



# **Post-Polio Canada**

## **Information Package**

## Table of Contents

<b>1</b>	<b>What is Post-Polio Canada®?</b>
<b>2</b>	<b>Peer Support Groups</b>
<b>3</b>	<b>Self Management of Post-Polio Syndrome</b>
<b>4</b>	<b>The History of Polio in Canada</b>
<b>5</b>	<b>What is Post-Polio Syndrome?</b>
<b>6</b>	<b>Living with Post-Polio Syndrome</b>
<b>7</b>	<b>Pacing and a Balanced Lifestyle</b>
<b>8</b>	<b>Surgery and Post-Polio Syndrome</b>
<b>9</b>	<b>Intimacy and Post-Polio Syndrome</b>
<b>10</b>	<b>Resources and Links</b>

Post-Polio Canada Email Address: [polio@marchofdimes.ca](mailto:polio@marchofdimes.ca)

202-885 Don Mills Road  
Toronto, ON, M3C 1V9

## What is Post-Polio Canada?

Our program links polio survivors and their family members to **peer support groups virtually or in the community**, offering **education, information and hope**. We provide Canadians with the resources needed to live more fully with post-polio syndrome.

### What is a Peer Support group?

Peer support groups give polio survivors, their families, friends and caregivers the opportunity to share their personal stories, struggles and triumphs they experience as polio survivors.

Peer support groups range in size, purpose, age, settings, and background, and offer a network of support, education and social activities.



### Post-Polio Canada® Services:

Polio survivors and their families have access to:

<p><b>Peer Support Groups</b></p>	<p>Contact us to <b>Join us nationally, virtually on Zoom or find a group in your area</b> or if you are interested in starting your own group.</p>
<p><b>Polio Warmline®</b>  <b>1-888-540-6666</b></p>	<p>A toll-free number that offers information and support for polio survivors and family. It operates Monday to Friday 9:30am to 4:00pm EST.</p> <p>A staff or volunteer will answer with <b>information</b> and help connect the caller with Polio Canada resources.</p>
<p><b>Newsletter</b>  <b>PoliO'Canada</b></p>	<p>This <b>FREE</b> monthly e-newsletter shares survivor stories, services, information and current research relevant to polio. Contact us to <b>join our email list!</b> <a href="mailto:polio@marchofdimes.ca">polio@marchofdimes.ca</a></p>
<p><b>Education and Information Services</b></p>	<p>Members can request and receive valuable <b>information</b> from our website, information packages, research, medical list, polio survivor stories and other events. <a href="http://www.marchofdimes.ca/polio">www.marchofdimes.ca/polio</a></p>

## ***What else does March of Dimes Canada offer for polio survivors?***

Post-Polio Canada® is a program of March of Dimes Canada, a leader in serving people with disabilities. For over 70 years, March of Dimes has been on the forefront of the disability movement, dedicated to helping Canadians with disabilities lead more independent and empowered lives.

### **More March of Dimes services include:**

- Stroke Recovery/After-Stroke Services
- Employment Services
- Home and Vehicle Modification® Program
- Attendant Care Services
- Technology Programs
- Communication Disability One (Aphasia)
- Community Programs

If you would like more information on any of these services, contact:

Post-Polio Canada Email Address: [polio@marchofdimes.ca](mailto:polio@marchofdimes.ca)

202-885 Don Mills Road  
Toronto, ON, M3C 1V9

## Peer Support Groups

### *Connecting polio survivors with each other*

It is estimated that up to 70% of polio survivors may experience the disabling effects of post-polio syndrome 25 to 45 years after their initial infection with the polio virus. There are approximately 125,000 Canadian polio survivors. Many of these polio survivors are members of support groups, ready to share, answer your questions and help alleviate your concerns.

#### ***Why join a peer support group?***

- To talk with other survivors about their stories
- Get emotional support from fellow survivors
- Participate in virtual and local meetings
- Find tips on how to cope day-to-day
- Share personal experiences
- Exchange valuable information about living with disabilities
- Develop new skills
- Make new friends
- Gain an understanding of post-polio syndrome and what to expect
- To provide a way to give back and volunteer



### ***Peer support groups help polio survivors...***

March of Dimes Canada investigated why people with disabilities believe that peer support groups are so important.<sup>i</sup> Below are some of the findings:

#### ■ ***Gain a better understanding of the impact of their disease***

Many survivors find that they did not feel they understood what it meant to acquire a disability or how to live with their disability

#### ■ ***Feel less isolated***

Feelings of isolation can be alleviated once people are connected with others in a similar situation.

