

Polio Survivors of Montana

POLIO THE LIFE AFTER



Larry Rapstad
and
Father

Surgery and Braces
Recovery and Rehabilitation



Larry Rapstad
and
Wife Cindy
the day they were wed

Possibility of a Normal Life

Relapse
Weakening of Muscles
Fatigue
Disability



Larry Rapstad
and wife Cindy
at Marine Corps Pinning
Ceremony for their son



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POST POLIO SYNDROME

As defined by the Mayo Clinic, March 2011:

Post-polio syndrome (PPS) refers to a cluster of potentially disabling signs and symptoms that appear decades — an average of 30 to 40 years — after the initial polio illness.

Polio was once one of the most feared diseases in America, responsible for paralysis and death. Shortly after polio reached its peak in the early 1950s, the inactivated polio vaccine was introduced and greatly reduced polio's spread.

Today, few people in developed countries get paralytic polio, thanks to the polio vaccine.

According to some studies, however, up to half the people who had polio at a young age may experience certain effects of the disease many years later — post-polio syndrome.

* * *

As defined by Post-Polio Health International, August 2011

Post-polio syndrome is a new condition that affects the survivors of polio decades after the acute illness of poliomyelitis. The major symptoms are pain, fatigue and weakness. New weakness is considered the hallmark of post-polio syndrome. Less commonly, survivors may have new sleep/ breathing/swallowing problems and some survivors may also experience muscle atrophy or muscle wasting.



SESSION S1

First Step in Pain Treatment: Finding the Cause

Amy Clunn, MD, Southeastern Rehabilitation Medicine, Ocala, Florida

Paul Peach, MD, Palmyra Post-Polio Clinic, Albany, Georgia

William DeMayo, MD, John P. Murtha

Neuroscience and Pain Institute (JPMNPI),

Johnstown, Pennsylvania

Dale C. Strasser, MD, Emory University School of Medicine, Atlanta, Georgia

The First Step in Treating Pain: Finding the Source

Amy Clunn, MD, Southeastern Rehabilitation Medicine, Ocala, Florida

Dr. Clunn will present the common pain generators in polio patients and help identify ways that the patient can better communicate with his or her physician in regard to symptoms, and outline the process by which the physician should identify the pain generators so that effective treatment can be determined.

Dr. Clunn completed medical school at the University of Cincinnati in 1993, followed by internship at Oakwood hospital and an additional 3 year residency in physical medicine & rehabilitation at the University of Michigan in Ann Arbor, where she also served as chief resident. She now practices with Southeastern Integrated Medical. PL., a multidisciplinary integrated health system in North Central Florida, (in Ocala) full-time.

Dr. Clunn is board certified in Physical Medicine & Rehabilitation and also in the subspecialty of Pain Medicine. She is a member of the American Academy of Physical Medicine & Rehabilitation, The American Academy of Pain Medicine & the American Academy of Electro diagnostic Medicine as well as the Florida Medical Association, Florida Society of PM&R and the Marion County Medical Society. Dr. Clunn is the Physician consultant for the North Central Florida Post-Polio Support Group.

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

Post-Polio Health International including International Ventilator Users Network www.post-polio.org

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 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 fractures with falls or even a traumatic 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 out of 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 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 walker users (repetitive gripping with or without direct compression), or a gluteal 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 of 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 more 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.

Living with Polio in the 21st Century at RWSIR, Warm Springs, GA April 23-25, 2009

The circulatory system can also be affected by polio, particularly in limbs that are paretic (weak or paralyzed), and 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 ulcerations. 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).

Pain Symptoms in Polio Survivors

Paul E Peach, MD

Medical Director & Post Polio Clinic

Albany, GA

- I. Polio survivors, like all people, experience pain throughout the course of their lives.

What distinguishes polio survivors, however, is that due to the residual effects of polio, they will be more likely to experience pain that is due to chronic effects of polio, as well as, in some cases experiences pain from common problems experienced in the general population, but potentiated by the effects of chronic polio.

II. Post Polio Pain

Post polio pain may manifest as pain in muscles, joints and tendons.

a. Myalgias-(muscle pain)

This commonly manifests as cramping, aching pain in muscles and often accompanied by fasciculations and fatigue.

b. Arthralgias-(joint pain)

Pain in the joints due to chronic and acute over stresses in joints and their ligaments, as well as, in many cases, degenerative changes in joints which have been potentiated by many years of abnormal over stressors.

c. Tendonitis-(tendon pain)

Pain that occurs near joints that is often due to chronic overuse of muscles. Pain in shoulders, elbows and hips are common problems.

