

# Disability Issues

formerly Together

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## The Late Effects of Polio: They are Real & There is Help

by Joan L. Headley

**A**s everyone grows old it is natural that physical limitations increase. With polios, the limitations come much earlier and, in these days, it is necessary to cope to the best of our ability and without much assistance from the 'medical profession.'

*"During the last few years, I find myself being able to do less and less and tire far too easily. I would, therefore, like to suggest that readers of **Rehabilitation Gazette**, which seems to be the last polio link, submit names of doctors they know in their home town who can easily relate medical problems to polio problems."*

Larry Schneider in *Rehabilitation Gazette* (Volume 22, 1979)

Gini Laurie, founder of Gazette International Networking Institute (GINI), responded to the polio survivor's plea and gathered together polio survivors, ventilator users, policymakers, physicians, and representatives from industry to explore the needs of aging polio survivors. This successful 1981 Chicago meeting was the catalyst for the expansion of the educational efforts of the nationwide and worldwide network now known as International Polio Network (IPN).

### Poliomyelitis Today

Poliomyelitis (infantile paralysis) has been eradicated from nearly every country in the world since the approval for use of the Salk (1955) and Sabin (1962) vaccines. In 1997, 5,185 cases of polio were reported worldwide; in 1998, 5,867. The increase in the number of cases is due to improved surveillance and reporting techniques. The World Health Organization (WHO) estimates that there are five to six times as many para-

lytic cases as reports received. Nevertheless, WHO has targeted the year 2000 for the complete eradication of acute poliomyelitis.

WHO estimates there are 12 million people worldwide with some degree of disability caused by poliomyelitis. A 1994 National Center for Health Statistics survey reported a preliminary estimate of one million survivors in the United States. About 33,000 of them reported paralysis resulting in some form of impairment.

### Survivors of Poliomyelitis May Experience Symptoms that 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.

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## Help for the Homebound

by Raymond E. Glazier, Ph.D.

When we think "homebound," chances are we visualize a frail elderly person, or at least someone with severe physical limitations. Yet there are thousands of people in Massachusetts alone who are unable to venture out of the house due to agoraphobia (an abnormal fear of having a severe panic attack in public or private areas), post-traumatic stress disorder, panic disorders, or other equally limiting psychiatric impairments like depression. For these persons, their "house arrest" is as real as if the door were padlocked or they were chained inside.

Phobics United Foundation (PUF) is a statewide non-profit organization founded by Joyce Caggiano Hamilton in 1996 to serve the many needs of its otherwise largely unserved or underserved consumer base; there are more than 3,500 citizens of Massachusetts whose psychiatric or physical state restricts them to home. Despite its acronym, PUF is no cream puff, but a working organization that stocks a food bank, staffs a crisis phone line, and maintains an in-

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# Late Effects of Polio

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-- 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 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.

## The Diagnosis of Post-Polio Syndrome 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 is 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**, a subcategory of the late effects of polio, is defined as a neurologic disorder characterized by increased weakness and/or abnormal muscle fatiguability (decreased endurance). The cluster of symptoms includes new weakness, intense fatigue, and pain in muscles and joints resulting in decreased endurance and diminished function. Most clinicians use the following criteria to diagnose post-polio syndrome.

-- Confirmed history of acute paralytic polio. Some clinicians perform an electromyogram (EMG) to document changes compatible with prior polio.

-- Recovery followed by 15 years or more of stability preceding the gradual or abrupt onset of new weakness and/or abnormal muscle fatiguability, with or without generalized fatigue, muscle atrophy, and/or pain.

-- Other conditions that might cause the problems listed above must be excluded.

To distinguish new, slowly progressive muscle weakness that is neurologic in origin from that which is due to musculoskeletal and/or wear and tear problems, researchers coined the phrase **Progressive Post-Polio Muscular Atrophy (PPMA)**, defined as progressive new weakness and atrophy in muscles with clinical or subclinical signs of chronic partial denervation/reinnervation compatible with previous acute poliomyelitis. The term is used less often today, giving way to post-polio syndrome.