*'You find you're not alone. [The group] is an extended family who knows what you're going through.'*

*– Angela, peer support member, 11 years*

### ■ **Overcome depression**

Many people who acquire disabilities experience depression. Support groups play a significant role in helping overcome depression.

*'Being together with such a happy group who had disabilities too helped me keep my spirits up so I don't let myself get down.'*

– Lena, 2 years, peer support member



### ■ **Relate to their peers**

Most survivors find that the experience of speaking with other survivors is vastly different from speaking with their family or friends. Groups provide an open and safe forum for survivors to voice concerns.

*'The [other survivors] speak to me and then they'll really listen. Other people would say 'oh, I can't be bothered'. They are friends because they are always willing to help you.'*

– Lillian, peer support member, 2 years

### ■ **Help others**

Often survivors express gratitude for the contributions their support group has brought to their lives and recovery. They are motivated to stay with the group to give back to others.

*'[The group] gave me strength and I want to give it back. We've all been there, we all understand. We can talk, cry and laugh together --- that's what's important about the group.'*

– Angela, Peer Support group member, 11 years

---

<sup>1</sup> March of Dimes Canada, *Health Recovery Social Networks: Exploring the experiences of participants in peer support groups*, 2009

## Self-Management of your disability

Experiencing symptoms of post-polio syndrome so many years after the affects of the original polio virus can be a difficult journey. Research articles indicate that one of the most important aspects of the maintenance of health in polio survivors is life style modification to adapt to your symptoms. Symptoms may be noticed gradually, and the maintenance of symptoms takes patience, strength and determination. Polio survivors must be **self-managers** of their health and life style.

### ***What is self management?***

You have been given the task of living well as a polio survivor – living well with a chronic (life-long) condition. Self management includes: **medical management; role management; and emotional management**<sup>i</sup>

### ***Components of self-management***

As a survivor, you have many components to contribute to your recovery:

- Problem solving skills
- Goal setting
- Social support
- Emotional health
- Individual assessment
- Links to community resources



### ***How does self management help?***

Self-management is a **decision** you make when faced with a chronic condition, such as post polio syndrome. Some people manage by withdrawing. Others stay in denial of their condition. Still others with similar symptoms somehow take action and manage to get on with their lives. Polio survivors must make the decision to live well and remember, “YOU are the manager”.<sup>ii</sup>

### ***What can you do to help manage your condition?***

- Join a support group
- Register for a self-management course about for chronic disease management
- Learn more about self-management and wellness
- Start setting goals and balancing your lifestyle

## ***Components of Wellbeing***

When thinking about self-management in regards to your health, a holistic, comprehensive approach is necessary. Consider these **six** areas of your health<sup>iii</sup>.

1. **Physical** – taking care of your body through proper nutrition, activity and fitness
2. **Emotional** - becoming aware of how emotions affect your body and recognizing their effects
3. **Intellectual** - examining one's opinions and judgments, and the connections to life
4. **Spiritual** - developing a set of values, principles and beliefs that give a sense of meaning and purpose in life.
5. **Social** - creating and maintaining healthy, satisfying relationships that are mutually loving and supportive.
6. **Environmental** – creating an environment that is conducive to living well



What are you doing in your life to address EACH area of your well-being? Are there some areas that are being neglected? Take some time to really think about which area of your wellness needs some attention.

### ***Resources***

- Living a Healthy Life with Chronic Conditions: Self-Management of heart disease, arthritis, diabetes, asthma, bronchitis, emphysema and others. *Lorig. Kate et al. 2006. Bull Publishing Company*
- Wellness Workbook: How to achieve enduring health and vitality. *Travis, John M.D., Ryan, Regina Sara; 2004, Ten Speed Press*
- Post-Polio Syndrome: A Guide for Polio Survivors and Their Families. *Julie Silver M.D.; 2001, Yale University*

<sup>i</sup> South West Local Health Integration Network, Self Management in Theory and Practice: A guide for health care professionals. 2009

<sup>ii</sup> Lorig et al. *Living a Healthy Life with Chronic Conditions: Self-management of heart disease, arthritis, diabetes, asthma, bronchitis, emphysema and others.* 2006. Bull Publishing Company

<sup>iii</sup> World Health Organization, 2009.



