



&

Colorado Post-Polio Organization

***Resource Book of Articles  
Related To  
Polio and Post-Polio  
Syndrome***

Provided to Polio Survivors and Their Families

By

The Colorado Post-Polio Organization

And

Easterseals Colorado

*Through the generosity of*

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The opinions expressed in this resource book are those of the individual writers and do not necessarily constitute an endorsement or approval by Easterseals Colorado or the Colorado Post-Polio Organization. If you have personal medical problems, consult your own physician.

These resources are current as of February 2022 and may change over time.

**March 2022**

**This updated edition contains some new articles that may help the polio community and its members have more recent information than the original edition as well as many articles that are timeless in their content. Also, some articles have been edited to reflect the most recent information, including the most current resources available. Use and enjoy!**

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## Introduction

To many in the U.S. medical community, polio is considered either an “orphan disease” or a rare disease. This is because the polio virus has been eradicated in the U.S., almost all the U.S. polio population is over 65, our population numbers are dwindling, and because there is no cure for its after-effects. This means that, with few exceptions, those in the medical profession do not focus on polio or post-polio syndrome, may only recognize that “we are still here,” and are not spending time, money and research to address our needs specifically.

So, rather than expending OUR energy searching for a polio specialist to meet our specific needs, we need to become our own best advocates whenever interacting with the medical professionals that are available. Our best healthcare outcomes occur when our medical professionals listen as we relate the impact of polio has on each of us specifically, and are willing to learn what polio is, what it does to the body and how it impacts or is impacted by the specific problem being addressed.

Finding professionals with those skills and that attitude allows us to then select our medical service providers based on our personal comfort/trust in them, our ability to work with them and on their skills in practicing their specialties. In seeking a good fit for polio needs, osteopaths (D.O.) and physiatrists, doctors who have more extensive training in muscular-skeletal issues, gerontologists, and physical therapists who specialize in neuro-muscular problems may have skills that better relate to polio and post-polio syndrome.

Being our own best advocate requires knowledge and communication skills on our part. We need to know our own bodies, minds and emotions, our strengths and weaknesses, our skills and limitations and be able to clearly articulate the relevant aspects to our service providers. Then, it is helpful to have some knowledge of the scientific and medical issues and resources that are available so we can carry on a dialogue about our issues. We need to listen to what our medical professionals have to say and offer, based on their expertise. Then we can work in partnership to address the issues and solve the problems based on the best outcomes available.

The mission of the Colorado Post-Polio Organization is to provide education, information, and support statewide for polio survivors and their support systems.

In keeping with that mission, CPPO has compiled this resource book as one tool to help polio survivors as they age with the aftereffects of polio so they will be able to interact with the medical professionals with some knowledge of the issues. The articles included are intended for information and education only and are not to be

considered prescriptive in any way. Prescriptions are the responsibility of the medical professionals.

The Colorado Post-Polio Organization and Easter Seals Colorado, through the generosity of the C. H. Bernklau Charitable Lead Trust, have selected and reprinted articles they see as most relevant to polio survivors as they age. These articles are from past issues of the Colorado Post-Polio Connections newsletter and from other sources, and they speak directly to the medical issues and the durable medical equipment issues that face many of us as we age.

This resource book can be used in several ways:

- As a resource to be read in general, or, when an issue comes up, as a go-to source to help the survivor and his/her family have some basic knowledge when seeking professional help.
- As an educational tool to help the survivor's health care professionals learn about polio and post-polio syndrome. In having the information, hopefully the providers can use that knowledge to provide more informed treatment for the polio survivor.
- As topics for discussion in post-polio support groups, when and where they are available.

Since these articles can be helpful in working with health care professionals, a suggested strategy for making the best use of doctor-patient communication is to copy and give them only the article(s) relevant to the issue at hand. For example, providing the anesthesiologist with the Dr. Calmes' article on anesthesia when planning to have elective surgery, or the articles by Dr. Eulberg and Dr. Enrietto about polio when selecting or seeing a new primary care doctor. A book of facts and information may not be read or may overwhelm a professional whereas one article can be easily and quickly read and acted upon.

Ultimately, we hope that this collection of articles can be a useful resource for polio survivors and their families. We also hope that by being informed on the issues that face us as we age, we can all maintain our quality of life for years to come.

The Colorado Post-Polio Organization

March 2022

# Post-Polio Basics—2022

## Did You Have Polio?

- ✓ Unexplained fever
- ✓ Flu-like symptoms
- ✓ Paralysis
- ✓ Severe neck pain and/or headache
- ✓ Was a spinal tap done? (Note: a spinal tap ruled out bacterial meningitis--it did not confirm one had polio!)

## What is Post-Polio Syndrome (PPS)?

- Late effects—any long-term effects from polio, whether a person has PPS or not
- PPS affects up to 50% of polio survivors
- Criteria for diagnosis of PPS—
  - Prior polio documented by exam, history, or electrodiagnostic tests (EMG)
  - Period of physical stability of at least 15 years
  - No other diagnosis to explain the symptoms (see **Symptoms of PPS**)

**PPS is a diagnosis of exclusion!!**

## What Causes Post-Polio Syndrome (PPS)?

Exact cause has not been determined  
Possible causes: decades of “overuse and abuse” of the body, motor neurons damaged by polio begin to fail, effects of aging on top of effects of polio.

## Are There Medications That Help PPS?

There are NO medications that address PPS problems directly. Some meds that are commonly used to treat arthritis or nerve pain can sometimes be helpful to treat some pain.

## How Is PPS Diagnosed?

There is no one test or group of tests that can definitively diagnose PPS. PPS is considered likely when other common causes of new symptoms have been ruled out.

## What Are Some of the Symptoms of PPS?

- New weakness in muscles—both those originally affected and those thought unaffected by the poliovirus
- Breathing or swallowing difficulties because of new muscle weakness or scoliosis
- Pain in muscles and/or joints
- Unaccustomed, unexplained fatigue—either rapid muscle tiring or feeling of total body exhaustion
- New or increasing atrophy of muscles
- Functional decline—more than would be expected from aging
- Wear and tear arthritis in stressed joints
- Nerve compression problems

## What Can Be Done?

- ✓ Determine what causes “overuse” & adjust activities to avoid/minimize overuse.
- ✓ “Conserve to preserve” but still maintain activity.
- ✓ Use assistive devices to maintain independence.
- ✓ Join a post-polio support group (in-person or on-line).
- ✓ Control your weight while maintaining nutrition --adequate protein essential; limit added sugars.
- ✓ Physical therapy, with goal to maintain function.
- ✓ Get professional mental health help if needed.

## What Should I Know Before Surgery and/or Procedures Requiring Anesthesia?

- ✓ Determine if the procedure will be done as an inpatient or as an outpatient.
- ✓ If planned procedure will be done as an out-patient, try to get it scheduled early in the day because additional post-operative recovery time may be needed.
- ✓ Ask if local or regional anesthesia (nerve blocks, spinal, or epidural) can be used instead of general anesthesia (being “put to sleep”)
- ✓ Ask if local or regional anesthesia can be used instead of general anesthesia (being “put to sleep”)
- ✓ Review your previous medication reactions with the surgeon, person administering anesthesia, and nursing staff.
- ✓ Talk to your healthcare provider about the planned procedure and your post-polio concerns.
- ✓ If at all possible, set up a consultation with the anesthesiologist/anesthetist during the pre-admission process about concerns. {Some of the drugs (esp. curare-type muscle relaxants) used in the past caused some problems in polio survivors; but these drugs are rarely used in the 2020s.
- ✓ Let staff know about any concerns you have regarding cold intolerance or positioning of your body during the procedure.
- ✓ Talk with your surgery team about exactly what is involved in recovery & rehabilitation. Don’t assume the team totally understands how you do things—for example, if you are having shoulder surgery, are they aware that you use your arm(s) to use a cane or push off from a chair or the toilet? Once you have the information, make a plan that will work for you.

## What About Breathing Problems?

Breathing problems can be due to diaphragm or chest muscle weakness because of prior polio, especially when the person needed the use of respiratory assistance during the acute polio illness or had/have severe scoliosis.

Breathing problems can also be due to lung conditions such as COPD or asthma.

Pulmonary function tests (PFTs) can determine if the cause of the breathing problem is restrictive (decreased chest movement such as from polio-weakened muscles) or obstructive (narrowing of the airways inside the lungs).

Treatment of each condition (restrictive/obstructive) is quite different. A person can have a mixed picture with both restrictive & obstructive issues.

## What About Swallowing Problems?

Swallowing problems, if not addressed, can lead to weight loss, malnutrition, and aspiration pneumonia. They can be caused by weakness of throat muscles or problems in the esophagus or a combination of both.

One test that can not only determine the cause but also possibly provide treatment tips is a modified barium swallow study (MBSS) that is done with a speech therapist and a radiologist. Most hospitals have the capability to do this test.

Many speech therapists have the skills needed to determine the cause and provide treatment because people who have had strokes often have similar swallowing problems.

## What To Do About Pain?

- ✓ Look at activity –if pain is from overuse/abuse of tissues—adjust activities.
- ✓ Use heat and/or ice on painful area(s)
- ✓ Massage the area.
- ✓ Try warm water therapy.
- ✓ Use assistive & adaptive aids to reduce stress on muscles & joints.
- ✓ Use topical medications before taking pills, ex. Salon-Pas, Ben-Gay, over-the-counter creams containing Lidocaine 4%, or diclofenac (brand name: Voltaren gel).
- ✓ Consider trial of CBD (if legal in your state, country, location)
- ✓ Use pain medication only as directed by your healthcare provider

## Aging with Polio—Safety issues

Normal aging can impact muscle strength, balance, and mobility. To live safely with polio, **prevent falling!**

- ✓ Keep home spaces open for easy navigation and floors clear of rugs.
- ✓ Use assistive devices such as canes, crutches, walkers/rollator walkers at home and when venturing out.
- ✓ Equip bathrooms with tub or shower chairs and grab bars, including by the toilet.
- ✓ Physical therapy can improve these issues and teach ways of coping.
- ✓ A physical therapist can teach you how to fall more safely and how to get up and recover from falls.
- ✓ Have a way to get assistance if you fall and cannot get back up—apps on some phones that detect falls and notify certain persons, and/or having a medical alert device.
- ✓ **Insure you always have a cordless/cell phone with you—even when moving around in your own home.**

## Did You Know?

People still get polio, but as of 2021 there were less than 600 cases in the whole world!

There are post-polio clinics and support groups scattered across the globe. Post-Polio Health International (PHI) has a directory at [www.post-polio.org](http://www.post-polio.org).

There are some resources for financial help for some equipment needed by polio survivors—check with CPPO or PHI.

Since 1988, Rotary International clubs have been actively working to eradicate polio. This would be only the second human disease to ever have been totally eradicated!

## Where Can I Find More Information?

### Post-Polio Health International (PHI)

St. Louis Missouri

(314) 534-0475

[www.post-polio.org](http://www.post-polio.org)

### Colorado Post-Polio Organization (CPPO)

Lakewood, Colorado

[www.eastersealscolorado.org](http://www.eastersealscolorado.org)

Click on “Our Programs” then on “Colorado\_Post-Polio”

Or contact:

Mitzi Tolman, Program Coordinator

message phone (720) 940-9291

[mtolman@eastersealscolorado.org](mailto:mtolman@eastersealscolorado.org)

*Adapted from information provided by Polio Epic, Inc.  
Tucson, AZ*

*Revised & updated February 2022  
by Marny Eulberg, M.D.*

## **What Having Polio Causes, Might Cause And Does Not Cause**

*By Marny Eulberg, M.D.*

*This article aims to provide basic information about what the poliovirus does to the human body and to provide some understanding when patients, families and/or their healthcare providers deal with new symptoms. Often a symptom can result from more than one cause and sometimes a combination of causes. Since nearly all people who contracted polio in the U.S. are now age 65 or older, hardly any polio survivor is a “pure” case of their polio anymore. Having had polio does not protect individuals from any of the other maladies that can happen to human beings. Many diseases, such as most cancers and heart disease, tend to happen more often as people live beyond their 50<sup>th</sup> birthday.*

*The article is not meant to be all-inclusive and list every possible disease cause, but to discuss the most common and frequent conditions. Polio survivors should tell their healthcare providers about their prior history of polio because it can directly or indirectly affect their current medical condition.*

**INTRODUCTION:** In the US, major poliomyelitis epidemics ended following the widespread introduction of polio vaccine in 1955. Polio survivors, their families, and healthcare providers often are confused about which symptoms polio might be responsible for and which cannot be attributed to one’s polio. Most healthcare providers practicing today have little experience or training to care for polio survivors.

