabilitation Gazette*.

International Polio Network publishes:

- *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors* covering the basic information about the late effects of polio (\$6.75 postpaid).
- *Polio Network News*, a quarterly newsletter keeping survivors and network informed about issues related to polio and its late effects, recommended for all polio survivors (USA \$16; Canada/Mexico Overseas Surface \$21; Overseas Air \$25). A sample copy is available upon request.
- *Post-Polio Directory* listing self-identified clinics, health professionals and self-help groups, published March of each year (USA \$4; Canada/Mexico Overseas Surface \$6; Overseas Air \$6).

Questions are welcomed.

The diagnosis is one of exclusion.

A definitive test is not yet available. Some of the confusion and doubt among polio survivors, health professionals, and family members is due to the lack of common understanding of terminology. It is helpful to think of post-polio problems in the following categories, remembering that the groupings are not distinct but parts of a continuum.

The largest and most inclusive category is called **late effects of polio or polio sequelae** and defined as specific new health problems which result from polio-caused chronic impairments, e.g., degenerative arthritis of overused joints, carpal tunnel syndrome and other repetitive motion problems, tendinitis, bursitis, failing joint fusions, overstressed joints due to compensatory body mechanics.

Post-polio syndrome is a sub-category of the late effects of polio and is defined as the symptom cluster of new muscle weakness, fatigue, and pain resulting in a decline in functional ability and/or a new disability. Most clinicians use the following criteria to diagnose post-polio syndrome:

- Confirmed history of acute paralytic polio. Many clinicians perform an electromyogram (EMG) to document changes compatible with prior polio.
- Recovery followed by years of stability between onset of polio and onset of new problems which may include: gradual or abrupt onset of weakness in affected, and/or seemingly unaffected muscles, which may or may not be accompanied by excessive fatigue, muscle and/or joint pains, decreased endurance and function, and muscle atrophy.
- Other conditions that might cause the problems listed above must be excluded.

A sub-category of post-polio syndrome is **post-polio progressive muscular atrophy** and is defined as progressive new weakness and atrophy in muscles with clinical or subclinical signs of chronic partial denervation/reinnervation compatible with previous acute polio.

Polio survivors may experience one or more of the problems described above and should not become unnecessarily concerned about the label for their symptoms.

Polio survivors may experience the same health difficulties as the general population some with symptoms mimicking post-polio syndrome, some magnified due to neurological damage from former acute polio.

The current consensus explaining post-polio symptoms focuses on the nerve cells and their corresponding muscle fibers. When the poliovirus destroyed or injured motor neurons, muscle fibers were orphaned and paralysis resulted. Polio survivors who regained movement did so because nerve cells recovered to a certain extent. Further recovery is attributed to the ability of non-affected neighboring nerve cells to "sprout" and reconnect to the orphaned muscles. Survivors living for years with this restructured neuromuscular system are now experiencing the consequences — overworked surviving nerve cells and overworked muscles and joints, compounded by the effects of growing older. While the search for a viral cause continues, there is no conclusive evidence to support the concept that post-polio syndrome is a reinfection of the poliovirus.

Poliomyelitis (infantile paralysis) has been eradicated from nearly every country in the world since the development of the Salk (1955) and Sabin (1961) vaccines. In 1995, 6197 cases of polio were reported worldwide. The World Health Organization (WHO) estimates there are ten times as many cases of paralytic poliomyelitis as reports received, due to incomplete reporting especially in developing countries. WHO has targeted the year 2000 for the complete eradication of acute poliomyelitis.

The WHO estimates there are 12 million people worldwide with some degree of disability caused by poliomyelitis. A 1987 National Center for Health Statistics survey reported over one million survivors in the United States. About 640,000 of them reported paralysis resulting in some form of impairment. For years most of these polio survivors lived active lives, their memory of polio long forgotten, their health status stable.

By the late '70s, polio survivors were noting new problems of fatigue, pain, and additional weakness. By the mid '80s, health professionals and policymakers recognized these new problems as being real and not "only in the patients' minds." Studies on this phenomenon called "post-polio syndrome" have been — and are still being — conducted in research institutions and medical centers.

Symptoms can include:

- Unaccustomed fatigue — either rapid muscle tiring or feeling of total body exhaustion.
- New weakness in muscles, both those originally affected and those seemingly unaffected.
- Pain in muscles and/or joints.
- Sleeping problems.
- Breathing difficulties.
- Swallowing problems.
- Decreased ability to tolerate cold temperatures.
- Decline in ability to conduct customary daily activities such as walking, bathing, etc.

These general symptoms are experienced in varying degrees, and their progression can be insidious. They should not be dismissed simply as signs of aging alone. Current research indicates that the length of time one has lived with the residuals of polio is as much of a risk factor as chronological age. It also appears that individuals who experienced the most severe original paralysis with the greatest functional recovery are having more problems now than others with less severe original involvement.