## What is polio?

Poliomyelitis, or polio for short, is a highly infectious **viral disease** that affects men, women, and children of all ages and ethnicities. Polio does tend to affect children more than adults, attacking the body's nervous system. There are three different strains of polio (Types 1, 2 and 3); the disease can lead to muscle paralysis and death in individuals infected by the virus.

### *How is the polio virus spread?*

Polio is spread through person-to-person contact by fecal-oral route, by direct contact with an infected person or by contamination of water, food and hands. The virus can remain alive in the environment for long periods of time and is therefore, considered a very infectious disease.

## The polio epidemic in Canada

During the 1930s, '40s, '50s, North America was devastated by the polio epidemic which caused death and disability in thousands of Canadian families. Thankfully, due in large part to the fundraising efforts by March of Dimes, Dr. Jonas Salk developed the first polio vaccine, which first became available to Canadians in 1955. Currently, there are two forms of vaccination: IPV (inactivated poliovirus containing dead virus and given by injection) vaccine was introduced in 1955 and the OPV (trivalent oral poliovirus vaccine containing live, weakened virus) in 1962.



Canada has been polio-free since 1994, largely due to the large immunization efforts of Health Canada, Pan American Health Organization and the World Health Organization. The last major polio epidemic in Canada was 1959 where over 1887 cases resulted in paralysis with over 190,000 poliovirus infections reported.<sup>i</sup>

Polio vaccination is part of standardized immunization procedures in Canada, and is available to all Canadians.

## ***March of Dimes and the polio epidemic***

Ontario March of Dimes was founded in 1951 to raise funds to eradicate the threat of polio in Canada. It takes its name from one of the best-known fundraising drives in Canadian history – the March of Dimes to end polio.

The Marching Mothers founded our door-to-door campaign, and with the help of this funding, the Salk vaccine was discovered within three years. Desperate to find a cure for polio, mothers across Canada joined a North America-wide fundraising drive towards research. Women canvassed their neighbours carrying pickle jars or canvassing kits. Home welcoming Marching Mothers® turned on their porch lights to signal their support.



Over the years, this simple, community-based process raised millions of dollars for polio research and rehabilitation. Long after the polio vaccine's discovery, women and men continued the annual marches.

With the threat of polio greatly diminished, the March of Dimes in Canada began funding centres for people who had already contracted the disease, and the early programs focused mostly on rehabilitation and job training. The organization continues to serve polio survivors and families through its program Post-Polio Canada®.

By the early 1960s, the organization had grown, with its mandate shifting considerably to serve the broader needs of all adults with physical disabilities, and in Ontario the legal name was changed to the Rehabilitation Foundation for the Disabled.

Today, March of Dimes is dedicated to "creating a society inclusive of people with physical disabilities."<sup>ii</sup>

<sup>i</sup> Public Health Agency of Canada – [www.phac-aspc.gc.ca](http://www.phac-aspc.gc.ca)

<sup>ii</sup> History of March of Dimes – [www.marchofdimes.ca](http://www.marchofdimes.ca)

## What is a post-polio syndrome?

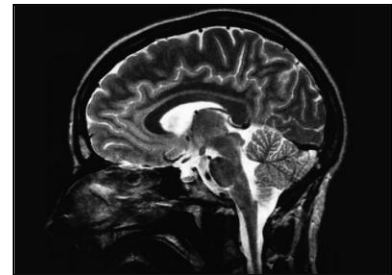
During the epidemic in North America, the polio virus affected thousands of children and adults. The polio virus attacks the nervous system, often causing paralysis and leaving some unable to breathe on their own. Several decades later, after polio survivors had adapted to their physical disabilities, a growing number of survivors began to experience new symptoms.

Post-polio syndrome refers to the new health issues and symptoms affecting individuals who contacted poliomyelitis earlier in their lives.

### ***Symptoms of post-polio syndrome***

**Symptoms may include:**

- New muscle weakness
- New muscle atrophy (decrease in muscle mass)
- Muscle and joint pain
- Increased muscle fatigue
- General fatigue
- Cold intolerance



The symptoms may vary between individuals and often encompasses generalized weakness, muscle and joint pain, and excessive fatigue. Respiratory deficiency, sleeping disorders, and problems swallowing (dysphagia or dysphonia) may also occur.<sup>1</sup>

In addition, emotional difficulties often result from encountering new problems after living so long in a stable condition. Symptoms of psychological stress may result because polio survivors don't know why they are experiencing these new symptoms.

