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)
4207 Lindell Boulevard #110
Saint Louis, MO 63108-2930
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 2012
The Post-Polio Directory 2012 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.

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
Office 263
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
Dr. Bruno’s Post-Polio Website
This site from Dr. Richard L. Bruno has information on post-polio sequelae and links to books and articles by Dr. Bruno, including one on applying for Social Security Disability benefits.

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
Brimingham, 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.

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

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

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.

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.

REEVE FOUNDATION
LENDING LIBRARY

The following books and videos are available for free loan from the PRC library. For more information, please visit the online catalog at:
http://www1.youseemore.com/ReevePRC/default.asp

Books

  Written for children.

  A biography of Higgins who was a ballerina until polio left her in an iron lung. She
  became a mouth painter and ballet choreographer.

  A biography of her husband Bob’s bout with polio while an Army Captain.

  Children’s fiction. Danny, recovering from polio in the 1940s, focuses on training a mustang named Little Billy.

  Baker wrote the book to explain to her grandchildren what PPS is.

  Autobiography.

• Banister, Betty. **Trapped: A Polio Victim’s Fight for Life.** Saskatoon, Saskatchewan, Canada: Western Producer Prairie Books, 1975.


• Beisser, Arnold, Dr. **Flying Without Wings: Personal Reflections on Loss, Disability, and Healing.** New York: Bantam Books, 1990.  
  Beisser contracted polio at the age of 24 after just completing a medical degree and becoming a nationally ranked tennis player.

• Berg, Elizabeth. **We Are All Welcome Here: A Novel.** New York: Random House, 2006.  
  Fiction. The main character’s mother has polio and is a vent user.

• Black, Kathryn. **In the Shadow of Polio: A Personal and Social History.** Reading, MA: Addison-Wesley, 1996.  
  Black’s mother was stricken with polio in 1954.


  For very young children. Olympic track star Wilma Rudolph had polio as a child.


• Christianson, Linda L. **All the Steps I Have Taken Then and Now.** Bloomington, Ind.: Inspiring Voices, 2012. Christianson was diagnosed with polio as a six-month old.

• Clarke, Joan. **All on One Good Dancing Leg.** Sydney, NSW, Australia: Hale & Iremonger, 1994. Autobiography of Australian Clarke.


For grade school children.


  A collection of his essays and writings. The author recounts his bout with polio.

  Gallagher documents President Roosevelt’s polio and his efforts to minimize its effects in public.


  Biography of growing up poor and with polio in New York City in the 1920s and 30s.

  Mariel tries to learn the truth about her past which includes a bout with polio. Fiction.


  A children’s biography of the German toy maker, who contracted polio at 18 months, whose company became famous for its teddy bears.


  A historical account of polio in the U.S.

  A biography of Hall.


  Tommy makes friends with a wheelchair user named William. They try to raise money to buy a wheelchair for an African boy with polio.


  A polio survivor since the age of nine, McPherson has served on the Canadian Premier’s Council on the Status of Persons with Disabilities.

  Children’s book.

  Hawksford is a nurse who recalls her brother’s polio.

• Higgins, Elizabeth Twistingon. **Still Life: The Story of a Struggle with Disablement.**
  Higgins’ autobiography details her career as a ballerina and then her life in an iron lung
  after she contracted polio.

  Paralyzed at two, Hogans developed her relationship with God.

• Hostetter, Joyce Moyer. **Blue.**
  Fiction.

• Hostetter, Joyce Moyer. **Comfort.**
  Honesdale, PA: Calkins Creek, 2009.
  Fiction

• Houck, Davis W. and Amos Kiewe. **FDR’s Body Politics: The Rhetoric of Disability.**
  College Station, TX: Texas A&M University Press, 2003.

• Irvin, Cass. **Home Bound: Growing Up with a Disability in America.**

• Johnston, Julie. **Hero of Lesser Causes.**
  Keely is devastated when her older brother Patrick is paralyzed by polio and starts a
  campaign to reawaken his waning interest in life.