Organizations such as Post-Polio Health International, which exists to provide information to polio survivors, often receives questions about various symptoms related to polio. Post-polio groups and expert professionals have learned that many people receive mistaken or confusing information.

Assigning symptoms or changes in functioning to one’s previous polio when the symptom is NOT due to polio can be dangerous. Polio clinics can help a person discover what is and what is not related to polio. The primary care doctor can treat the non-polio related symptoms and manage polio-related symptoms with guidance from knowledgeable post-polio professionals and the polio survivors themselves.

## WHAT DOES THE POLIOVIRUS DO? (PATHOLOGY)

The diseases named “infantile paralysis,” “acute poliomyelitis” or “acute polio-encephalo-myelitis”, or simply “polio” were all caused by one of the three polioviruses (Type 1, Type 2, and Type 3 poliovirus). The exact virus causing a person’s disease can now be identified in the laboratory, but that was not true in the 1930s, 1940s and 1950s. Each virus can cause a similar pattern of disease when they infect an individual, so looking at what parts of the body were affected cannot predict which of the 3 types of polio virus infected that person. As used here poliovirus or virus refers to one or more of the three polioviruses.

The virus causes a “flu-like” illness with nausea, vomiting, diarrhea, a fever and perhaps a headache and muscle aches. In a small percentage of individuals, it causes varying degrees of paralysis. Most people infected with the virus had only the flu-like illness did not develop any paralysis and were thereafter immune to that virus.

Less than 5 percent of all individuals infected with the virus developed paralysis of muscles ranging from a few to nearly all the muscles of their body; some people died from the infection. The virus circulates in the cerebrospinal fluid all around the brain and up and down the spinal cord. In the spinal cord, the virus attacked the anterior horn cells (the nerve cells that go out to the muscle and tell the muscle what to do) but did not affect the nerves that go back to the spinal cord with messages about touch, pain, temperature sensation or position sense (where the body part is in space, i.e., “is my foot on the floor or in midair?” Or “Is my foot on a flat surface or a slanted surface?”)

The poliovirus primarily affected nerves leading to voluntary muscles. Those are muscles that you can control with thought, such as, “I think I’ll point with my right index finger.” This may include the muscles involved in taking a deep breath, in swallowing, of the face, of the trunk, of the abdomen, and of the limbs. There is lack of consensus among medical professionals about how much the poliovirus affected non-voluntary muscles such as those in the bladder or gastrointestinal tract. The poliovirus did not seem to cause permanent damage to the heart (cardiac) muscle.

## **WHAT SYMPTOMS OR SIGNS ARE LIKELY RELATED TO POLIO (PRIMARY EFFECT)?**

**ATROPHY (MUSCLE WASTING).** The “skinny arm” or “skinny leg” is a result of the muscle or part of the muscle not getting the message from the nerve that it should contract or move and thus it gets smaller and weaker. Related to this is the possible shortening of the limb. In a growing child, bone grows because of the muscle pull on it and/or weight bearing. Therefore, many who contracted polio as a growing child may have one arm, leg or foot that is shorter and smaller than the nonaffected/less affected limb.

**NEW WEAKNESS.** More than 40 percent of polio survivors may develop post-polio syndrome (PPS). Increasing muscle weakness in muscles previously affected or new weakness in muscles thought not to have been affected is one of the defining features of the condition.

**LOSS OR ABSENCE OF REFLEXES AT A JOINT.** For example, when the healthcare provider hits your knee with the reflex hammer, and it does not “kick” out. Rarely, a polio survivor may have an exaggerated or hyper-active reflex, but hyperactive reflexes are usually due to some lesion in the brain or higher up in the spinal cord.

**MUSCLE FATIGUE OR DECREASED ENDURANCE.** When a muscle does not have a full supply of “motor units” it may still be able to function for a limited number of repetitions but it “wears out” sooner. The person may be able to “sprint” but could not run a mile or a marathon.

**MUSCULAR PAIN.** Polio survivors generally describe this as an “achy, burning or sore feeling.” It is thought to be caused by overuse of the muscle(s) in the area. Individuals who had acute polio when they were old enough to remember the event, say it feels similar to the muscle pain that occurred with the acute polio. Others describe it differently, but polio-related muscular pain is rarely sharp and stabbing.

**BIOMECHANICAL PROBLEMS.** These are problems related to abnormal positions of a limb around a joint, e.g., one leg being shorter than the other or abnormal curvature(s) of the spine. This can cause mechanical low back pain, increase the likelihood of “wear and tear” arthritis in the joint or an acute tendonitis, bursitis or even nerve compression problems.

**POLIO “COLD LEG OR COLD ARM”.** There are several theories about what causes it, but it is real! Generally, the person doesn’t sense the limb as feeling as cold as it feels when it is touched. It occurs when the environment is cold – such as

in winter or in an air-conditioned room. Polio caused “cold leg” or “cold arm” will not cause delayed healing of fractures or injuries. It is mostly an inconvenience to the individual and his or her bed partner. {Other causes of “poor circulation” such as hardening of the arteries in the limb or vascular complications of diabetes do require medical attention and can impact healing of injuries.}

**SOME PROBLEMS WITH BREATHING.** These include decreased ability to move enough air in and out of the lungs to get enough oxygen into the lungs or to breathe out enough carbon dioxide because of new respiratory muscle weakness or from residual muscle weakness from the early polio. Medically this is called “restrictive lung disease.” Problems also can include “not remembering” to take a breath, taking breaths that are too shallow, not taking enough breaths per minute when asleep. This is broadly called sleep apnea (central). Weakness of some throat muscles can also cause intermittent blockage of the air passages in the throat, termed obstructive apnea.

**CERTAIN PROBLEMS WITH SWALLOWING.** These can cause choking while swallowing, especially thin liquids such as water. Sometimes some of the swallowed material will go into the lungs instead of down into the stomach causing a pneumonia known as “aspiration pneumonia.” Some people lose weight and have difficulty maintaining adequate nutrition because eating is so time-consuming or difficult. Note: Many people above age 50 have other problems unrelated to polio, such as scarring of the esophagus from long-term acid reflux, that can cause problems swallowing. Various tests, including a modified barium swallow study, can discover the exact cause of the disorder (dysphasia.)

**OSTEOPOROSIS OR OSTEOPENIA.** Weight bearing exercise is necessary for bones to become and remain strong. In persons who had paralytic polio, the affected limb(s) may have bone that has less than the normal mineral (calcium) content. The terms osteoporosis and osteopenia refer to decreased amount of normal bone tissue. Osteoporosis (low bone density) is more severe than osteopenia (less bone density). These conditions can mean the bone is more “brittle” and may break more easily than normal bone. (Either can also occur in certain medical conditions increasing with age and may not be totally related to polio.)

## **WHAT SYMPTOMS OR SIGNS MAY BE RELATED TO POLIO (SECONDARY EFFECTS)?**

Increased wear and tear on joints including osteoarthritis, tendonitis, tendon tears, and bursitis are fairly common in polio survivors. When a person has a weak limb, the unaffected or lesser affected leg or arm does more work to compensate which can contribute to “wear and tear arthritis”. People who use their arms in place of their legs (crutch walkers, users of canes, manual wheelchair users) put more stress on the joints of the upper extremities than someone who has normal use of their legs. This can result in damage to cartilage, tendons and ligaments in the wrists, elbows, and shoulders.

**NERVE COMPRESSION.** Carpal tunnel syndrome can result from pressure on the heel of the hand and palm. Using crutches, canes or propelling a manual wheelchair is often the cause. Abnormal positions of joints and the vertebrae in the spine may compress nerves. Numbness, tingling, an “electric shock” sensation are symptoms of nerve compression. Progressive weakness may also result around the body part supplied by that particular pinched nerve.

**INCREASED RESPIRATORY PROBLEMS.** Can result from increasing curvature of the spine which results in less room for lungs and internal organs.

**FATIGUE FROM INCREASED ENERGY EXPENDITURE.** Walking with an abnormal gait, use of crutches and propelling a manual wheelchair all require more energy than unimpeded walking. For example, walking with a locked knee can use up to 20 percent more energy than walking with an unlocked knee. Walking with two crutches can burn up to twice as much energy as a nondisabled person walking the same distance.

**HEADACHES.** “Muscle contraction” headaches may be caused by chronically overused neck muscles. Headaches, especially on awakening, could be from inadequate ventilation (breathing) overnight from respiratory muscle weakness and or sleep apnea that might or might not connect to prior polio. Abnormal or unusual positions of the neck muscles when doing daily tasks may also cause muscle imbalance or scoliosis.

**EMOTIONAL ISSUES** can include post-traumatic stress disorder from hospitalizations, medical procedures, dysfunctional family interactions or teasing by others.

## **WHAT OTHER (TERTIARY) SYMPTOMS MAY BE COMBINED WITH POLIO EFFECT?**

HIGH BLOOD PRESSURE AND/OR CORONARY HEART DISEASE. Limitations from polio may result in decreasing daily exercise and/or obesity.

WEIGHT GAIN, including overweight and obesity may be linked to decreased activity and exercise. Significant obesity can by itself, lead to obstructive sleep apnea and restrictive lung disease, osteoarthritis of hips and knees plus other problems.

DIABETES, in susceptible individuals, may be related to decreased activity or weight gain.

SKIN BREAKDOWN OR PRESSURE SORES may be caused from prolonged sitting without shifting position, sleeping in one position because of difficulty turning in bed or from poorly fitting braces or corsets.

SITUATIONAL DEPRESSION associated with decreased functioning and independence.

Finding a treatment or solution for the medical problem is more important than connecting it with prior polio. Post-polio experts agree treatment plans for the secondary and or tertiary problems are the same as for people who did not have polio.

## **WHAT SYMPTOMS OR SIGNS ARE NOT RELATED TO POLIO?**

- Arm, leg or head tremors - especially when that body part is at rest (usually due to a condition called “benign essential tremor”.)
- Problems with “sense organs” – Vision, Hearing, Taste, Smell
- Seizures
- Allergies to medicines or items in the environment
- Dizziness or vertigo (“the room spinning”)
- Sharp, shooting, or severe burning pain with numbness - Generally, polio itself does not cause numbness, but nerve compression may result from abnormal positions around a joint. (From walking with crutches, canes or propelling a manual wheelchair).
- Inability to know the position of a part of the body or where it is in space (decreased proprioception).
- Food stuck in the lower esophagus - (in the mid-chest or lower).
- Abdominal pain or diarrhea

- Cancer of any kind.
- Liver disease.
- Kidney disease.
- Most infectious diseases - except perhaps a few forms of pneumonia
- Skin rashes, (but unrelieved pressure on areas of the skin can cause skin breakdown and redness)
- Diabetes--but weight gain and decreased activity often worsen blood sugar control in persons with other risk factors for diabetes.
- Hardening of the arteries - (atherosclerosis) in the heart, legs, neck, brain. Although life- style changes induced by polio may increase the likelihood of developing this when added to other risk factors.

*Marny K. Eulberg, MD, is a polio survivor who has worn a brace for more than 30 years. She is a family physician who founded a post-polio clinic in 1985 and has seen more than 1,500 polio survivors. Dr. Eulberg was named "Colorado Family Physician of the Year" by the Colorado Academy of Family Physicians in 2005. She is a member of the PHI Board of Directors and serves as Secretary. Marny K. Eulberg, MD, Mountain & Plains Post-Polio Clinic 303-829-1538*

Edited with author's permission from POST-POLIO HEALTH Spring 2012 Vol. 28, No. 23. Revised and updated February 2022 by Marny Eulberg, M.D.

# Aging and Polio: What's Polio and What's Aging

*Presented by Paula J. Enrietto, Ph.D  
Senior Health Insights*

*Notes from a PowerPoint presentation at the Colorado Post-Polio Educational Conference, June 2, 2012*

## What's Aging and What's Polio

Today's talk:

- Review organ systems affected by polio
- Review the overlay of normal aging on these systems
- Understand how to manage normal aging as a polio survivor

## What's Polio: A Quick Review

- Poliomyelitis is a viral infection caused by an *Enterovirus* known as poliovirus (PV).
- Poliovirus enters the body through the mouth and grows in the gastrointestinal tract — specifically the oropharynx and the intestine.
- The incubation time (to the first signs and symptoms) ranges from six to 20 days.
- Poliomyelitis is highly contagious via the oral-oral and fecal-oral routes.
- Poliovirus divides within gastrointestinal cells then spreads to lymph tissue where it multiplies abundantly.
- The virus is subsequently absorbed into the bloodstream.
- Polio enters the central nervous system in about 3% of infections.
- These patients develop nonparalytic meningitis.
- About one to five in 1000 cases progress to paralytic disease.
- Depending on the site of paralysis, paralytic poliomyelitis is classified as spinal, bulbar, or bulbospinal.