### ***Who is at risk of post-polio syndrome?***

- Polio survivors (especially those who have had paralytic polio)
- People aged 55 and older
- People who were born or lived in a country where a polio epidemic has occurred or continues today
- Anyone who has not received the polio vaccine

## ***Diagnosing post-polio syndrome***

*It is important to note that many health professionals may not be familiar with post polio syndrome. Polio survivors often must act as advocates and bring awareness about post polio syndrome to healthcare professionals.*

To determine if a patient has post-polio syndrome, medical professionals will use a **diagnosis of exclusion**: this means all other diagnoses (neurological, medical, orthopedic or psychological causes for the deterioration) must be ruled out before the classification of post polio syndrome is assigned.



Post-polio symptoms may still exist with the presence of other medical conditions and may be classified as post-polio sequelae or the late effects of polio.

Doctors will most likely complete a full clinical workup and follow the proposed diagnostic criteria<sup>ii</sup>:

- History of paralytic polio with motor neuron (muscle function) loss and related symptoms
- A period of partial or full recovery of the initial illness followed by an extended time interval (usually around 15 years or more) of stable functioning
- A gradual or sudden onset of progressive muscle weakness and fatigue and other new symptoms (above)
- New symptoms lasting for at least a year
- Exclusion of other neurological, medical, and orthopedic problems that may cause similar symptoms

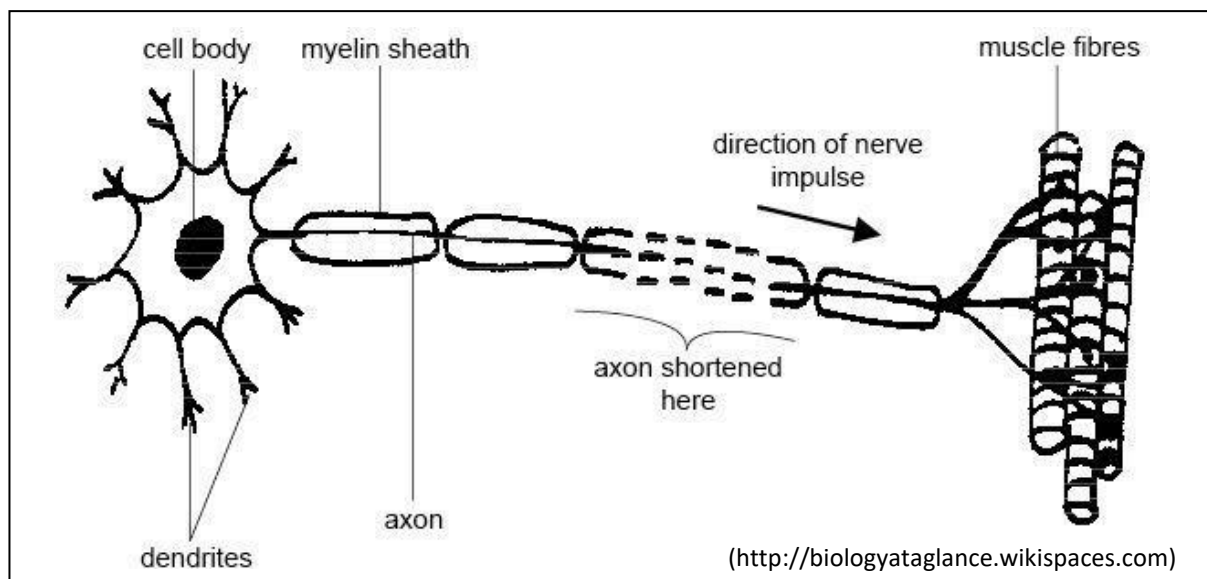
Polio survivors who are female or had widespread initial muscle weakness from original polio virus are said to be more at risk of post polio syndrome.

Some doctors may use CT or MRI scans to detect muscle cell loss. There is no single test to diagnose post-polio syndrome.

## What causes post-polio syndrome?

The most generally accepted theory behind post-polio syndrome involves the degeneration of motor neuron cells (nerve cells in the muscle). During the initial polio episode, the poliomyelitis virus invades motor neuron cells which normally branch to contact different parts of the muscle. The infected cells are destroyed by the virus resulting in a lack of supply of neurons to polio-affected muscles. On a large scale, these changes can result in muscle weakness and/or paralysis.