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, of course, experience the same

health difficulties as everyone else, some with symptoms mimicking post-polio syndrome, some magnified due to neurologic damage from former acute polio.

## As the First Step in 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.

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 over-indulging 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 over exercise or continue to exercise through pain. Avoid activity that causes fatigue lasting more than ten 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, their families, and if need be, their health professionals.

The IPN will gather once again  
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in Saint Louis, June 8-10, 2000 for GINI's Eighth International Post-Polio and Independent Living Conference. For details, contact GINI, 4207 Lindell Blvd., #110, Saint Louis, Missouri, 63108, or telephone (314) 534-0475, (314) 534-5070 fax, e-mail [gini\\_intl@msn.com](mailto:gini_intl@msn.com), or the web site [www.post-polio.org](http://www.post-polio.org).

## Resources

The following publications are available, as noted, from GINI at the above address:

**Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors** (ISBN 0-931301-04-1 pbk), revised in 1999, is a 120-page book in dictionary format containing 90 entries which are a compilation of the research and experience of more than 40 experts. Edited by Frederick M. Maynard, MD and Joan L. Headley, MS.

For 1-5 copies: \$15 each, plus total s&h of \$3.50 in USA; plus total s&h of \$4.50 outside USA (Contact IPN for bulk order pricing.)

**Polio Network News** (ISSN 1066-5331), the quarterly newsletter of International Polio Network, contains current information about the late effects of polio, encourages research, and promotes networking among the post-polio community worldwide. Published quarterly in February, May, August, November. Edited by Joan L. Headley.

Subscriptions: USA \$20; Canada/Mexico & Overseas surface \$25; Overseas air \$30. (Four most recent issues - USA \$20, Overseas surface \$250).

**IVUN News** (ISSN 1066-534X), the quarterly newsletter of International Ventilator Users Network, links ventilator users, their families, and peers with each other and with health professionals committed to home mechanical ventilation. Published quarterly in March, June, September, December. Edited by Judith Raymond Fischer.

Subscriptions: USA \$17; Canada/Mexico & Overseas surface \$22; Overseas air \$27. (Four most recent issues - USA \$17, Overseas surface \$22).

**Rehabilitation Gazette** (ISSN 0361-4166), an update on disability issues, publications, resources, equipment, conferences, GINI activities, and other information useful in living independently. Published bi-annually in January and July. Edited by Joan L. Headley.

Subscriptions: USA \$12; Canada/Mexico & Overseas surface \$14; Overseas air \$16.

## Massachusetts Support Groups

Shirley Nisbet  
The Cape Cod Support Group  
North Falmouth, MA 02556  
(508) 564-4957  
(508) 564-4958 (fax)

Elaine Burns  
Greater Boston Post-Polio Assn.  
Wellesley, MA 02482  
(781) 596-8245  
*meets Saturday, Quarterly*

Carroll Dwyer, III  
Post-Polio Information Connection  
Springfield, MA 01108  
(413) 732-4895

The following Directories are also available:

**Post-Polio Directory** lists self-identified clinics, health professionals, and support groups knowledgeable about the late effects of polio. The *Directory* contains over 500 entries including an international section.

Published annually in March.  
USA \$5; Canada/Mexico/Overseas surface \$6; Overseas air \$7

**IVUN Resource Directory** is an excellent networking tool for health professionals and both long-term and new ventilator users. Sections include health professionals, ventilator users, equipment and mask manufacturers, service and repair, organizations, etc. Compiled by Judith Raymond Fischer. Published annually in October.

USA \$5; Canada/Mexico/Overseas surface \$6; Overseas air \$7

Joan L. Headley is Executive Director of Gazette International Networking Institute (GINI) in St. Louis, MO.



The National Mobility Equipment Dealer's Association (NMEDA), the trade organization for vehicle conversion dealers, has recently released their new logo. They say it "represents a fresh, positive, image for our association and....conveys a sense of freedom and independence." We thought you might like to see it.

For information on NMEDA, contact them at 909 E. Skagway Avenue, Tampa, FL 33604, or (800) 833-0427.