## Organ Systems Affected by Polio

Primary:	Neural system Brain
Secondary:	Respiratory system Muscular system Skeletal system

## Primary Organ Systems Affected by Polio

In 1% of infections, poliovirus spreads along nerve fiber pathways, and destroys motor neurons within the spinal cord, brain stem, or motor cortex.

This leads to the development of the three forms of paralytic poliomyelitis that differ in which region of the Central Nervous System was affected.

### Three Forms of Paralytic Polio

#### **Spinal polio:**

The most common form of paralytic poliomyelitis, results from viral invasion of motor neurons of the spinal column responsible for movement of muscles in the trunk, limbs, intercostal muscles, and occasionally muscles of the face/neck.

#### **Bulbar polio:**

Makes up 2% of cases of paralytic polio and occurs when poliovirus destroys nerves within the bulbar region of the brain stem. Nerves affected are:

- the glossopharyngeal nerve which controls swallowing and tongue movement
- the vagus nerve which sends signals to the heart, intestines, and lungs
- the accessory nerve which controls upper neck movement

#### **Bulbospinal polio:**

Approximately 19% of all paralytic polio cases have both bulbar and spinal symptoms affecting the upper part of the cervical spinal cord with paralysis of the diaphragm and resultant breathing difficulties.

Other destructive changes associated with paralytic disease occur in the forebrain region, specifically the hypothalamus and thalamus.

### Secondary Organ Systems Affected by Polio: Respiratory

Respiration is a two-part process

An active component driven by the diaphragm and muscles of the rib cage which expand it. Muscle movement creates negative pressure to increase lung volume allowing air to enter the lungs through the nose.

Expiration is normally less active. The abdominal muscles pull the ribs down and push the diaphragm up. The internal intercostal muscles pull the ribs down and squeeze the air out.

If either the inspiratory or expiratory muscle groups, or both, are not functioning properly, some type of respiratory assistance may be needed.

### Secondary Organ Systems Affected by Polio: Muscle

When spinal neurons die, Wallerian degeneration takes place, leading to weakness of those muscles formerly innervated by the now-dead neurons.

With the destruction of nerve cells, the muscles no longer receive signals from the brain or spinal cord.

Without nerve stimulation, the muscles atrophy, becoming weak, poorly controlled, and/or paralyzed.

### Secondary Organ Systems Affected by Polio: Bone

Survivors of paralytic poliomyelitis have a greater risk for osteoporosis-related fractures because weakness results in a chronic reduction in weight-bearing activity, with a decrease in bone mass.

Osteoporosis results from a decrease in bone density below that needed for the skeletal function and mechanical support.

Secondarily, residual weakness from past paralytic polio may predispose post-polio individuals to more frequent falls.

Long periods of immobilization at the time of acute poliomyelitis can produce significant bone demineralization—up to 30-40%.

### Post Polio Syndrome

Between 25% and 50% of individuals who survive paralytic polio develop additional symptoms decades later.

Most notable symptoms are new muscle weakness and extreme fatigue.

The symptoms are thought to involve failure of the over-sized muscle units created during recovery from paralytic disease.

Risk factors for PPS are:

- the length of time since acute poliovirus infection
- the presence of impairment after recovery from the acute illness
- both overuse and disuse of neurons.
- Normal aging in polio survivors

## **How does the normal aging process impact polio survivors?**

What is the normal aging process?

- Definitions of aging
- Organ systems affected by polio and the impact of normal aging

What is normal aging?

Aging is a process of gradual maturation.

Senescence is the process by which the capacity for cell division and the capacity for growth and function are lost over time, ultimately leading to death.

Aging is a positive state of development (e.g., increased wisdom, experience, and expertise) accompanied by a negative state of decline.

The term senescence is the most common term for the decline component and refers only to changes that are deleterious.

Aging vs. Disease

The changes that occur with aging can be categorized in two ways:

1. Those that result from aging itself.
2. Those that result from diseases, lifestyle, and environmental exposures.

With aging, many physiologic functions decline. Many of these declines are attributed to aging itself; in other words, they are considered normal, not disease related.

The distinction between normal and disease-related may simply be defined by statistical distribution.

For example, presbyopia (decreased accommodation of the lens of the eye resulting in difficulty seeing near objects), the distinction is clear because presbyopia occurs in virtually all elderly people and no cause has been identified other than aging itself.

In contrast, cognitive decline is nearly universal with aging and is considered to be normal aging; however, dementia, although common in late life, is considered a disease.

## Why do we age?

Some theories of aging focus on what controls the degenerative processes that occur with aging and why the controls exist as they do.

Other theories focus on the evolutionary origins of senescence.

All of these theories generally agree that senescence does not offer a genetic advantage and developed mainly because it is not selected against.

### **The evolutionary senescence theory of aging:**

The most widely accepted overall theory of aging is currently the evolutionary senescence theory of aging.

Unlike the earlier theories of evolution and aging, which tried to find reasons why evolution might favor aging, evolutionary senescence theory focuses on the failure of natural selection to be able to affect late-life traits.

Natural selection operates through reproduction and, thus, has little effect late in life.

Genes and mutations that have harmful effects late in life and cause aging that function only after reproduction is over do not affect reproductive success and therefore can be passed on to future generations.

### **Organ systems affected by polio and aging**

#### Respiratory system

There are two age-related changes in the respiratory system that affect the ability of the lungs to provide adequate balance between for O<sub>2</sub> and CO<sub>2</sub>.

- The maximum rate of gas exchange is lower in aging lungs and there is an increase in the work of breathing because of decreased breathing efficiency.
- There is a decreased rate of breathing and a decrease in the adaptability of respiratory system leading to faster dyspnea (shortness of breath) on exertion.

Polio related respiratory muscle weakness is revealed by stressors such as:

- Surgery
- Infections that persist because muscle weakness prevents the clearing of secretions.
- Medications that suppress breathing, ex. sleeping or pain medications
- Exercise requires efficient breathing

- Weight may lead to chronic respiratory insufficiency resulting in abnormal gas exchange (with low oxygen and a rise in carbon dioxide)
- Aging that leads to lower gas exchange and decreased adaptability of the respiratory system

### **Suggestions for management . . .**

Aggressive treatment of infections and regular chest physical therapy to improve the movement of air in the lungs.

### The Muscular System

Role of the muscular system:

- To support movement
- To support other body parts such as bones
- Heat production—muscles replace lost heat when used

Normal changes in muscle during aging:

- Decrease ability to be stimulated by nerve impulses
- Decreased energy storage and supply
- Decreased ability to thicken upon exercise
- Decreased ability to be stretched affecting range of motion

### **Consequences of changes in muscle:**

- Decreased strength
- Decreased precision control and reaction time
- Decrease accuracy of movement
- Decreased coordination and falls
- Altered posture
- Need to adjust medications due to changes in proportion of body fat to body mass

### **Solution:**

Exercise!!

Managing the muscular changes that come from polio and aging:

Muscular strengthening is absolutely necessary.

However, historically, any type of exercise was thought to be bad for people with neuromuscular disease .

Research shows that exercise is of great benefit.

Exercise the muscle groups that are still healthy.

What kinds of exercise should you do?

- Aerobic training: Exercise of low or moderate intensity over a longer period of time, ex. walking treadmill.
- Aquatic physiotherapy: Hydrotherapy done in waist high, warm water. Focus on balance, range of movement, strength and conditioning.
- Muscle strength training: non-fatiguing progressive resistive exercises. Perform small number of repetitions until fatigue of the muscle group. Ex. lifting weights, using bands.

How to exercise:

Muscle strengthening programs should focus on muscle groups that are still functional.

Exercise programs must be individualized, moderate and used regularly.

Results of exercise:

Improvements in heart rate, oxygen use, blood pressure and pain reduction.

Build the strength of healthy muscle groups!

The Skeletal System:

- Provides support for soft organs preventing damage and distortion so soft organs can function.
- Supports movement by providing stable attachment sites for muscles.
- Provides mineral storage and supplies minerals to all body cells.
- Supports blood cell formation to maintain adequate levels of blood cells.

**Normal aging and bone**

- No changes to bone cells!!
- Decrease in protein:mineral ratio
- Quality of bone matrix changes
- Menopause causes change in bone matrix

Consequences of normal aging on bone:

- Increased brittleness of bones and more fractures
- Anemia
- Reduced range of motion
- Postmenopausal bone loss

Normal bone loss resulting from aging may exacerbate the bone loss experienced by polio survivors.

Survivors of paralytic polio have a greater risk for osteoporosis and related fractures because weakness results in a chronic reduction in weight-bearing activity, with a decrease in bone mass.

Recommendations:

- Increase calcium intake to 1500 mg per day since calcium is absorbed less efficiently with age.
- Vitamin D is needed for intestinal absorption of calcium from vitamin D fortified foods or supplements.
- Daily weight-bearing activity, if possible, to improve skeletal health.
- Don't smoke or use alcohol in excess since both can induce bone loss.

Those who have a low or relatively low bone mass may need medications to reduce age-related bone loss such as:

- Estrogen
- Calcitonin
- Biphosphonates,
- Parathyroid hormone

Prevention of osteoporosis-related fractures should also include strategies to reduce the risk for falls that focus on improving balance, using assistive devices such as canes, and managing household hazards.

### Fatigue, Aging and Post Polio Syndrome

Fatigue is one of the most common complaints of normal aging.

In polio survivors damage to the brain may exacerbate fatigue:

Poliovirus damages areas of the brain responsible for keeping you awake, the brain's reticular activating system. The virus causes lesions in the reticular formation, basal ganglia and substantia nigra resulting in impairment of cortical activation, attention and fatigue.

Post-polio fatigue may be exacerbated by age-related attrition of neurons that survived the original polio infection in the reticular formation (also called the reticular activating system or RAS), hypothalamus and putamen--all parts of the

brain's "activating system" that turns on the cortex (the brain's super computer), keeps you awake and allows you to focus attention.

Changes in the number and function of mitochondria may also affect energy levels.

What are mitochondria?

- Intracellular organelles that generate the energy used by cells to function and grow
- By product is free radicals
- Thought to be derived from bacteria incorporated into cells 1.7-2 billion years ago
- Have their own DNA
- The "**mitochondrial theory of aging**" postulates that damage to mtDNA free radicals leads to loss of mitochondrial function and loss of cellular energy (with loss of cellular function).
- If mitochondria stop functioning cells don't have the energy that they need to survive.

Building muscle mass as we age may reduce fatigue.

Building muscle mass as a polio survivor may help reduce fatigue.

How??

Exercise increases muscle mass and the number of mitochondria in those muscles. With more mitochondria more energy is generated reducing the risk of fatigue.

### Aging Successfully with Post Polio

Understand what changes are the result of post polio syndrome or damage from acute polio.

Understand the overlay of normal aging.

Manage those changes with appropriate exercise, dietary supplementation and interventions when stressed.

Knowledge helps you live as independently as you can for as long as possible.

## **Have You Heard About the Late Effects of Polio?**

### **For Health Professionals**

Survivors of polio may seek your medical advice for new weakness, overwhelming fatigue and/or pain. Some patients may describe these symptoms and "forget" to tell you they had polio. This triad of symptoms is typically presented at least fifteen years after the acute case of poliomyelitis, as the North American, Western European and Australasian experience documents. Individuals, now in their seventh or eighth decade, are facing a combination of new polio problems and aging. Because poliomyelitis has not yet been eradicated from the world, survivors will be seeking assistance for years to come.

As early as 1875, Raymond and Charcot described a polio patient who reported new weakness and atrophy in his right arm - the arm he used excessively due to residual weakness in his left arm. As survivors from the 1950s epidemics sought medical assistance for "tiring more easily," researchers explored these new complaints and, over the years, have developed the following criteria for post-polio syndrome:

- Prior paralytic poliomyelitis with evidence of motor neuron loss, as confirmed by history of acute paralytic illness, signs of residual weakness and atrophy of muscles on neurologic examination, and signs of denervation on electromyography (EMG).
- A period of partial or complete functional recovery after acute paralytic poliomyelitis, followed by an interval (usually 15 years or more) of stable neurologic function.
- Gradual or sudden onset of progressive and persistent new muscle weakness or abnormal muscle fatiguability (decreased endurance), with or without generalized fatigue, muscle atrophy, or muscle and joint pain. (Sudden onset may follow a period of inactivity, or trauma or surgery.)
- Less commonly, symptoms attributed to post-polio syndrome include new problems with breathing or swallowing.
- Symptoms persist for at least a year.
- Exclusion of other neurologic, medical, and orthopedic problems as causes of the symptoms.