• Jones, James A. with Peggy L. Jenkins. **Just Another Bump.**
  Jones contracted polio at the age of four and later became a pastor.

• Kane, William J. **Let Yourself Be Loved: The Life and Letters of Will Jenks.**
  Jenks became a quadriplegic as a result of polio in 1951.

• Kehret, Peg. **Small Steps: The Year I Got Polio.**
  Kehret’s account of contracting polio at the age of 12.

• Kloeppping, Kent. **The Upside of the Downside: Journeys with a Companion Called Polio.**

• Kluger, Jeffrey. **Splendid Solution: Jonas Salk and the Conquest of Polio.**

• Kluger, Jeffrey. **Splendid Solution: Jonas Salk and the Conquest of Polio.**
  Tantor, 2005.
  Read by Michael Prichard. Unabridged **audiobook.**  11 audio CDs.
  Essays on life growing up with polio.

• Kriegel, Leonard. *Flying Solo: Reimagining Manhood, Courage, and Loss*. Boston: 
  Kriegel writes about life as a man who lost the use of his legs to polio.

• Krohn, Katherine. *Jonas Salk and the Polio Vaccine*. Mankato, Minn.: Capstone Press, 
  2007. 
  In graphic novel format (comic book style), it tells the story of Jonas Salk’s development of 
  the polio vaccine.

• Krull, Kathleen. *Wilma Unlimited: How Wilma Rudolph Became the World’s Fastest 
  Children’s book about Olympian Wilma Rudolph who had polio as a child.

• Lake, Louise. *Each Day a Bonus: Twenty-five Courageous Years in a Wheelchair*. 

• Lawrence, Marjorie. *Interrupted Melody: The Story of My Life*. New York: Appleton 
  Century Crofts, 1949. 
  Autobiography of opera singer.

• Leff, Wenzel A. *Traveling Without a Spare: A Survivor’s Guide to Navigating the 
  Dr. Leff lends his professional expertise as a physician to his personal experience of 
  being a polio survivor in this book.

• Levy, Chava Willig. *A Life Not With Standing*. North Charleston, SC: CreateSpace, 
  2013. 
  A biography that chronicles polio.

• Lindell, John Earl and Ethel Brooks Lindell. *Oh God, Help Me! For I Cannot Help 
  Myself: A True Story of Faith in the Life of a Polio Survivor*. 1988. Published by the authors.


• Mason, Martha. *Breath: Life in the Rhythm of an Iron Lung—A Memoir*. Asheboro, 

• Mason, Mary Grimley. *Life Prints: A Memoir of Healing and Discovery*. New York: 
  Mason was the nation’s first poster child for polio. She became a scholar specializing in 
  women’s autobiography.


  Written for children


  There is a video of the same name.


  Fiction


  Phelan’s biography of life with polio.

  A collection of essays.

• Presley, Gary. **Seven Wheelchairs: A Life Beyond Polio**. Iowa City, IA:: University of Iowa Press, 2008.
  Biography.


The true story of a camp turned into an emergency polio hospital in 1944 in Hickory, North Carolina.


Fiction. Pablito contracted polio when he was seven and lived in Puerto Rico. He has an operation to help him walk again.


Autobiography of a British polio survivor.


Fiction for children.


Wieler became an attorney after contracting polio in 1955 as a teenager.
• Williams, Daniel R. **Keep Smiling and Never Give Up!** Bloomington, IN: 1st Books Library, 2002. Biography of a person who survived polio for 44 years. He was married and the father of one child.


• Wilson, Daniel, J. **Polio (Biographies of Disease).** Santa Barbara, CA: ABC-CLIO, 2009.


• Youdath, Raymond. **50 Years of Miracles and Adventures.** Baltimore: PublishAmerica, 2006.

**Videos**


• **Coming to Terms.** New York: Cinema Guild. 1990 (57 minutes) Profiles writer Hugh Gallagher.