III. Non Polio Pain

Non polio pain may occur acutely or chronically potentially due to a wide range of etiologies, some serious and other easily treatable, and must be accurately diagnosed to distinguish from post polio pain etiologies. Additionally, Post polio pain symptoms and non polio pain symptoms, not uncommonly exist.

a. Compressive Neuropathies

-Carpal Tunnel Syndrome

-Ulnar Neuropathy

- b. Radiculopathies
- c. Degenerative Joint Disease
- d. Fibromyalgia

IV. Summary

The foregoing list of causes of both post polio and non polio pain touch on a relatively few etiologies of pathologies that can manifest as pain symptoms in either post polio survivors or people with no history of polio.

- this underscores the importance of getting an accurate medical diagnosis.
- as earlier stated, pain symptoms may be due to relatively benign disorders or symptoms of more serious disease.
- in either case, an early diagnosis will lead to an earlier diagnosis and appropriate intervention and treatment.

PAUL E. PEACH, MD
MEDICAL DIRECTOR AND PALMYRA POST POLIO CLINIC
810 13TH AVENUE, SUITE 105
ALBANY, GA 31701
229-446-8960



Anesthesia Use in Polio Survivors: What's New?

Selma H. Calmes, MD, Chairman and Professor (retired), Anesthesiology Department, Olive View/UCLA Medical Center, Sylmar, California, shcmd@ucla.edu



Selma H. Calmes, MD, is a polio survivor and a member of PHI's board of directors.

Do we know anything new about anesthesia for polio survivors? By reviewing reports in medical journals we find that in the last two years, 2008-2010, there were five case reports (each about a single post-polio patient having anesthesia) in the medical literature and one study of a group. We will look at useful aspects of these cases and also comment on two other aspects of anesthesia care that are important.

Three of the five case reports were about regional anesthesia (RA). Regional anesthesia means that a local anesthesia drug, such as lidocaine, is injected to numb nerves in the back (spinal or epidural) or other body locations such as arms or legs (various nerve blocks). It is very safe and is preferred to general anesthesia, because it blocks the pain signals coming from the surgery site to the brain. This is very favorable for patients' well-being. However, some operations can't be done with regional anesthesia. It is often technically hard to do RA in post-polio patients with scoliosis, especially if Harrington rods are present.

There is a new tool to help place RA: portable ultrasound (US) devices that help anesthesiologists find exactly where to administer the anesthesia drug. This technique is now commonly used in the United States, especially in teaching hospitals. One of the five cases was the first to report using US to place a spinal anesthetic in a post-polio patient with Harrington rods. Another case of regional anesthesia involved severe scoliosis and reported using a computed tomography (CT) scan to look at a post-polio patient's back

anatomy before trying spinal anesthesia. Both techniques helped the anesthesiologists know where to place the needle for local anesthesia successfully and easily. The third case report on regional anesthesia was about a nerve block of the leg for postoperative pain relief after surgery on that leg.

The group study was from Brazil and reported on 123 patients having 162 operations, mostly orthopedic surgery. Mean patient age was young – 35 years, and only three patients had serious medical diseases in addition to having had polio. Regional anesthesia was used for 64 percent of patients. No significant anesthesia complications occurred. These patients were followed for 22 months postoperatively, and there was no change in neurologic status.

This study documents that young post-polio patients do well during anesthesia, especially with RA. However, American patients are much older, in their 70s and 80s, and so also have diseases of aging, such as heart disease, diabetes and hypertension, all significant for anesthesia risk.

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Often, these diseases of aging are much more important than any post-polio issues. So, we still need a large group study of the U.S. polio population during anesthesia.

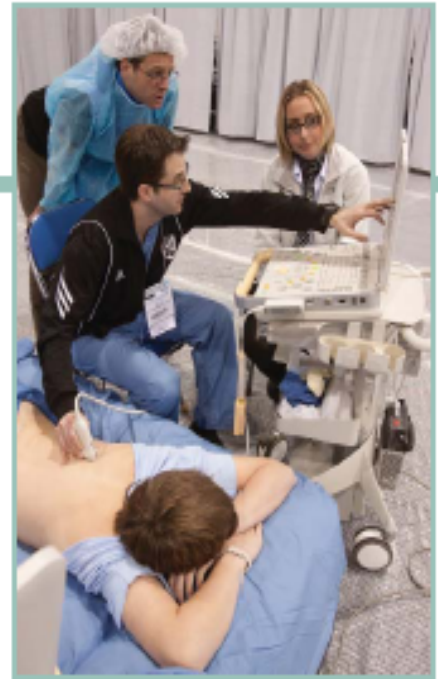
What do we learn from these reports? First, this is increasing evidence that RA can be safely used in post-polio patients. And, so far, there is no evidence that PPS gets worse after RA. (This had been a concern after inflammatory proteins were found in the spinal fluid of some post-polio patients.) Technical difficulties can be overcome by using US or CT imaging. Also, regional anesthesia can safely be used for postop pain relief. So polio patients can experience the many benefits of modern anesthesia care!

