Polio and Post-Polio Syndrome

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.

The World Health Organization (WHO) estimates there are 12 million people worldwide with some degree of disability caused by poliomyelitis. The National Center for Health Statistics estimates there are one million polio survivors in the United States. About 433,000 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 1970s, polio survivors were noting new problems of fatigue, pain, breathing or swallowing problems, and additional weakness – medical professionals called this the "post-polio syndrome (PPS)."

Some people experience PPS-related fatigue as a flu-like exhaustion that worsens as the day progresses. This type of fatigue can also increase during physical activity, and may cause difficulty with concentration and memory. Others experience muscle fatigue, a form of muscle weakness that increases with exercise and improves with rest.

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.

The current consensus of opinion 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.
Polio survivors take care of their health by seeking periodic medical attention, by being nutrition-wise, avoiding excessive weight gain, and by stopping smoking or over-indulging in alcohol.

Survivors should listen to their bodies. Avoid activities that cause pain – this is a warning signal. Avoid un-restrained use of painkillers, 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 ten minutes. Conserve energy be avoiding tasks that are nonessential.

PPS is not typically a life-threatening condition, but it may cause significant discomfort and disability. The most common disability caused by PPS is deterioration of mobility. People with PPS may also experience difficulties performing daily activities such as cooking, cleaning, shopping, and driving. Assistive devices such as canes, crutches, walkers, wheelchairs, or electric scooters may be necessary for some people. If symptoms are extremely severe, these individuals may be required to change occupations or stop working altogether.

Many individuals have difficulties adjusting to new disabilities. For some with PPS, reliving their childhood experiences with polio can be a traumatic and even terrifying experience. Fortunately, PPS is gaining increasing attention in the medical community, and there is a growing number of health care professionals who understand PPS and can provide appropriate medical and psychological help. In addition, there are PPS support groups, newsletters, and educational networks that provide up-to-date information about PPS while offering individuals the knowledge that they are not alone in their struggle.

Sources: International Polio Network, Montreal Neurological Hospital Post-Polio Clinic


Web Sites

http://www.post-polio.org/
Post-Polio Health International (formerly GINI)
50 Crestwood Executive Center #440
Saint Louis, MO 63126-1916
Phone: 314-534-0475
E-mail: info@post-polio.org
PHI offers information for polio survivors and promotes networking among the post-polio community. The organization publishes the quarterly Polio Network News and The Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors.

http://www.post-polio.org/net/PDIR.pdf
Post-Polio Health International: Post-Polio Directory 2020
The Post-Polio Directory 2016 lists clinics, physicians, support groups and associations which specialize in post-polio syndrome around the world. It can be downloaded; print copies are available for $12.

http://www.ventusers.org/net/vdirhm.html
This directory lists resources for equipment, health care, long-term care, networking, and more.

https://www.cdc.gov/polio/
Centers for Disease Control and Prevention: Polio

http://www.polioplace.org
Polio Place
This service of Post-Polio Health International has a lot of information on the history of the disease and survivors’ stories.

http://www.polioquebec.org
Polio Quebec Association
3500, Decarie Boulevard
Bureau 219A
Montreal, Quebec H4A 3J5
Canada
Phone: 514-489-1143, 877-765-4672 (Toll-free)
E-mail: association@polioquebec.org
Polio Quebec Association provides information and services to people affected by polio and post-polio syndrome.

http://www.postpolioinfo.com/centre.php
International Centre for Post-Polio Education and Research
Harvest Center
151 Prospect Ave, Suite 17A
Hackensack, NJ 07601
The International Centre for Polio Education conducts PPS research and education.

http://www.skally.net/ppsc/
Post-Polio Syndrome Central (PPSC)
PPSC has extensive links to resources for information and support, including e-mail discussion lists and newsgroups.

http://www.americanhistory.si.edu/polio
Smithsonian National Museum of American History: Whatever Happened to Polio?
This site is related to an exhibition that opened on April 12, 2005, to mark the fiftieth anniversary of the announcement that Dr. Jonas Salk’s polio vaccine was safe and effective, and closed on September 4, 2006. It includes historical photos, a timeline, and information on polio, its eradication in the U.S., its legacy on disability rights and medical research, and current efforts to fight the disease.

Medscape: Postpolio Syndrome
This page has clinical information on post-polio syndrome.


National Center on Health, Physical Activity and Disability: Post Poliomyelitis
NCHPAD
4000 Ridgeway Drive
Birmingham, AL 35209
Phone: 800-900-8086 (Toll-free voice and TTY)
E-mail: email@ncpad.org
This fact sheet has recommendations for cardiovascular and strength training for people with post-polio syndrome.


National Center on Health, Physical Activity and Disability: To Reap the Rewards of Post-Polio Exercise
This fact sheet has recommendations for people with post-polio syndrome who want to start exercise programs.

https://www.ninds.nih.gov/Disorders/All-Disorders/Post-Polio-Syndrome-Information-Page

National Institute of Neurological Disorders and Stroke (NINDS): Post-Polio Syndrome Information Page
This page has information on treatment, prognosis, and research.

https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Post-Polio-Syndrome-Fact-Sheet

National Institute of Neurological Disorders and Stroke (NINDS): Post-Polio Syndrome Fact Sheet
This fact sheet has information on diagnosis, treatment, and exercise.


National Institute of Neurological Disorders and Stroke (NINDS): Post-Polio Syndrome booklet

http://www.polioeradication.org/

Global Polio Eradication Initiative
The Global Polio Eradication Initiative is a public-private partnership led by national governments and spearheaded by the World Health Organization (WHO), Rotary International, the US Centers for Disease Control and Prevention (CDC), and the United Nations Children’s Fund (UNICEF). Its goal is to eradicate polio worldwide.

www.poliowarriors.org

World-Wide Fellowship of Polio Warriors
11 Windmill Court
East Wittering, Chichester
West Sussex
UK PO20 8RJ
A not-for-profit charity registered in England and Wales that offers direct links to useful resources including world maps of the locations of polio survivors, support groups, and medical professionals experienced in post-polio syndrome.

Internet Discussion Groups

http://www.skally.net/ppmed/
Post-Polio Med Web Pages
Post-Polio-Med is a forum for questions and answers to and from post-polio syndrome researchers, physicians and other post-polio syndrome medical professionals, polio survivors, family, friends, students and others who are interested in post-polio syndrome. This includes, but is not limited to: questions, answers and information about post-polio syndrome research, clinical issues, clinical trials, current treatment practices and support group meetings and information.

http://groups.yahoo.com/group/postpolio/
Yahoo! Groups: Post-Polio
Post-polio is a HealthShare International Support Network community for individuals affected by post-polio syndrome.

Newsletters

http://www.post-polio.org/edu/pphnews/index.html
Post-Polio Health
This newsletter is published quarterly by Post-Polio Health International.

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