Following the initial polio viral infection, surviving motor nerve cells of the spinal cord and brain stem create new branches, or 'sprouts', to re-connect the nerve cell to muscles affected. These new branches are responsible for triggering contractions in the muscles, often regaining lost muscle function. The normal aging process and 'wear and tear' of muscles over several decades result in new symptoms of muscle fatigue and weakness.<sup>iii</sup>



Above: A motor neuron cell. According to this theory, many of these cells are destroyed by the original polio virus. Several decades later, the shortage of these motor neuron cells will result in new muscle weakness as muscle function is affected by the lack of nerve cells to muscle cells.

<sup>i</sup> Farbu E. *Update on current and emerging treatment options for post-polio syndrome*. Neurocenter and National Competence Center for Movement Disorders, Stavanger University Hospital, Stavanger, Norway. *Therapeutics and Clinical Risk Management* 2010;6 307-313

<sup>ii</sup> March of Dimes (M.o.D. in the United State) Diagnostic Criteria

<sup>iii</sup> Julie Silver M.D., *Post-Polio Syndrome: A Guide for Polio Survivors and Their Families*. Julie Silver M.D.; 2001, Yale University

## Living with post-polio syndrome

Living with post-polio syndrome and managing your symptoms is based on lifestyle change, physiotherapy, specialized training programs and avoiding secondary disease complications (obesity, heart disease, chronic diabetes, etc.). Health professionals recommend several rehabilitation-based practices.

It is important to talk with your healthcare professionals and help them understand the symptoms you are experiencing and work together to find therapies and lifestyle changes that work for you. Below is an outline of the most current practices, as found in published medical research articles.

### ***Management of fatigue, pacing and lifestyle modifications***

- Periods of rest to conserve energy and simplifying movements are suggested to maintain energy levels and reduce the onset or aggravation of symptoms
- General balance of healthy lifestyle habits, balanced diet, weight control, physical activity, proper sleep habits, adaptation to assistive devices and modifying daily activities to manage fatigue are recommended

### ***Exercise and physical activity***

- Non-fatiguing exercises can improve muscle strength, prevent fatigue and help prevent the further decrease of functioning.
- Different types of exercises can include:
  - Isokinetic (exercises at a constant speed)
  - Isometric (strength training exercises that are held in static position)
  - Endurance muscle training
- Programs must avoid overuse of affected muscles, leave sufficient rest periods between intervals, and train every-other day.
- Non-fatiguing exercises that have short duration and minimal applied workload are suggested.
- There is some evidence that supports training in warmer result in longer-lasting effects
- Water exercises (not swimming), especially performed in warm water, have been proven to reduce stress on joints and are a good alternative.



## ***Social Support***

- Sharing your experiences with other polio survivors creates a sense of belonging, understanding, helps to prevent isolation and depression. Connect with one of our peer support groups or talk to a fellow survivor on the phone.

## ***Bracing, orthoses and assistive devices***

- It is recommended that use of lightweight carbon orthoses (braces) can improve function in polio-affected limbs, especially while walking
- Use of mobility devices, such as motorized wheelchairs and scooters, are great ways to help polio survivors pace while still living an active life.



## ***Respiration and vocal changes***

- Many polio survivors acquire respiration difficulties
- Respirators (intermittent positive pressure ventilation or biphasic positive pressure ventilators) are often recommended
- Speech therapy and laryngeal muscle training may improve vocal cords

## ***Pharmological investigations***

There have been some small-scale studies conducted since post polio syndrome was first being investigated looking at the use of different anti-inflammatory treatment; however, results have not shown any conclusive benefits of the drug therapy. Studies have included investigation of prednisone, pyridostigmine, Intravenous immunoglobulin (IVIG) and coenzyme Q10 have been studied in limited researches and success has been modest. More research must be undertaken to find the long-term effects of different pharmacological interventions for survivors with post polio syndrome.<sup>iiiiiiiiv</sup>

## ***Alternative and complementary therapies***

There are several alternative therapies that polio survivors have found success practicing in order to manage their symptoms.

<sup>i</sup> Farbu E. *Update on current and emerging treatment options for post-polio syndrome*. Neurocenter and National Competence Center for Movement Disorders, Stavanger University Hospital, Stavanger, Norway. *Therapeutics and Clinical Risk Management* 2010;6 307-313

<sup>ii</sup> Julie Silver M.D., *Post-Polio Syndrome: A Guide for Polio Survivors and Their Families*. Julie Silver M.D.; 2001, Yale University

<sup>iii</sup> Tiffreau V. et al. Post-polio syndrome and rehabilitation. *Annals of Physical and Rehabilitation Medicine* 52(2010) p.42-50)

<sup>iv</sup> Boyer, F.C. et al. Post-polio syndrome: Pathophysiological hypotheses, diagnosis criteria, medication therapeutics. *Annals of Physical and Rehabilitation Medicine*. (2010) 34-41.