It is important to note that there are consequences to having had polio that may not fit the criteria. Polio survivors who visit your office may be reporting a variety of neurologic, orthopedic, medical, musculoskeletal, emotional, and rehabilitation

complaints, all of which need to be methodically addressed and not dismissed simply as signs of aging.

Post-Polio Health International recommends that all polio survivors receive consistent, basic medical evaluations. If a patient's symptoms are not explained and alleviated by general medical approaches and the symptoms persist or worsen, a referral is in order. A physiatrist or neurologist can conduct a neuromuscular evaluation to establish a diagnosis and to recommend a management plan that will be sent to you and your patient.

*Article from Post-Polio Health International Newsletter: Reprinted with permission.*

## Tools to Use in Evaluating Treatment Choices\*

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### **Five Basic Steps**

Following are five basic steps to help you cope with your diagnosis, make decisions, and get on with your life.

#### **Step 1: Take the time you need.**

Do not rush important decisions about your health. In most cases, you will have time to carefully examine your options and decide what is best for you.

#### **Step 2: Get the support you need**

Look for support from family and friends, people who are going through the same thing you are, and those who have “been there.” They can help you cope with your situation and make informed decisions.

#### **Step 3: Talk to your doctor.**

Good communication with your doctor can help you feel more satisfied with the care you receive. Research shows it can even have a positive effect on things such as symptoms and pain. Getting a “second opinion” may help you feel more confident about your care.

#### **Step 4: Seek out information.**

When learning about your health problem and its treatment, look for information that is based on a careful review of the latest scientific findings published in medical journals.

#### **Step 5: Decide on a treatment plan.**

Work with your doctor to decide on a treatment plan that best meets your needs.

As you take each step, remember this: Research shows that patients who are more involved in their health care tend to get better results and be more satisfied.

### **Ten Important Questions to Ask Your Doctor After a Diagnosis**

These 10 basic questions can help you understand your disease or condition, how it might be treated, and what you need to know and do before making treatment decisions.

1. What is the technical name of my disease or condition, and what does it mean in plain English?
2. What is my prognosis (outlook for the future)?
3. How soon do I need to make a decision about treatment?
4. Will I need any additional tests, and if so what kind and when?
5. What are my treatment options?
6. What are the pros and cons of my treatment options?
7. Is there a clinical trial (research study) that is right for me?
8. Now that I have this diagnosis, what changes will I need to make in my daily life?
9. What organizations do you recommend for support and information?
10. What resources (booklets, Web sites, audiotapes, videos, DVDs, etc.) do you recommend for further information?

Now that you know your treatment options, you can learn which ones are backed up by the best scientific evidence. “Evidence-based” information—that is, information that is based on a careful review of the latest scientific findings in medical journals—can help you make decisions about the best possible treatment for you.

### **Evidence-based information comes from research on people like you.**

Evidence-based information about treatments generally come from two major types of scientific studies:

- **Clinical trials** are research studies on human volunteers to test new drugs or other treatments. Participants are randomly assigned to different treatment groups. Some get the research treatment, and others get a standard treatment or may be given a placebo (a medicine that has no effect), or no treatment. The results are compared to learn whether the new treatment is safe and effective.
- **Outcomes research** looks at the impact of treatments and other health care on health outcomes (and results) for patients and populations. End results include effects that people care about, such as changes in their quality of life.

### **Take advantage of the evidence-based information that is available.**

Health information is everywhere—in books, newspapers, and magazines, and on the Internet, television, and radio. However, not all information is good information. Your best bets for sources of evidence-based information include

the Federal Government, national nonprofit organizations, medical specialty groups, medical schools, and university medical centers.

Some resources are listed below, grouped by type of information. The on-line version of *Next Steps After Your Diagnosis* lists many more, and includes links to Internet sites.

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### **Current medical research.**

You can find the latest medical research in medical journals at your local health or medical library, and in some cases, on the Internet. Here are two major online sources of medical articles:

- **PubMed Central:** <http://www.pubmedcentral.nih.gov/> PubMed Central is the National Library of Medicine's database of journal articles that are available free of charge.

### **Clinical Trials.**

Perhaps you wonder whether there is a clinical trial that is right for you. Or you may want to learn about results from previous clinical trials that might be relevant to your situation. Here are two reliable sources:

- **ClinicalTrials.gov:** <http://clinicaltrials.gov> ClinicalTrials.gov provides regularly updated information about federally and privately supported clinical research on people who volunteer to participate. The site has information about a trial's purpose, who may participate, locations, and phone numbers for more details. The site also describes the clinical trial process and includes news about recent clinical trial results.
- **Cochrane Collaboration:** [www.cochrane.org](http://www.cochrane.org) The Cochrane Collaboration writes summaries ("reviews") about evidence from clinical trials to help people make informed decisions.

### **Steer clear of deceptive ads and information.**

While searching for information either on or off the Internet, beware of "miracle" treatments and cures. They can cost you money and your health, especially if you delay or refuse proper treatment. Here are some tip-offs that a product truly is too good to be true.

- Phrases such as “scientific breakthrough,” “miraculous cure,” “exclusive product,” “secret formula,” or “ancient ingredient.”
- Claims that the product treats a wide range of ailments.
- Use of impressive-sounding medical terms. These often cover up a lack of good science behind the product.
- Case histories from consumers claiming “amazing” results.
- Claims that the product is available from only one source, and for a limited time only.
- Claims of a “money-back guarantee.”
- Claims that others are trying to keep the product off the market.
- Ads that fail to list the company’s name, address, or other contact information.

## Where to Find More Information

### Get the support you need.

National Board of Certified Counselors (NBCC) 3 Terrace Way, Suite D  
Greensboro, NC 27403-3660 336-547-0607. [www.nbcc.org](http://www.nbcc.org)

National Institute of Mental Health  
Public Information and Communications Branch 6001 Executive Boulevard, room 8184,  
MSC  
9663 Bethesda, MD 20892-9663  
Phone: 866-615-6464 (toll free) TTY: 301-443-8431

### Talk to your doctor.

Be Informed: Questions to Ask Your Doctor Before You Have Surgery and use hospitals and clinics. Agency for Healthcare Quality and Research. 2021. <http://ahrq.gov/consumer/surgery.htm>. Phone 800-358-9295.

Talking with Your Doctor: A Guide for Older People. National Institute on Aging. 2018. [www.nia.nih.gov](http://www.nia.nih.gov). and search “how to talk to your doctor” Phone: 800-222-2225.

Adapted from AHQR Publication No. 05-0049, July 2005.

*\*Presenter’s notes from Post-Polio Health International’s 10th International Conference, “Living with Polio in the 21<sup>st</sup> Century,” Warms Springs, Georgia. April 23, 2009. Revised and updated by CPPO, 2022.*

## **The First Steps in Treating Pain: Finding the Source**

*Amy Clunn, M.D., Southeastern Rehabilitation Medicine, Ocala, Florida*

Polio survivors have been found to have multiple potential sources of pain as they age. The pain can interfere with function and add further physical decline, lead to depression, poor sleep, and fatigue, which are already problems in most post-polio patients. Therefore, it is important to be aggressive in treating pain in order to optimize physical and mental function.

The primary findings on physical exam in polio patients are muscle weakness and atrophy (shrinkage) in the affected limbs. Part of the post-polio syndrome includes progressive weakness with or without atrophy in the limbs that were affected originally, and occasionally in limbs that were not affected originally. The atrophy and weakness occurs because the virus affected the anterior horn cell of the peripheral nervous system in a patchy pattern. This then causes the nerve supply to be poor to the receiving muscle, and it can no longer work fully (the nerve supply is the hard wire that gives the muscle its power and its signal to move). Without actively contracting, the muscle atrophies (shrinks) rapidly. What is left is a muscular system that must struggle to maintain posture, activate joints and work with possibly only 10-80% of its usual power. With this understanding of the disease mechanism, it is easy to see the first reason polio patients often have pain: chronic muscle strain. The muscles in the affected limbs are often overused or strained even in everyday activities, such as walking or using arms. Muscle strain pain presents with aching soreness and soreness in muscles that become tender to touch. The tenderness can be in the belly of the muscle or at its distal, tendinous insertion near the bone (enthesopathy).

Bones and joints are another source of pain in polio. If a bone is not subjected to regular weight-bearing activity, it becomes osteoporotic (loses its mineral content). This can cause pain and lead to the compression or stress fractures that can occur even with normal activity (walking or bending for example). Stress or compression fractures present with acute, focal intense pain often with swelling, made worse with weight-bearing. It is even more important that post-polio patients undergo bone density studies than the normal population in order to treat osteoporosis if it exists, as it predisposes bones to fracture with falls or even atraumatic activities. Joints can become painful due to arthritis or due to contracture from tightness. Capsulitis (inflammation of the joint capsule) can also occur and presents with very painful and restricted range of motion of a joint. This is particularly common when weakness has made it difficult to move a joint, and the capsule shrinks or tightens because it is not ranged. Subluxation (slippage of a

joint position) can be commonly found in feet, sacroiliac (pelvic) joints and shoulders when the surrounding musculature is weak. This presents as pain in range of motion or with weight-bearing, deformity, or crepitation (crunching or “rice Krispies” sound with range of motion).

Nerve pain can present as part of an “overuse” syndrome when certain activities are overdone, often in response to substituting one function for another where weakness exists. An entrapment of the nerve can occur with the repetitive motion. An example of this is carpal tunnel syndrome, particularly common in manual wheelchair or crutch/cane/walker users (repetitive gripping with or without direct compression), or sciatic nerve injury in response to hip weakness and pelvic instability and strain with walking.

Spine pain is also common in polio patients. Spine pain has potential sources such as discs, joints, muscles, ligaments, tendon, bone and nerve roots. Wheelchair users are susceptible to degenerative disc disease (seated position increases intradiscal pressure, atrophy of the paraspinal muscles and scoliosis (curvature)). Sitting also creates tightness in tendons or flexor muscles and can lead to pain when in extension, such as lying down. Joints in spines where weakness is present in a lower limb or in the spine itself are subject to premature and more severe arthritic change than usual. Discs are also subject to strain injuries such as tears and herniations when gait is unbalanced. They present with intense focal back pain and, if pressure on the nerve root ensues, radiating pain to the abdomen, groin or leg & foot (if lumbar). Osteoporosis also affects the spine commonly with compression fractures.

The circulatory system can also be affected by polio, particularly in limbs that are paretic (weak or paralyzed), in wheelchair users due to sitting. Venous return of the blood is usually impaired in this instance, and blood can pool in the extremity causing swelling, aching and even ulceration. Patients can get angina (chest pain due to cardiac ischemia (decreased blood flow) due to cardiac disease hastened by lack of cardiovascular exercise).

If polio survivors are facing any pains that are severe or that last more than a few weeks, they should have an evaluation by a musculoskeletal physician, primarily orthopedists and physiatrists. A careful history should be taken, including information regarding the patient’s polio history, other past medical history, functional history and how the pain problem is affecting mobility. The patient should be clear and give an example, such as “I used to be able to lift a gallon of milk with my right arm and now it is difficult to hold a coffee cup.” This tells the examiner the time frame of the problem as well as the severity. After that,

a thorough physical examination should follow including gait evaluation, if the patient is able. Strength, range of motion, sensory testing and inspection/palpation of the affected areas should be evaluated. Subsequent diagnostic testing may be necessary, including x rays, MRIs, bone scans, EMGs and lab work. With this information an appropriate diagnosis can be rendered with treatment to follow.

Beware: one of the worst things a polio survivor can do is feel that all his or her symptoms are part of a post-polio syndrome and think that nothing can be done to help. Hopefully this talk has given polio patients the knowledge to understand some of their unique potential pain generators and what can be done to evaluate them (and formulate a treatment plan).

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## **Finding Causes of and Managing Fatigue**

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*Edited and revised by CPPO, 2022.*

### **Summary**

Fatigue is the most frequently mentioned complaint of people with post-polio syndrome (PPS). And fatigue is often severe. However, fatigue is not very specific and is a prominent complaint in many neuromuscular disorders, in many chronic diseases such as multiple sclerosis, in oncology and even on itself in chronic fatigue syndrome. How to understand fatigue in PPS and how to deal with it is the aim of these sessions.