• **The Doctor Is In…Polio and Postpolio Syndrome.** Princeton, NJ: Films for the Humanities and Sciences, 1993. (28 minutes)

• **Eleanor and Franklin: Double Feature The Early Years and The White House Years.** HBO, 1997. 2-disc set DVD. (204 minutes and 156 minutes)

• **FDR: American Experience.** PBS Home Video, 2006, 1994. 2-disc set DVD.


• **The Final Inch: In the Fight to Eliminate Polio, the Last Step is the Biggest.** HBO. DVD
  Consists of 2 films: Unconditional Surrender (1956) shows the production of the polio
  vaccine and the history of polio. Babies and Breadwinners (1961) shows the polio
  vaccination program in Columbus Ohio.

• **Horace Parlan by Horace Parlan.** Chatsworth, CA: Image Entertainment, 2000. DVD.
  (58 minutes)
  Parlan is a jazz musician whose childhood polio restricts the use of his right side.

• **Hyde Park on Hudson.** Universal, 2013. DVD (95 minutes)
  Bill Murray stars as FDR.

• **In Search of the Polio Vaccine.** A&E Television Networks, Inc. DVD. (50 minutes)
  Modern Marvels series: The History Channel.

• **Interrupted Melody.** Santa Monica, CA: Turner Entertainment Company, 1955. (106
  minutes)
  Dramatization of opera singer Marjorie Lawrence’s life.

• **Just the Way You Are.** MGM, 1981. VHS (96 minutes)
  A romantic comedy that stars Kristy McNichol as a person with polio who uses a leg
  brace.

• **The Last Child: The Global Race to End Polio.** Oley, PA: Bull Frog Films, 2004.DVD
  and VHS. (56 minutes)

• **The Life and Times of Frida Kahlo.** Daylight Films, Distributed by PBS, 2004. DVD
  (90 minutes)

• **Modern Marvels: Polio Vaccine.** The History Channel. New York: A&E Television,
  1997. (50 minutes)

• **A Paralyzing Fear: The Story of Polio in America.** PBS Home Video, 1998. DVD (89
  minutes)

• **Polio and Post-Polio Syndrome.** Princeton, NJ: Films for the Humanities, 2003. DVD

• **The Polio Crusade.** PBS Home Video, 2009. DVD (60 minutes)

• **Post Polio Water Work.** 2005. DVD.
  The video can be ordered from [www.maryessert.com](http://www.maryessert.com)

• **Ride a Wild Pony.** Walt Disney Home Video. VHS. (86 minutes)
  Drama. The character of the little girl featured is a polio survivor.
• **The Science of Hope: Jonas Salk.** Princeton, NJ: Films for the Humanities and Sciences, 1994. DVD (30 minutes)

• **Sister Kenny.** Turner Entertainment, 2015. DVD (116 minutes)
  1946 film about a nurse in the Australian bush who follows her instincts to treat children with polio.

• **A Very Long Engagement.** Warner Brothers. DVD. (133 minutes)
  The main character has polio and at times uses a wheelchair. In French with English subtitles.

• **Warm Springs.** HBO Films 2005. DVD. (120 minutes)
  Stars Kenneth Branagh as FDR and Cynthia Nixon as Eleanor Roosevelt.

• **Wilma: The True Story of One of America's Greatest Olympic Athletes.** S'More Entertainment, 1997. DVD (147 minutes)
  Wilma Rudolph had polio as a child.

• **A World Without Polio.** Princeton, NJ: Films for the Humanities & Sciences, 2005. DVD and VHS. (54 minutes)

• **Young Lovers.** Reel Enterprises, 2007. DVD (82 minutes)
  Drama. 1949 film about talented and beautiful Carol Williams who is devastated when she learns she has polio. She breaks her engagement to her fiancé and dance partner but he is determined to stay by her side. She eventually is able to bring herself to participate in life again.

**Audio CDs**

- **Remembering Polio.** Canadian Broadcasting Corp. 2007 (2 hrs.) 2 audio CDs CD One: The Epidemics of the 1950s. CD Two: The Aftermath.
  Documentary on the history of polio in Canada.

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