## Pacing and balancing your lifestyle

Pacing and energy conservation is one of the most important and effective methods that polio survivors practice to adapt to symptoms of post-polio syndrome to maintain independence. By developing creative ways to balance daily activities, exercise, rest and sleep, proper nutrition, recreation and social activities, polio survivors can achieve their personal goals and live a full life. It is essential for managing chronic pain associated with post polio syndrome symptoms.



Pacing, energy conservation and exercise are topics that should be thoroughly discussed with your healthcare provider.

### ***What is pacing?***

Pacing is a method of learning to recognize one's own body limits, working to achieve the most out of the day and being sensitive to one's own work load. This can be achieved by taking breaks, stopping when necessary, and working at a steady pace to reduce the chances of exhaustion and over activity of muscles.

Pacing is a necessary supplement for chronic pain management because it allows the muscles to relax and prolongs the amount of activities you can do throughout the day by spacing them to avoid aggravation, fatigue and causing strenuous pain. Scheduling activities incorporating the concept of pacing maximizes productivity during the day and minimizes pain.

### ***The pacing theory***

The theory of pacing teaches people to manage their energy wisely so that their energy levels will be maintained and gradually increase. Pacing also brings about a structure to the day, giving a person a better sense of control. The key is to find the correct balance of activities for every individual. The idea is to take needed breaks before pain becomes unbearable.

Often people will unconsciously frame their lifestyles to be balanced. For example, Doris, a polio survivor gets tired from climbing up a flight of stairs. Now, Doris aims to climb only half the stairs while taking a short break at the landing, then continuing up the rest of the stairs. She also makes an effort to schedule her day so that she only has to go up and down her stairs a maximum of twice a day.<sup>1</sup>



The main goals of pacing techniques are to:

- spread activities evenly over the day and week to avoid pain or fatigue
- increase the overall level of activity
- take regular short breaks before the pain becomes strong
- alternate activities - to help change the amount of energy needed

Without pacing, individuals may suffer from chronic pain and fatigue as polio survivors. This could lead to chronic long-term effects, including: Inactivity for fear of increasing pain, social withdrawal and gaining excess weight.

### **Things to avoid**

Under-activity:

- Lack of properly assessed and planned exercise
- Increased muscle pain due to a lack of proper therapy
- Decrease in muscle flexibility and overall stamina

Over-activity:

- Increased pain and fatigue due to un-balanced pace of activities
- Constantly pushing one's self over the healthy limits of their body
- Increased pain due to fatigue, exhaustion, and ongoing flare-ups



### ***How to Pace***

The London Pain Consultants (2007) developed a set of pacing techniques:

1. Measure activity
  - Take note of the exact amount of time spent on a particular activity
  - Note which activities cause an increase in pain
  - Calculate the average amount of time needed per activity
2. Set the limit
  - The limit is the amount of activity which should be followed in a regular and disciplined manner – it is 80% of time spent on particular activity
3. Stick to the Limit
  - Once the limit has been reached stop doing the activity even if you are in the middle of it and feel that you want to push yourself
4. Increase the limit
  - Listen to your body - Once a routine has been established and you feel that you can do a little more, gradually increase the limit
  - Increase slowly as your stamina increases

<sup>i</sup> London Pain Consultants, 2007; *British Polio.org.uk*, 2010

## Surgery and post-polio

Polio survivors should be aware of special considerations regarding surgical procedures requiring anesthesia. There are several considerations anesthesiologists (doctors that specialize in sedation during surgery) should consult with the patient before surgery.

Make sure that your anesthesiologist is aware of your history of polio. He or she may not be aware of the special precautions that must be taken, as polio patients may have respiratory impairment, sleep apnea, swallowing difficulties, chronic pain and cold intolerance. They may also display altered sensitivity to any of the medications commonly used for regional and general anesthesia. Once aware of these considerations, surgery attendants will be better prepared to provide safe care to patients with post-polio syndrome or any patient with a history of polio.