. . .

## Causes of fatigue

Fatigue is mentioned by up to 80% of people with post-polio syndrome and the scores on fatigue questionnaires are often high, indicating severe fatigue. But, what is fatigue? Fatigue can be defined as ‘a persistent, subjective sense of tiredness that interferes with usual functioning.’ This refers to the general feeling of fatigue, however local muscle fatigue is also often present and is among the symptoms to define post-polio syndrome: ‘new muscle weakness or abnormal muscle fatigability.’”

In post-polio syndrome fatigue is most frequently related to physical factors.

## Local muscle fatigue

Local muscle fatigue is the decline in the ability of the muscles to generate force.

Several factors have been identified that may play a role in this:

- I. Failure to drive muscles from the central nervous system due to alterations in the central nervous system to activate the nerve cells due to polio—the precise mechanism is not understood
- II. Transmission failure from the nerves to the muscle fibers due to the fact that nerve connections with muscle fibers that were formed in the recovery phase after the acute polio are of less quality and therefore less able to sustain the transfer of the signal from the nerve to the muscle
- III. Decreasing capacity of the muscles due to post-polio syndrome to meet the physical requirements needed to execute daily life activities. The muscles that slowly decline in strength have to work at an increased level of their maximal capacity, and this will be inversely related to the duration physical activities can be maintained
- IV. A decrease in endurance properties of muscles. Muscles that are chronically used at a certain load, especially leg muscles, change their properties towards endurance, however not fully. Shortages of relevant enzymes have been reported
- V. Especially less affected and not affected muscles may be chronically under loaded in daily life and suffer from disuse. As a consequence, they are less loadable.

## **General fatigue**

General fatigue, the feeling of being tired, may have several causes.

- I. People with post-polio syndrome may feel fatigued due to the fact that they are constantly acting above or in the upper range of their physical capacities. This may result in a chronic state of exhaustion. It is important to realize that movement efficiency is often reduced. This implies that walking may cost twice (or even more) the energy of normal walking in the case of two affected legs.
- II. Brain alterations due to poliovirus damage have been suggested as a possible cause of general fatigue.
- III. Recent studies have demonstrated signs of chronic inflammation in the cerebrospinal fluid in PPS. This may also play a role in fatigue.
- IV. Deconditioning of the cardiorespiratory system. Persons with post-polio syndrome have been found to be deconditioned, or to have a condition comparable to a sedentary lifestyle.
- V. Psychological factors, such as ‘giving up the fight,’ social factors related to the person’s life situation, and sleep problems may all contribute to fatigue. However, these are not the main causes of fatigue in post-polio syndrome.

## **Other causes of fatigue**

It is very important to rule out other causes of fatigue. Of course, the list of potential causes is very long, but a few common causes such as anemia, hypothyroidism, unregulated blood sugar and depression need to be mentioned.

## **Factors associated with fatigue in PPS**

In a recent study, so far unpublished data, several of the above-mentioned factors were found to be associated with fatigue. Lower physical functioning, more pain, sleep problems, lower well-being and an ineffective coping style were found to be associated with fatigue. Of course, in this study not all potential factors were included.

## **Pharmacological treatment**

No pharmaceuticals have been proven effective in reducing fatigue. Randomized controlled trials (RCT’s) in which drugs are tested against a placebo and both investigators and patients are blinded for the intervention are the gold standard to prove effectiveness of interventions. Results from such studies have so far been disappointing in that NO drug was found to be effective.

## **Assessment of and managing fatigue in individuals with PPS**

### **Assessment**

#### I. Medical evaluation

It is very important to start with a thorough medical evaluation to exclude other pathologies as mentioned earlier.

#### II. What is meant by fatigue?

The next thing is to go into a full consideration of the complaint of fatigue. Is it local or general, related to activity and which activities, does it increase over the day, does it respond to rest?

#### III. Are other contributing factors present?

Consideration has to be given to sleep quality, mood disorders and coping styles.

#### IV. What is the activity pattern?

The activities of daily life have to be inventoried. What is the activity level of a person, what kind of work does someone do, what are social and home activities, how is mobility outdoors. Are there any aids being used for walking, mobility in and outdoors and so on?

#### V. What is the social system?

How is the person's social environment, does he or she have sufficient support and understanding at home and work?

#### VI. What are the person's own perceptions?

How does someone value his or her complaints of fatigue (and other complaints, post-polio syndrome, polio residuals and so on)?

#### VII. What are the physical capacities?

What is somebody able to do given the polio residuals and comorbidities? What is the physical burden of activities such as standing, walking, transfers, stair climbing, and the individual's various activities?

#### VIII. Conclusion

Finally a conclusion can be made on which factors cause or sustain fatigue. These are to be targeted in interventions.

### **Assessment tools**

Tools that may be of value in the assessment of fatigue are validated questionnaires to assess fatigue severity, pain, coping styles, mood, and physical functioning.

Diaries to inventory daily life activity are extremely useful to gain insight in what someone's life looks like, in what a person actually does over the days. A common

finding is that people with PPS appear to be much more active than they spontaneously report.

Clinical tests may be included to determine the extent of the polio residuals, and capacity tests to assess physical abilities.

## **Management**

The first important thing is that the person obtains insight into the factors contributing to fatigue. The next and crucial thing is readiness to change. Many factors contributing to fatigue are related to behavior and to cogitations. For instance, if someone is constantly overusing oneself, but considers that as normal, it will be impossible to obtain any change in behavior. It is well know that many polio survivors are so-called ‘over achievers’ who are not easily prepared to reduce their activities. Occasionally, the reverse is also seen that some polio individuals may avoid physical activity, for instance, if they think that this may damage muscles, and they may very well be mainly having fatigue due to the vicious circle of fatigue, inactivity, physical deconditioning and so on.

To diminish fatigue, energy conservation skills are often to be learned. This may be done individually or in group therapy programs. On the other hand regular physical activity is advised to maintain physical functioning. This implies an individual non-fatiguing exercising program that can be easily done at home, or in an (adapted and accessible) fitness setting. Environmental adaptations at home or work, transportation aids, braces and assistive devices may all need to be tailored to the individual’s needs. Rehabilitation therapy is therefore usually multidisciplinary organized and may involve physical and occupational therapists, social workers, psychologists, orthotists, shoe technicians and adaptation technicians.

Preferably, the effect of multidisciplinary interventions to reduce fatigue should evaluate the achievements obtained after the program and during follow-up.

*\*Presenter’s notes from Post-Polio Health International’s 10<sup>th</sup> International Conference, “Living with Polio in the 21<sup>st</sup> Century,” Warm Springs, Georgia. April 24, 2009.*

## Special Circumstances

### Post-Polio Breathing and Sleep Problems Revisited

*Judith R. Fischer, MSLS, Editor, Ventilator-Assisted Living, and Joan L. Headley, MS, Editor, Post-Polio Health*

*“Post-Polio Breathing and Sleep Problems” was published in the fall of 1995 (Polio Network News, Vol. 11, No. 4) As a result of the continual flow of phone calls and emails from polio survivors and family members about this life and death topic, Judith Fischer, editor of Ventilator-Assisted Living (our other quarterly newsletter), and I decided to revisit and revise the original article. Our goal is to educate and to clarify misinformation about breathing problems of polio survivors. –Joan L. Headley, Editor, Post-Polio Health. [www.ventnews.org](http://www.ventnews.org)*

New breathing and sleep problems in aging polio survivors can be insidious and often go unrecognized by either polio survivors, their family members or their health care providers. Polio survivors may have weakened breathing muscles as a result of the initial damage by the poliovirus; the lungs themselves were not affected. Those who were in an iron lung during the acute phase should be aware of the potential for developing problems later in life and educate themselves in order to recognize important signs and symptoms which may indicate underventilation which may lead to respiratory failure. Even those who did not need ventilatory assistance during the acute phase may also be at risk for underventilation and should be aware of problems with breathing and sleep.

Underventilation (hypoventilation is the medical term) means that not enough air reaches the lungs to fully inflate them. The result may be too little oxygen and too much carbon dioxide (CO<sub>2</sub>) in the blood. Underventilation can be caused by one or more of the following: weakness of the inspiratory muscles (mainly the diaphragm and rib muscles) for breathing in, weakness of the expiratory muscles (the abdomen) for breathing out and producing an effective cough to clear secretions, scoliosis (curvature of the spine), and sleep apnea.

Other factors contributing to a polio survivor’s breathing problems are a history of smoking, obesity, undernutrition, and other lung diseases such as asthma, bronchitis and emphysema.

Vital capacity (VC) is the volume of air that can be expelled after taking a big breath and is a measure of how well the lungs inflate. VC normally decreases with age, but this decrease in VC is more serious in an aging polio survivor with

weakened breathing muscles. Many polio survivors had impairment of their inspiratory muscles, and the normal changes due to aging may cause them to lose VC at a greater rate. Polio survivors may not experience symptoms of underventilation until their VC falls to 50% or less of predicted (normal).

Signs and symptoms of underventilation during sleep include:

- ❖ Inability to breathe when lying flat—the need to sleep sitting up (orthopnea)
- ❖ Inability to fall asleep and/or to stay asleep (insomnia)
- ❖ Anxiety about going to sleep
- ❖ Restless fragmented sleep with frequent awakenings
- ❖ Shallow breathing or pauses in breathing (Continued on page 4)
- ❖ Awakening from sleep with choking sensation
- ❖ Nightmares, night sweats, bedwetting or need to urinate frequently
- ❖ Excessive daytime sleepiness
- ❖ Morning headaches
- ❖ Worsening mental status and impaired memory, concentration and cognition

Other symptoms may include:

- ❖ Shortness of breath on exertion
- ❖ Fatigue or exhaustion from normal activities
- ❖ Claustrophobia and/or feeling that the air in the room is somehow bad
- ❖ General anxiety
- ❖ Difficulty in speaking for more than a short time
- ❖ Low voice/volume speech with fewer words per breath
- ❖ Use of accessory muscles, such as neck muscles, to breathe
- ❖ Weak cough with increased respiratory infections and pneumonias.

Polio survivors experiencing one or more of the above signs and symptoms should seek a respiratory evaluation (simple and noninvasive pulmonary function tests) by a pulmonologist, preferably one experienced in neuromuscular disorders. Physicians are listed in the *Resource Directory for Ventilator-Assisted Living*. [www.ventnews.org](http://www.ventnews.org)

Pulmonary function tests should include the following measurements. The values that indicate a warning sign for respiratory problems are in parentheses.

- ❖ VC—upright (<50%)
- ❖ VC—supine (a drop of >25% from upright to lying down)
- ❖ MIP—maximum inspiratory pressure (<60 cm H<sup>2</sup>O)
- ❖ MEP—maximum expiratory pressure (<60 cm H<sup>2</sup>O)
- ❖ Peak expiratory cough flow (<300 L/min)
- ❖ End-tidal CO<sup>2</sup> (>45 mm Hg)

- ❖ Overnight oximetry may be prescribed to detect episodes of oxygen desaturation (<88% during sleep).

Management of breathing and sleep problems can be achieved largely through the use of nocturnal noninvasive ventilation, commonly in the form of small, lightweight bilevel positive pressure units. The units have a long tube/circuit that attaches to a mask (nasal, facial or oral), nasal pillows or mouthpiece worn during sleep. Polio survivors may find themselves gradually extending periods of ventilator use, perhaps during a daytime nap. Some polio survivors may need to use a volume ventilator to guarantee delivery of a larger volume of air than a bilevel unit can provide. Noninvasive ventilators may eventually fail, and invasive tracheostomy positive pressure may be necessary.

Treating underventilation with oxygen therapy instead of ventilation can lead to respiratory failure and death because supplemental oxygen can blunt the function of the brain's respiratory control center. However, polio survivors who use assisted ventilation and have additional medical problems such as COPD, pneumonia or heart problems, or who are undertaking long airplane flights (ed. Note—or who live at higher altitudes), may benefit from oxygen therapy under careful supervision.

Polio survivors may also have sleep apnea contributing to underventilation. Sleep apnea, an interruption of breathing, during sleep can be obstructive, central or mixed. Obstructive sleep apnea (OSA) is the most common form and is prevalent in the general population. The standard test for OSA is a sleep study; the standard treatment is the use of a continuous positive airway pressure (CPAP) unit with a nasal mask or nasal pillows during sleep. However, polio survivors with both weakened breathing muscles *and* sleep apnea should use bilevel positive pressure or volume ventilation, not CPAP.

