



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 by 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

The above excerpt is from the Christopher & Dana Reeve Foundation Paralysis Resource Center website. <https://www.christopherreeve.org/living-with-paralysis/health/causes-of-paralysis/post-polio-syndrome-poliomyelitis>

Web Sites

Post-Polio Health International (formerly GINI)

<http://www.post-polio.org/>

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*.

Post-Polio Health International: Post-Polio Resource Locator

<https://post-polio.org/networking/directory/>

The Post-Polio Resource Locator is in map format and you can search it by category such as clinics, physicians, support groups and associations which specialize in post-polio syndrome around the world.

International Ventilator Users Network: Resource Directory for Ventilator-Assisted Living

<https://www.ventnews.org/>

This directory lists resources for equipment, health care, long-term care, networking, and more.

https://06081135-7570-4e39-a49e-ae9bc019b264.filesusr.com/ugd/fef361_7e10e6d897304271bad4cb4b3ac7fc16.pdf for 2020 Directory.

Centers for Disease Control and Prevention: Polio

<https://www.cdc.gov/polio/>

Polio Place

<http://www.polioplace.org>

This service of Post-Polio Health International has a lot of information on the history of the disease and survivors' stories.

Polio Quebec Association

<http://www.polioquebec.org>

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.

International Centre for Post-Polio Education and Research

<http://www.postpolioinfo.com/centre.php>

Harvest Center

151 Prospect Ave, Suite 17A

Hackensack, NJ 07601

The International Centre for Polio Education conducts PPS research and education.

Post-Polio Syndrome Central (PPSC)

<http://www.skally.net/ppsc/>

PPSC has extensive links to resources for information and support, including e-mail discussion lists and newsgroups.

Smithsonian National Museum of American History: Whatever Happened to Polio?

<http://www.americanhistory.si.edu/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

<http://emedicine.medscape.com/article/306920-overview>

This page has clinical information on post-polio syndrome.

National Center on Health, Physical Activity and Disability: Post Poliomyelitis

http://www.nchpad.org/disability/fact_sheet.php?sheet=63&view=all

NCHPAD

4000 Ridgeway Drive

Birmingham, AL 35209

Phone: 800-900-8086 (Toll-free voice and TTY)

E-mail: email@nchpad.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

http://www.nchpad.org/disability/fact_sheet.php?sheet=136

This fact sheet has recommendations for people with post-polio syndrome who want to start exercise programs.

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

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

This page has information on treatment, prognosis, and research.

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

<https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/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

<https://catalog.ninds.nih.gov/pubstatic//12-4030/12-4030.pdf>

Global Polio Eradication Initiative

<http://www.polioeradication.org/>

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.

Internet Discussion Groups

Post-Polio Med Web Pages

<http://www.skally.net/ppmed/>

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.

Newsletters

Post-Polio Health Newsletter

<https://post-polio.org/education/post-polio-health-newsletter/>

This newsletter is published quarterly by Post-Polio Health International.

The information contained in this message is presented for the purpose of educating and informing you about paralysis and its effects. Nothing contained in this message should be construed nor is intended to be used for medical diagnosis or treatment. It should not be used in place of the advice of your physician or other qualified health care provider. Should you have any health care related questions, please call or see your physician or other qualified health care provider promptly. Always consult with your physician or other qualified health care provider before embarking on a new treatment, diet or fitness program. You should never disregard medical advice or delay in seeking it because of something you have read in this message.

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