### Medications

- Analgesics (narcotics such as codeine, morphine, valium, etc.) may depress the cough reflexes, decreasing the ability to breathe or cough properly. This may lead to the inability to clear the lungs of secretions with increased muscle weakness
- Muscle relaxants may further impair the ability to breathe, cough, move your body or do routine activities
- Sedatives and hypnotic drugs – will decrease the respiratory drive and increase drowsiness
  - This will lead to shallow breathing, ineffective coughing and even deep vein thrombosis with lack of movement

### Discuss your Symptoms

As always, discuss your symptoms and concerns with your doctor before any procedure. If your medical team is unaware of the symptoms of post-polio syndrome, take the time to make them aware of your symptoms. Regardless of your diagnosis, coming up with solutions to address your symptoms such as respiration issues or cold intolerance, will result in a better outcome for everyone.

## Preparing for Surgery

In preparation for your surgery, consider the following:

- Will you be able to use your assistive devices (cane, crutches, wheelchair, etc.) after surgery?
- Will there be aids like grab bars and other assistive devices during your stay in hospital?
- When is your surgery scheduled? What will be your level of fatigue?
- If there are pre-surgery tests or procedures, will your energy levels be able to accommodate this?
- Have you properly planned a routine upon your return home – extra help or assistive devices in place to ensure your safety and independence?

### ***Article References for Medical professionals***

- ◇ ***Post-polio syndrome and Anesthesia.*** Lambert, D. M.D. Anesthesiology 103:638-44. 2005.
- ◇ ***Orthopaedic surgery considerations in post-polio syndrome*** by Sheth, NP, and Keenan, MA, Department of Orthopaedic Surgery, Hospital of the University of Pennsylvania, Philadelphia, Pennsylvania in *The American Journal of Orthopedics*, 2007 Jul;36(7):348-53.
- ◇ ***Preventing Complications in Polio Survivors Undergoing Surgery.*** Richard L. Bruno, Ph.D.2000.
- ◇ ***You are going to have surgery: A Guide for Polio Survivors.*** Walker, J.M. (P.T.), 1996.
- ◇ ***Post-Polio Syndrome: A Guide for Polio Survivors and Their Families.*** Julie Silver M.D.; 2001, Yale University.

## Intimacy and post-polio

Dealing with the symptoms of post-polio syndrome may seem overwhelming to most. With many different issues that polio survivors face, sexuality and intimacy with your partner may not seem like the first item to tackle. However, polio survivors and their partners have sexual needs just like everyone else that important to address.

Sexual intimacy can:

- strengthen self-esteem
- create intimacy with your partner,
- while acting as an important source of pleasure, and relaxation.
- Has been shown to boost the immune system
- relieve stress
- burn calories
- even reduce pain in some circumstances.



## Straight Talk about post-polio and sex

Symptoms of post-polio syndrome do not directly cause impotency or sexual dysfunction. However, post-polio syndrome does affect energy levels – energy plays an important part of sexual acts.

As with any other physical activity, polio survivors must approach sexual acts with a sense of balancing energy expenditure and pacing their lifestyle to match their sexual priorities. To put this idea into context, the amount of physical effort required for a person to achieve an orgasm is equivalent to climbing a set of stairs. Just as balancing how often a polio survivor decides to walk up stairs, so to must they create a sense of equilibrium with acts of intimacy throughout their daily lives.



## Readjustment and Planning for Success

Couples can benefit from having open discussions about their desires and how to achieve them. Along with open communication with your partner, here are some guidelines to consider:



- Remember that it takes time to rediscover what works best for you as a couple
- Expect a certain amount of frustration and, as much as possible, maintain good humor and don't take setbacks too seriously
- Break away from typical stereotypes – just because someone is aging, doesn't mean that they don't enjoy sex.
- Look after their personal hygiene and appearance.
- Different degrees of muscle weakness may require adjustments in seeking a comfortable position for sex. It may be further complicated by muscle stiffness, bowel or bladder incontinence, fatigue, vision problems, and lack of balance.
- Keep an open mind - there are many ways to enjoy sex besides intercourse! The tenderness and warmth conveyed in cuddling and touching can be a continuing source of physical satisfaction and fulfillment.
- Your doctor can help by providing information, clearly discussing sexual function, arranging for sexual counseling if necessary, or by prescribing medications.

***To learn more about this topic, check out these great resources:***

- **The Ultimate Guide to Sex and Disability: for All of Us Who Live with Disabilities, Chronic Pain and Illness.** Miriam Kaufman, Cory Silverberg and Fran Odette.
- **Enabling Romance: a Guide to Love, Sex and Relationships for the Disabled.** Ken Kroll & Erica Levy Klein
- **'Post Polio: A Guide for polio survivors and their families.** Ch.25, Dr. Julie Silver, M.D.