*Thanks to Lisa Krivickas, MD, Spaulding Rehabilitation Hospital, Boston, Massachusetts; E.A. Openheimer, MD (retired), Lost Angeles, California; and Mark H. Sanders, MD, University of Pittsburgh Medical Center, Montefiore University Hospital, Pittsburgh, Pennsylvania, for their review of this article.*

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## **Swallowing Difficulty and the Late Effects of Polio**

*Barbara C. Sonies, PhD, CCC, BRS-S, College Park, Maryland,  
[bsonies@hesp.umd.edu](mailto:bsonies@hesp.umd.edu)*

A major polio epidemic in the mid-20th century left many survivors with a wide variety of physical limitations including problems swallowing foods. Many persons with swallowing problems also had original bulbar signs of polio including difficulty breathing, clearing the throat, speaking and singing.

Some persons however, had no overt signs of swallowing difficulty and seemed to recover many of their original physical abilities. Twenty to 30- plus years after the original polio episode, many people began to experience new signs of muscle weakness with difficulty walking or breathing and new problems with swallowing. Many polio survivors are now beginning to complain of difficulty swallowing and food getting stuck in their throats.

In a series of studies completed at the National Institutes of Health in 1991-1996 by Dr. Barbara Sonies and Dr. Marinos Dalakas, and in other studies, it has been substantiated that new swallowing complaints begin to emerge decades after the initial polio onset. Many people are only mildly aware of any change, and others who deny swallowing problems actually do have symptoms. An informal survey taken in 2003 of 23 persons diagnosed with post-polio syndrome (PPS) indicated that more than half had both new complaints of swallowing difficulty.

### **What are some signs of swallowing difficulty?**

A wide but consistent range of complaints is noted including food sticking in the throat, trouble swallowing pills, coughing during eating, food backing up from the throat, eating a meal takes longer and unintentional weight loss. A self-assessment questionnaire for dysphagia (swallowing disorders) listed below can help determine if you need further attention (adapted from Sonies, BC, Parent LJ, Morrish K, Baum, BJ, *Dysphagia* 1:178-186, 1987).

If you answer YES to more than three of the following questions, seek consultation from a physician and speech-language pathologist.

If you have many of these symptoms, contact a speech-language pathologist at a hospital or rehabilitation center who specializes in dysphagia. (Go to [www.swallowingdisorders.org](http://www.swallowingdisorders.org) to see a listing of specialists in your state.)

Do you have difficulty swallowing?

Do you have difficulty chewing hard foods?

Do you have an overly dry mouth?

Do you have excessive saliva or drooling?

Do you cough or choke during or after swallowing?

Do you have a feeling that food catches or remains in your throat?

Do you have continual mucous dripping into the throat?

Does your voice become hoarse or gurgly after you swallow?

Do you have food particles backing up into your throat or mouth?

Do you have heartburn or indigestion? Do you have difficulty swallowing liquids?

Do you have difficulty swallowing solids?

Do you have difficulty swallowing pills?

Do liquids sometimes come out of your nose?

Does it take you longer than everyone else to eat a meal?

Have you had episodes of airway obstruction during eating?

Have you had frequent pneumonia or aspiration pneumonia?

### **What are the possible causes of changes in swallowing?**

Current thinking is that muscle over-use is responsible for swallowing problems that are emerging as new symptoms or reappearing in persons who recovered from swallowing problems years ago. The assumption is that the remaining fewer healthy nerve fibers and muscles they innervate (motor units) become overused. This overuse appears to cause a slow deterioration of the function of the head and neck bulbar muscles needed to swallow. Once-healthy muscles of the face, palate, tongue, throat, lips and larynx become weakened. Because many of the muscles and nerves that control swallowing also control speech and voice, changes making swallowing more difficult may also make speaking more difficult.

### **What should I expect from a swallowing diagnostic examination?**

To evaluate and make an appropriate treatment plan for someone with a swallowing disorder, a clinical swallowing assessment should be conducted. In this examination, the strength and coordination of the various muscles used to swallow will be assessed during a series of activities. If weakness or incoordination of the muscles of the mouth and throat are found, strategies for treatment will be suggested.

Swallowing safety will be observed during eating a meal or with liquids and soft foods in a clinical setting. A thorough history of medical/surgical diagnoses, medications, allergies and family and caregiver observations will be included along with a history of the polio progression. Oral hygiene and condition of the teeth will also be evaluated.

If the swallowing problem is such that the person is at risk for aspiration, where food enters the airway, an instrumental swallowing examination will be conducted. The two primary techniques are the modified barium swallow and a fiberoptic swallowing examination of the throat. These procedures will help to determine if the problem is in the oral, pharyngeal, or esophageal phases of the swallow. Both of these techniques are objective and can assist in determining the severity of a problem and allow the clinician to suggest proper treatment.

### **What can I expect from swallowing treatment?**

Most of the swallowing problems experienced by persons with PPS can be treated. For example, if one side of the body is weaker, specific strategies can be used that can help swallowing be more efficient. There are other strategies that can help to develop better oral sensation, move food from the mouth through the throat, alter foods so that they can be swallowed safely and reduce risk of aspiration. Postures and positions can be used to help food enter the throat and esophagus without sticking. Some treatments use food, and others focus on muscle strengthening, biofeedback, and re-habilitation without food until the strategy is safe to use while eating.

Depending on what was found in the clinical and instrumental examination, treatment will be individualized to suit the findings and provide optimal help for each person.

Although PPS may be progressive in some cases, the strategies to improve swallowing can assist in stabilizing the swallow to maximize safety and provide adequate nutrition.

**Modified Barium Swallow:** A radiologic examination, performed while the patient swallows barium-coated substances, that assesses quality of the swallowing mechanisms of the mouth, pharynx and esophagus.

**Fiberoptic Swallowing Examination:** A procedure to diagnose swallowing disorders by inserting a flexible fiberoptic endoscope through the nasal passage into the hypopharynx, allowing direct observation of the pharyngeal and laryngeal structures during swallowing.

### **Suggested Readings and Websites:**

BC Sonies, Speech and Swallowing in Postpolio Syndrome (2004) in (Eds.) Silver JK & Gawne AC, Postpolio Syndrome, Hanley and Belfus, Philadelphia.

BC Sonies, Long-term Effects of Post- Polio on Oral-Motor and Swallowing Function. (1995). In (Eds) Halstead LS & Grimby G. Post-Polio Syndrome. Hanley & Belfus, Philadelphia.

Board Recognized Specialists in Swallowing and Swallowing Disorders website: [www.swallowingdisorders.org](http://www.swallowingdisorders.org)

American Speech Language Hearing Association, Special Interest Division on Swallowing.  
Rockville MD, [www.asha.org](http://www.asha.org)

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POST-POLIO HEALTH \_ Summer 2010 \_ Vol. 26, No. 3 [www.post-polio.org](http://www.post-polio.org)

## Swallowing

*By Frank C. Snope, MD*

Swallowing difficulties (dysphagia) occur in 10-15% of individuals with acute poliomyelitis and 10-20% of individuals experiencing the post-polio syndrome according to Terry Molsen, a speech pathologist from Ringwood, NJ. Ms. Molsen conducted a workshop on swallowing difficulties at the recent NJ Conference on Post-Polio Syndrome.

Ms. Molsen explained that swallowing was a complex mechanism involving many muscles and nerves in and around the throat. Polio can weaken these muscles, with the result that swallowing problems can arise.

The kind of swallowing problems that can occur in post-polio syndrome are coughing and choking, during and after eating, “sticking” in the throat, regurgitation of food, and difficulty managing secretions (e.g., saliva). The type of foods that cause the most problems are tough meats, nuts, popcorn, peanut butter, crisp vegetables, (e.g. carrots, apples), dry breads, medications, certain cheeses, and carbonated drinks.

Ms. Molsen provided a list of things that can be done to make swallowing easier:

1. Chew all food well
2. Slow the rate of eating
3. Alternate food with liquids to “wash” food down
4. Take smaller bites
5. Swallow everything before the next bite
6. Swallow several times per bite

7. Eat when less fatigued
8. Eat in a relaxed atmosphere
9. Eat the most difficult food first (when swallowing muscles are less fatigued)
10. Avoid problematic food or prepare it in a way that is easier to swallow (e.g. peel apple, blend carrots, etc.)

In addition to these suggestions, Ms. Molsen also noted that some individuals can reduce swallowing problems by turning the head to the right or left, or tucking the chin down when swallowing.

Finally, Ms. Molsen cautioned that swallowing difficulty is a symptom not a disease. Any persistent or unusual problems that do not respond to the suggestions given above should be discussed with one's physician. A referral to a speech pathologist for further evaluation may be necessary to eliminate other causes of swallowing problems and to plan proper management.

*Taken from New Jersey Polio Network Newsletter Fall 1995.*

### **Anesthesia—More recent information**

Dr. Calmes and Joan Headley of Post-Polio Health International have continued to research the relationship of polio to anesthesia in surgery and Dr. Calmes has come to the conclusion that based on the advances in types of anesthesia and anesthesia delivering techniques as found by reviewing the literature that “there is no reason polio patients should experience the problems of the past.” To read the full article, go to <http://www.polioplace.org/living-with-polio/more-mayo-clinic-study>.

## **Anesthesia Specifics for PPS**

*Selma Calmes, MD, (ret) Anesthesiologist*

*In the absence of any significant published information, the following is based on my clinical experience and ideas developed after extensive study of polio and PPS.*

*As more information becomes available, these will change. These are the recommendations on the PHI web site ([www.post-polio.org/ipn/anes.html](http://www.post-polio.org/ipn/anes.html)). I reviewed them and added an additional one, #9, and a comment.*

### **ANESTHESIA ISSUES FOR POST-POLIO PATIENTS:**

1. Post-polio patients are nearly always very sensitive to sedative meds, and emergence can be prolonged. This is probably due to central neuronal changes, especially in the Reticular Activating System, from the original disease.
2. Non-depolarizing muscle relaxants cause a greater degree of block for a longer period of time in post-polio patients. The current recommendation is to start with half the usual dose of whatever you're using, adding more as needed. This is because the poliovirus actually lived at the neuromuscular junctions during the original disease, and there are extensive anatomic changes there, even in seemingly normal muscles, which make for greater sensitivity to relaxants. Also, many patients have a significant decrease in total muscle mass. Neuromuscular monitoring during the operation helps prevent overdose of muscle relaxants.
3. Succinylcholine has often caused severe, generalized muscle pain postop. It's rarely used in the 21<sup>st</sup> Century.
4. Post-operative pain is often a significant issue. The anatomic changes from the original disease can affect pain pathways due to "spill-over" of the inflammatory

response. Spinal cord "wind-up" of pain signals seems to occur. Proactive, multi-modal post-operative pain control (local anesthesia at the incision plus PCA, etc.) helps.

5. The autonomic nervous system is often dysfunctional, again due to anatomic changes from the original disease (the inflammation and scarring in the anterior horn "spills over" to the intermediolateral column, where sympathetic nerves travel). This can cause gastro-esophageal reflux, tachyarrhythmias and, sometimes, difficulty maintaining BP when anesthetics are given.

6. Patients who use ventilators often have worsening of ventilatory function post-operatively, and some patients who did not need ventilation have had to go onto a ventilator (including long-term use) post-operatively. It's useful to get at least a VC (Vital capacity Measurement) pre-operatively, and full pulmonary function tests (PFT) may be helpful. One group that should all have pre-operative PFTs is those who were in iron lungs. The marker for real difficulty is thought to be a VC less than 1.0 liter. Such a patient needs good pulmonary preparation pre-operatively and a plan for post-operative ventilatory support. Another ventilation risk is obstructive sleep apnea in the post-operatively period. Many post-polios are turning out to have significant sleep apnea due to new weakness in their upper airway muscles as they age.

\*COMMENT: Post-operative respiratory failure in these patients can be difficult to manage. The patient's pulmonary physician could help by doing a pre-operative evaluation and being involved in post-operative ventilatory management. This situation might call for the resources of an ICU in a major medical center.

7. Laryngeal and swallowing problems due to muscle weakness are being recognized more often. Many patients have at least one paralyzed vocal cord, and several cases of bilateral cord paralysis have occurred post-operatively, after intubation or upper extremity nerve blocks. ENT (Ear, Nose & Throat specialist) evaluation of the upper airway in suspicious patients would be useful.

8. Positioning can be difficult due to body asymmetry. Affected limbs are osteopenic and can be easily fractured during positioning for surgery. There seems to be greater risk for peripheral nerve damage (includes brachial plexus) during long cases, probably because nerves are not normal and also because peripheral nerves may be unprotected by the usual muscle mass or tendons.

\*9. NEW IDEAS/THOUGHTS:

*Above-the-clavicle blocks (supraclavicular and interscalene):* These have a high risk for diaphragmatic paralysis and should probably not be used in PPS patients, unless the patient can tolerate a 30% decrease in pulmonary function.

**SUMMARY:** PPS patients can have anesthesia and surgery safely, with careful preparation. Anesthesia and surgery is a process that involves anesthesia, surgery and hospital care. For an optimal outcome, ALL must be at high levels of performance and achievement! You, the patient, must work to be sure you get these. Remember, few surgeries are truly urgent and you usually have time to get data from the web, the state's hospital licensing department, the state's medical board and other resources. You should also research the operation and its consequences, to be sure you can deal with them. Don't rush into anything until you're satisfied you'll get the best. You deserve it.

**Source:** Post-Polio Health International. [www.polioplacement.org](http://www.polioplacement.org). search Anesthesia.

## Post Polio Syndrome and Exercise?

*David Guy, M.S., CPT, Retired*

Yes, you can exercise even with post polio syndrome. What follows are a few short steps to get started.

1. Get a prescription from your physician for physical therapy.
2. Research whether there are PT who are knowledgeable about polio or specialize in neuromuscular conditions or geriatrics.
3. Set up an appointment with the physical therapist.
4. When you see the therapist:
  - a. Explain your concerns about your post polio
  - b. Explain your concerns and past experiences with physical therapy and exercise
  - c. What you wish to accomplish as result of exercise; what are your goals? Be specific and list the things you would like to do or do better as a result of the exercises
  - d. What you fear about starting to exercise
  - e. Other problems that you have that might interfere with your exercises.

5. Develop a daily schedule with your therapist's assistance
  - a. When to exercise and for how long
  - b. When to rest and for how long (rest is as important as exercise)
  - c. How to develop your schedule so that your chores are spread out through the day
  - d. How to assure that you never get fatigued
6. Ask your therapist to list the signs when continuing to exercise is okay and when you need to stop when exercise is not okay.
7. When you start to exercise see if there is a family member or friend that can be there for the first few times you do the exercises.
8. Start slowly and gradually build up:
  - a. The amount of time you exercise
  - b. The number of repetitions of the exercises you complete
  - c. The number of times per day that you exercise
9. Talk with your therapist and develop a program that is focused on your needs but also assure that the exercise program, at some point, includes:
  - a. Flexibility and strengthening exercises
  - b. Endurance improving exercises
  - c. Work simplification strategies (how to do things easier with less strain on your body)
  - d. Breathing exercises
  - e. Stabilization exercises (how to limit your risk for falls and strengthen your abdomen, chest and back)
  - f. Transfer activities (how to get in and out of things easily and safely)
  - g. Walking exercises
10. Be ready to reap the rewards of an exercise program designed specifically for you. You, indeed, can exercise with post polio syndrome by following these steps. If you do you will take back more control of your life and limit the effects of your post polio syndrome.

## Assistive Devices and Accessibility

### You got That Darn Cane, Crutch(es), Walker and Now What?

*By Marny K. Eulberg, M.D.*

These days frequently, especially if your insurance is an HMO, after the doctor has written a prescription for the cane, the crutch or crutches, or the walker, the prescription is sent to a Durable Medical Equipment vendor who then gives it to a truck driver to deliver to your home. The truck driver has no training or skills in fitting these devices or teaching you how to use it; he/she is hired for their delivery and driving skills! Or, you may decide to get that cane out of the closet that a relative used, dust it off, and use it yourself!

So, you have this piece of equipment sitting in your front room. What do you do with it? First of all, recall what its purpose is—to help you walk better and/or prevent falls. The ideal situation would be that, in addition to the prescription, for the equipment, your health care provider also wrote a prescription for one or more physical therapy appointments so that a physical therapist can adjust the device to fit you and help you learn to use it the most effectively. This is especially useful if you are using this type of assistive equipment for the first time.

What height should the handgrip on the device be? Most of us have observed a person using a cane or walker that seems too low as they are bent far forward leaning on the device or they are walking with their elbows bent nearly to a 90-degree angle and thus are only able to put a small amount of pressure on the handgrip.

Here are a few guidelines for correct height of the handgrips of canes, crutches, and walkers: 1) when using the hand-held device the elbow should be bent at about 15 degrees (so slightly bent), 2) the hand grip should be at a level that is opposite the bony prominence of your thigh bone {medical term = greater trochanter of the femur}; depending on your height, this is usually about 6 ½ inches below your waist, and 3) with your arms hanging loosely at your sides, the hand grip should be even with the crease in your wrist or the place where you'd wear a wristwatch. (This guideline may not work if you have had surgery to stop the growth of one of your legs and hence your leg lengths are not proportional to your arm length and upper body proportions.)

Generally, it is recommended that you use a cane or a single crutch in the hand **OPPOSITE** the weaker or painful leg. Intuitively, this seems to be the *wrong*

side but it allows the most natural walking pattern! Don't model your cane use after actors on TV – Fraser Crane's father and Dr. House both use the cane on the wrong side on the TV screen!! When you watch people walk, they swing their right arm forward as the left leg moves forward and the left arm goes forward with the right leg. So, if you use a cane or single crutch usually it is best to hold it in the opposite hand (left hand for weak right leg and right hand for weak left leg) and swing the cane forward as you move the weaker leg forward. Using it in this manner also decreases the lean of the trunk/body to the side of weakness. But, of course, if you have a weak hand/arm or painful shoulder/wrist/elbow on the "correct" hand then you may need to use the cane or crutch on the same side as the weak leg.

There are attachments that can be purchased for cane and crutch tips to allow better traction in snow and ice, but they must be "retracted" when going indoors to avoid punching holes in tile and linoleum and to allow the better traction provided by the rubber tip when on smooth surfaces. Some attachments for canes go around the wrist so that a person can reach for an object without having to put the cane down, helping prevent losing the cane. There are also devices that allow one to balance a cane on the edge of a table or counter and keep it nearby and out of the way of others.

So, walk well and safely!

On-line resources:

<https://www.healthline.com/health/how-to-walk-with-a-cane>

<https://www.verywellhealth.com/tips-for-walker-use-2552074>

<https://seniorsafetyadvice.com/how-to-use-a-walker-properly/>

## Bracing in the 21<sup>st</sup> Century

*By Marny K. Eulberg, M.D.*

Polio survivors experiencing both old and/or new weakness may benefit from some of the new or improved bracing technology now available. Survivors who wore bracing in their younger days but then were able to “graduate” from the braces may now seek the help of the orthotist (brace maker) for the first time in years. Others may be needing a brace for the first time in their lives. Those who have worn braces since their acute polio may wonder if orthotic technology has improved (We all have seen the amazing advances made in prosthetics.) and if there are new materials and/or new designs that might better meet their needs. For some long-time brace users, the trusted orthotist that they have worked with for decades is now retiring. And some discover that it is getting more difficult to find someone who can make a brace using the tried-and-true materials or someone who can repair their trusty old brace.

The questions, concerns, and needs of each of these groups of people are frequently different. It is important that multiple factors and desires for each individual be considered in the design of the brace or it may end up in a closet, basement, or attic and never be worn. This outcome benefits no one except, perhaps, the orthotic company’s bottom line!

*For a complete overview on lower extremity bracing, including a workbook to help you get your best brace, search [www.HumanGaitInstitute.org](http://www.HumanGaitInstitute.org)*

*To find a certified orthotist in your area, go on-line to the American Board of Certification of Orthotists, Prosthetists at [www.abcop.org](http://www.abcop.org).*

## **Informed Consumer Information—Bracing**

*By Margaret Hinman and John Callan, C.O, L.O, orthotist, Colorado Springs, Colorado.*

Acquiring bracing, whether for the first time or as a replacement for a current brace, involves not only a major financial decision but also has significant physical and emotional implications. For polio survivors who have not used brace(s) in many years and who celebrated the time when they got rid of that old leather and metal monstrosity, the return to bracing because of returning weakness and the effects of aging can result in grief for the loss of former mobility. It can also recall the memories of the times when they originally wore braces.

For those people, dealing with those issues will help the wearer be more amenable to wearing the brace(s), which will ultimately improve mobility, provide for increased safety and improve the quality of life. By dealing with the emotional issues up front, wearers can then focus on orthopedic problems or neuromuscular problems, can seek out the many bracing options such as custom fabrications or make use of off-the-shelf orthotics.

1. Bracing options—Find out what kinds of braces this orthotist can/is willing to provide. There are many different orthotic products available and an exploration of the options will help you make the decision about what will work best for you. Find out what materials are available, what kinds of joints are available and what the different designs will do and not do. Also, involved in this part of the decision is whether the brace will come off the shelf, will be custom built in house or come from another vendor.

New bracing technology and changes in functionality can mean that one may not need the same kind of brace that has been traditionally worn. For example, persons who have traditionally worn a short leg brace (AFO or ankle-foot orthotic) may need to now use a long leg brace (KAFO or knee-ankle-foot orthotic). And technology is also available that allows some traditional KAFO wearers to only need an AFO.

2. Casting—Learn how the orthotist is going to do the casting. To be fitted for a custom brace, a cast will be made to provide a mold for the fabrication of the brace. How the cast is applied will affect how the brace fits. Orthotists can cast with the client lying down, sitting up or standing. A standing casting will more closely approximate how the client will use the brace while standing and walking. For those of us who cannot stand

independently, the orthotist should have parallel bars so that the client will have something stable to grasp while being casted.

Also, learn if the orthotist will cast you as you are or will include corrections in the brace. For example, corrections can include such things as realigning foot and leg deformities and correcting leg length differences.

3. Building the brace—Find out who does the design work, who modifies the cast, who makes (fabricates) the brace. Usually, the orthotist who has done the casting can best modify the cast because (s)he has done the casting and knows the intricacies of your particular case. However, some orthotists specialize only in doing the casting, leaving the modification process to a technician and then sending the cast to a fabricator who builds the brace based on the modified mold.

There may not be an issue with this process but knowing that this is how the process is done by this orthotist can help pinpoint potential problems in the future, if they arise.

4. Follow-up and repairs—The next issue to discuss is what the orthotist will do after you take possession of the brace. Does getting the brace from this orthotist include follow up, and how much, and modifications, or are you stuck with the brace you take home? Is the orthotist willing to work with the client until the brace fits right and comfortably? Some orthotists will not do this, so it is wise to have this information up front. Does the orthotist guarantee satisfaction for the brace, and what does that guarantee mean? What happens if the brace does not work to your satisfaction? And is there additional cost for this service?

Repairs and turn-around time when something goes wrong or breaks are part of the reality of wearing a brace, especially if worn for a long time. When a person has only the brace (s)he wears and the brace needs to be modified or repaired, the wearer can be immobilized without it. Some orthotists are sensitive to this, and some are not, so it is helpful to know up front what the policy is and what to expect, particularly in an emergency.

The wearer's expectations also factor in. Many brace wearers get a new brace after wearing the old comfortable one for years and years and want the replacement to be exactly like it. Duplicating a brace exactly may not be possible even if the materials and the design are the same, because over time a brace structure changes gradually and often subtly, leaving the

wearer of the new brace with feelings that the duplicate is not like the old one.

5. Physical therapy—It is beneficial to have some training in wearing the new brace. Because learning to wear a new brace takes time and practice, a physical therapist can provide invaluable help in adjusting to it, helping with gait and balance issues and in helping identify whether modifications might make the brace work better, fit better or be more comfortable. This is especially helpful if the client is requiring a duplicate of an old brace. Learn whether the orthotist works with a physical therapist. If not, find a physical therapist who will help you. Also, find out if you can bring that physical therapist with you to the casting and the fitting. Such a team approach will help you function better and provide more comfort and satisfaction in wearing the brace.
6. Insurance—It pays to check with the orthotist to make sure that the insurance company will pay their share of the cost of the brace. Also, before being casted, find out if the orthotist needs to check with the insurance company. This can save the surprise of getting that bill when you expected the insurance company to pay for it.

These are some of the issues that should be considered when getting a new brace. This will facilitate achieving the ultimate goals of bracing, to increase and improve functionality, to provide safety and to improve the quality of life of the wearer. Being informed about the brace you will be wearing before you get it will go a long way towards achieving those goals.