## Resources and Links

### Online Resources for polio survivors

#### Canadian Links

- March of Dimes Canada – [www.marchofdimes.ca/polioCanada](http://www.marchofdimes.ca/polioCanada)
- Polio Quebec – [www.polioquebec.org](http://www.polioquebec.org)
- Post Polio Network (Manitoba) – [www.postpolionetwork.ca](http://www.postpolionetwork.ca)
- PolioRegina – <http://nonprofits.accesscomm.ca/polio>

–

- Polio Alberta - <http://www.polioalberta.ca/>
- Polio Nova Scotia - <http://www.easterseals.ns.ca/programs-and-services/family-and-community-support/polio-nova-scotia/>

#### International Links

- Post Polio Health International – [www.post-polio.org](http://www.post-polio.org)
- Poliotoday (Salk Institute) – [www.poliotoday.org](http://www.poliotoday.org)
- Polio Place – [www.polioplace.org](http://www.polioplace.org)
- European Polio Union – [www.europeanpolio.eu](http://www.europeanpolio.eu)
- Polio Network Victoria (Australia) – [www.polionetworkvic.asn.au](http://www.polionetworkvic.asn.au)
- British Polio Fellowship – [www.britishpolio.org.uk](http://www.britishpolio.org.uk)
- Lincolnshire Post-Polio Network – <http://www.ott.zynet.co.uk/polio/lincolnshire/>
- International Rehabilitation Center (Spaulding Rehab) - <http://www.spauldingrehab.org/ourlocations/framingham/ircp>
- Global Polio Eradication Initiative – [www.polioeradication.org](http://www.polioeradication.org)
- End Polio Now – Rotary International – [www.rotary.org/endpolio](http://www.rotary.org/endpolio)
- Post Polio Syndrome Central – [www.skally.net/ppsc/](http://www.skally.net/ppsc/)

### JOIN Post-Polio Canada today!

- ✓ Get connected to local survivor and caregiver **Peer Support groups**
- ✓ Call the **Warmline**® and connect with resources
- ✓ Receive *Polio Canada* national **e-newsletter FREE**
- ✓ Link to people, educational information and **resource services**

Post-Polio Canada Email Address: [polio@marchofdimes.ca](mailto:polio@marchofdimes.ca)

202-885 Don Mills Road  
Toronto, ON, M3C 1V9



## Post-Polio Canada Topics

Post-Polio Canada® has a continually growing library of resources. Please contact us for more information about any of the following issues that can affect polio survivors and their families or check out our website [www.marchofdimes.ca/polio](http://www.marchofdimes.ca/polio) . If you would like a copy of articles references to forward to your health professional, please contact us.

- |   |   |
|---|---|
| <input type="checkbox"/> Accessibility                        | <input type="checkbox"/> Peer Support                   |
| <input type="checkbox"/> Alternative Medicine and Therapies   | <input type="checkbox"/> Physical Activity              |
| <input type="checkbox"/> Assistive Devices                    | <input type="checkbox"/> Recreation and Adapted Hobbies |
| <input type="checkbox"/> Caregiver Needs                      | <input type="checkbox"/> Self-Management and Care       |
| <input type="checkbox"/> Falls and Safety                     | <input type="checkbox"/> Sexuality and Relationships    |
| <input type="checkbox"/> Nutrition                            | <input type="checkbox"/> Stress Management              |
| <input type="checkbox"/> A Guide to Online Health Information | <input type="checkbox"/> Others? _____                  |

## Feedback - What do you think?

Post-Polio Canada would like to know what you think of this information package. Please send us your feedback.

■ PLEASE CIRCLE

○ Did you find this information package...?

▪ Useful	<b>YES</b>	<b>NO</b>
▪ Easy to read	<b>YES</b>	<b>NO</b>
▪ Presented clearly	<b>YES</b>	<b>NO</b>
▪ Right amount of content	<b>YES</b>	<b>NO</b>

■ What further information are you looking for? \_\_\_\_\_

■ Are you a:  Polio survivor  Caregiver  Other: \_\_\_\_\_

■ Other comments: \_\_\_\_\_

\_\_\_\_\_

Post-Polio Canada Email Address: [polio@marchofdimes.ca](mailto:polio@marchofdimes.ca)

202-885 Don Mills Road  
Toronto, ON, M3C 1V9