**Colorado Post-Polio Connections—Winter 2009**

## Being an Informed Consumer When Buying Wheels

*By Margaret Hinman*

Purchasing wheelchairs, scooters, vans, lifts and other wheeled mobility devices means a significant outlay of money and time, so it makes sense to do the work and the research needed before getting “wheels.” Getting the correct wheeled device for the user is important not only from a financial point of view but also, and especially, from a health and well-being perspective. The wrong device can be harmful physically and can affect the motivation to use it. So, here are some things to consider when getting “wheels”:

- **Medicare and most other insurances pay for its portion of the cost of a wheelchair only if it is needed to help you get around in your home.** This applies to manual wheelchairs as well as powered mobility devices. To qualify for a powered mobility device, you must be unable to propel a manual wheelchair independently.
- **Find out up front what your DME (Durable Medical Equipment) part of your insurance covers**—Check either with the customer service representative of your medical insurer or your vendor before ordering a chair/scooter to see what the procedures and the limits are on getting a chair/scooter. Be aware that not all wheelchair vendors are able to bill Medicare or other health insurances.
- **Know your goals and your limitations**—before purchasing a wheeled device, ask yourself what your goals and limitations are in relation to what you are getting. Look at such factors as how and where you want or need to use the device. Assess your ability to get into and out of the device and what you will need to access it. Look at the long term, particularly in making a decision about getting a scooter or a chair and think about what your physical capacity might be in the future. Medicare recipients need to look especially at the long term because benefits for chairs are available only once every five years.
- **Know your vendor and the range of the products that are available**—There are many durable medical equipment vendors and products, not only in cities but also on the Internet. When shopping for vendors, be sure to assess your comfort in working with the vendor because you don't want to feel pressured into buying something that does not fit within your needs and your goals. Also, there are many bells and whistles available for the various

choices and it helps to know which ones are necessary for you and which ones you can live without or not need at all.

- **Learn about follow-up and repairs before you purchase a chair or scooter**—Different vendors and chair/scooter companies have different policies regarding follow-up and repairs, so it makes sense to ask questions before ordering a chair from a vendor. This is particularly important if you are being fitted with a custom wheelchair. Some of the questions to ask include: What is the policy on follow up? What happens if the chair/scooter does not fit to my satisfaction and meet my needs? Do I have to pay for modifications on the original chair and, if so, within what time period? How much follow-up and modification is allowed before the client has to pay for further modifications? Can repairs and modifications be done in my home, or will my chair need to go to the shop to be repaired? If my chair needs to go to the shop, do you have a replacement loaner policy until the work is done? How long does the warranty last?
- **Be aware of issues related to using it in your environment**—Knowing how you are going to use a wheelchair or scooter at home and how you are going to transport it when going out may determine which wheels you choose. In your home, will you need to widen doorways and halls to be able to move around? Will it fit into your bathroom, and can you transfer to and from it to the toilet? Will you need to move or remove furniture to accommodate the use of the machine? When you leave home, are you going to need a ramp to get it into and out of your home? What is involved in getting it into and out of a vehicle? Will it fit into your current vehicle? Can and will your current vehicle need to be modified by adding, for example, a ramp or a lift to fit or transport the chair or scooter? Will you need a more accessible vehicle, instead? These concerns are complicated by the fact that Medicare and most other insurance companies will only pay for the chair or scooter and not the modifications needed to accommodate it. Answers to these questions can help you determine which wheelchair or scooter best fits your needs.

By being an informed consumer, you can prevent what could potentially be a nightmare experience and can look forward to many years of improved mobility.

**Colorado Post-Polio Connections—Spring 2009, edited January 2022**

## **Accessible Technology — Making Life Easier!**

*By Paul Snell*

The 21<sup>st</sup> century has brought a revolution in communication tools and the 2020's have opened up the use of electronics to making our lives easier in our home, particularly if we have a disability.

First, let's talk about the smart phone. Almost everyone in our generation uses their smart phone to make phone calls or to send text messages. Many of us didn't really embrace texting at first but found that to communicate with the younger generation it was a necessity. As the phones developed so did the cameras in the phones and we started taking and sending more and more pictures. Then came the internet on the phone and with that came email. So now we have a great communication device. It really doesn't matter if you have an Apple iPhone or one of the variations of the Android operating system, they both work very well. Now we are discovering that our smart phone is a remarkable control device for our home.

In addition, the smart phones have picked up several very useful "accessibility" functions. When I was first diagnosed with post-polio syndrome, my head seem to dwell for a time on "What if." What if I hadn't had polio, what if my leg would work and didn't hurt, just what if. Gradually I began to change my focus to "What if" I can find ways for technology to make my life better. That is what the phone makers have been doing.

As a couple of examples, the iPhone has a terrific "magnifier" that uses the camera and the screen on the phone as an electronic magnifying glass. It is incredibly useful especially if you have any limited vision. There are other multiple assistive functions for people with vision problems as well as multiple functions for those of us with hearing disabilities. Those can be found under the "Accessibility" section of Settings. In addition, there are alternative ways to "trigger" the device if your disabilities are in your hands and arms. These are just a few of the features specifically designed to work for those of us with disabilities.

For many of us, the phone has now become our primary control device for many products that are specifically designed for persons with disabilities. Let's start with lighting. In the past it has been necessary to select lighting products based on the operating system of your phone. In 2022, some products currently work with Siri on Apple phones, others worked with Android operating system on phones such as Samsung, LG and others, and some with Google phones. Now, some manufacturers have been able to create products that will work with multiple operating systems. Phillips Lighting has been a leader, but their bulbs have been

very expensive and required an Alexa device to control them. Now the big Three (Apple, Amazon and Google) have developed a new protocol so that any device can use any product made by third party companies. This will be on the market soon and is great news for consumers.

In my house I have a bulb in my lamp in my living room made by Nanoleaf. The A-19 bulb can be controlled by Android or Apple phones and is very useful. For instance, to turn my lamp on or off, I used to have to get out of my lift chair and walk around the table just to reach the switch. Now I push a button on my phone or by voice control and the light comes on. I can also control the color of the bulb (Green at Christmas perhaps) as well as controlling the on/off/dimming function. And the bulb is only \$20.00 (in 2022). Instead of just a bulb, you can also select a smart plug and control anything that plugs into the wall from your phone. At this time, you must select a brand that works with the phone that you use. Check the Apple App Store or the Google Play store for products that work with your phone.

“Smart” thermostats on the furnace and/or air conditioner can “learn” how you want the temperature to be at various times of day. If you want to modify it either up or down, again you can do it by voice control through your smart phone.

A secure “smart” dead bolt lock on the front door allows you to unlock the door for anyone you want to let in your home without having to struggle to get to the door. And it is a safety feature which will allow first responders to enter your home if you cannot get to the door.

In 2022, there are a few other home devices that work well for those of us with mobility issues or dexterity issues. For example, those of us who have issues in their arms and upper body may have difficulty adjusting window coverings. That makes opening drapes or blinds difficult or impossible to open and close. There are now several brands of shades that can be controlled by your phone, by a small remote control or by voice control. These are a game changer for many people.

The next useful device is a Wi-Fi connected garage door opener. This may sound unnecessary, but it saves going to the garage when you need to check the door to be sure it is down. And it can let a delivery person into the garage. That task is made much easier by just checking on your smart phone.

Another incredibly useful Wi-Fi addition is for a ceiling fan. Many of us have an impossible task of reaching the chains on the older fans and a difficult time getting to a fixed switch on the wall. Several very good brands have added Wi-Fi allowing you to control the fan and the light from your chair or bed.

Finally, let's look back at the phone. Its function has obviously changed a lot. My grandparents' phone had no dial, no buttons, and to use it to make a call you simply picked up the receiver, an operator answered and connected your call. This has been quite a change in our lifetime. The important thing to remember is that we now have a powerful tool that will continue to evolve and to provide additional assistance to those of us with disabilities.

## Some Resources for Polio Survivors in Colorado

**SOME MEDICAL PROFESSIONALS THAT CPPO KNOWS ARE FAMILIAR WITH POLIO AND POST-POLIO SYNDROME.** This list is temporary and incomplete.

- **Marny Eulberg, M.D.**  
 Mountain & Plains Post-Polio Clinic  
 9461 W 37<sup>th</sup> Place  
 Wheat Ridge, CO 80033  
 303-829-1538 (call for an appointment)  
*This is the only Post-Polio Clinic in Colorado, and its purpose is to evaluate and make recommendations for polio survivors.*
- **Steve Medberry, DPT**  
 Colorado Orthopedic Rehabilitation  
 11325 Colorado Blvd.  
 Thornton, Co 80233  
 303-457-2022
- **Julie Trail, DPT**  
 A Personalized Physical Therapist  
 720-448-6820  
[Julie@apersonalizedPT.com](mailto:Julie@apersonalizedPT.com)
- **Christian Bailey, CPO (Certified Prosthetist/Orthotist)**  
 Rise Prosthetics & Orthotics  
 695 South Colorado Boulevard  
 Denver, Colorado  
 303-346-1906  
 866-856-2070  
<https://RiseProsthetics.com>  
*Rise P & O has several locations in the metro Denver area*
- **Evergreen Prosthetics & Orthotics**  
 Evergreenpo.com  
*Offices in Denver & Lakewood*
- **Hanger Clinics: Prosthetics & Orthotics**  
<https://Hangerclinic.com>  
*Many locations across Colorado*

## **LOW-COST RESOURCES FOR HEALTH-RELATED EQUIPMENT/SUPPLIES**

### **Good Health Will**

Stores and warehouses in Greeley & Loveland

[www.goodhealthwill.org](http://www.goodhealthwill.org)

### **Dave's Locker**

[www.daveslocker.org](http://www.daveslocker.org)

**Thrift stores** often have a supply of canes, walkers, and other assistive Devices.

### **Colorado Post-Polio Organization**

Supplemental grants to help defray the costs of assistive devices

Available for Colorado post-polio survivors only

*Loan closets and other lending services may have specialized or limited equipment to loan. They also may have loan term limits. Check carefully to see what they offer and how they work.*

### **South Metro Medical Equipment Loan Closet**

720-443-2013

<https://medicalequipmentloan.org/>

### **Assistance League Denver Hospital Equipment Lending Program**

720-638-3650

<https://www.assistanceleague.org/denver/2020/05/12/hospital-equipment-lending-program/>

### **Tri-Lakes Cares**

235 North Jefferson St (Physical Location)

P.O. Box 1301 (Mailing Address)

Monument Colorado 80132

<https://tri-lakescares.org>

### **Center for Independence**

740 Gunnison Avenue

Grand Junction, Colorado, 81501

970-241-0315

[www.cfigj.org](http://www.cfigj.org)

Offices in Grand Junction, Montrose, Glenwood Springs, and Salida

## **WEB SITES THAT PROVIDE ARTICLES, ISSUES AND DISCUSSION REGARDING POLIO AND POST-POLIO SYNDROME**

- [www.post-polio.org](http://www.post-polio.org) This is the official web site for Post-Polio Health International in St. Louis, MO. It not only provides articles relevant to polio and Post-Polio Syndrome, but also lists locations of support groups, medical professionals, and sources of financial assistance.
- [www.polioplace.org](http://www.polioplace.org) Stories, video lectures on topics related to polio.
- [www.ventusers.org](http://www.ventusers.org) Information specific to using mechanical ventilation.
- [www.eastersealscolorado.org](http://www.eastersealscolorado.org) From the home page, click on Our Programs and then Post-Polio. This links to news about polio survivors in Colorado, recent past issues of the *Colorado Post-Polio Connections* newsletter and other resources.
- [www.papolionetwork.org](http://www.papolionetwork.org) Monthly newsletter.
- [www.mayoclinic.org](http://www.mayoclinic.org) General website related to health issues, including polio, post-polio syndrome, vaccinations and other related topics.
- [www.newmobility.com](http://www.newmobility.com) The magazine and online site is devoted to active wheelchair users and encourages the integration of active-lifestyle wheelchair users into mainstream society.
- [www.webmd.com](http://www.webmd.com) A general medical web site that has information related to polio, post-polio syndrome and other polio related topics.

## **BOOKS, DVDS, VIDEOS, CASSETTES**

The Colorado Post-Polio Organization (CPO) has a lending library available to Colorado Support Group Facilitators, and post-polio survivors. To get a list of and borrow available resources, contact:

Mitzi Tolman, Program Co-Ordinator  
 message phone (720) 940-9291  
[mtolman@eastersealscolorado.org](mailto:mtolman@eastersealscolorado.org)

*\*DISCLAIMER: Health Care Professionals and web site referrals are not endorsed or approved by either the Colorado Post-Polio Organization or Easteseals Colorado. ALWAYS check with your personal physician for all medical questions, concerns, and referrals.*