The importance of two other aspects of anesthesia care for post-polio patients is becoming clearer: the need for preoperative pulmonary function tests and sleep apnea issues. Respiratory muscle function gets worse as we age, especially for those who had polio. It is important to know what a particular patient's pulmonary status is before most operations, especially upper abdominal or chest operations. This is measured with pulmonary function tests (PFTs) by a pulmonary physician. Those who used iron lungs should definitely have preop PFTs, because they seem to be at higher risk for postop respiratory failure. Lung function should be optimized by treating any infection, controlling bronchospasm and assisting coughing before high-risk patients have major surgery, and a pulmonolo-

gist needs to be involved in the postop care.

Sleep apnea is common in post-polio patients, and many need CPAP/BiPAP devices. Sleep apnea is well-documented to be a risk factor for anesthesia incidents, both at the beginning of anesthesia and, especially, at the end of the case as patients begin to breathe on their own. Useful guidelines are in place to improve safety during anesthesia. Patients with sleep apnea, especially those on CPAP/BiPAP, should let the surgeons know this early in the surgery scheduling process, so they can alert everyone on the surgical team. Patients should bring their CPAP devices to the hospital and, after the breathing tube is removed, CPAP should begin. This requires someone to set up the machine, usually a respiratory therapist. If regional anesthesia is used, the CPAP device can even be used during the procedure, although not all anesthesiologists are comfortable with this.

Should we make any changes in the present recommendations for anesthesia for polio survivors? Regional anesthesia appears to be safe for post-polio patients, and the benefits – in terms of pain relief and anesthesia safety – are worth a possible small risk. So, the recommendations stand as is. It is essential to realize that the recommendations are not based on actual data; there is no significant data yet about how polio patients actually do during anesthesia. See the sidebar for other resources about anesthesia. ▲



Anesthesiologists at their annual meeting learn how to use ultrasound to place a nerve block of the arm or shoulder.

Photo by Steve Dorlach courtesy of the American Society of Anesthesiologists

For more information on anesthesia:

Recommendations: www.post-polio.org/edu/hpros/sum-anes.html

Anesthesia update. Separating fact from fear: www.post-polio.org/net/10thConfAnesthesiaCalmes.pdf

Sleep apnea issues: www.post-polio.org/edu/pphnews/pph22-1.html

Lambert DA et al. Postpolio syndrome and anesthesia. *Anesthesiology* 2005; 103:838-844

SUMMARY OF ANESTHESIA ISSUES FOR THE POST-POLIO PATIENT

SELMA H. CALMES, MD, (SHCMD@UCLA.EDU) CHAIRMAN AND PROFESSOR, (RETIRED)
DEPARTMENT OF ANESTHESIOLOGY, OLIVE VIEW
UCLA MEDICAL CENTER, SYLMAR, CALIFORNIA

Polio results in widespread neural changes, not just destruction of the spinal cord anterior horn (motor nerve) cells, and these changes get worse as patients age. These anatomic changes affect many aspects of anesthesia care. No study of polio patients having anesthesia has been done. These recommendations are based on extensive review of the current literature and clinical experience with these patients. They may need to be adjusted for a particular patient.

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 intraop helps prevent overdose of muscle relaxants. Overdose has been a frequent problem.
3. Succinylcholine often causes severe, generalized muscle pain postop. It's useful if this can be avoided, if possible.
4. Postop 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-op 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, tachyarrhythmia's and, sometimes, difficulty maintaining BP when anesthetics are given.
6. Patients who use ventilators often have worsening of ventilatory function postop, and some patients who did not need ventilation have had to go onto a ventilator (including long-term use) postop. It's useful to get at least a VC preop, and full pulmonary function studies may be helpful. One group that should all have preop

PFTs is those who were in iron lungs. The marker for real difficulty is thought to be a VC <1.0 liter. Such a patient needs good pulmonary preparation preop and a plan for postop ventilator support. Another ventilation risk is obstructive sleep apnea in the postop period. Many post-polios are turning out to have significant sleep apnea due to new weakness in their upper airway muscles as they age.

7. Laryngeal and swallowing problems due to muscle weakness are being recognized more often. Many patients have at least one paralyzed cord, and several cases of bilateral cord paralysis have occurred postop, after intubation or upper extremity blocks. ENT 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.

For more info: Review "Post polio Syndrome and Anesthesia" by David A. Lambert, MD; Elenis Giannouli, MD; & Brian J. Schmidt, MD, The University of Manitoba, Winnipeg, Canada, in the September 2005 issue of *Anesthesiology* (Vol. 103, No. 3, pp 638-644). This article reviews polio, post polio syndrome and anesthetic considerations for this patient population.

Post-Polio Health International (PHI)

Including International Ventilator Users Network

4207 Lindell Blvd., #110, Saint Louis, MO 63108-2930 USA

314-534-0475 (Hours: 8:30 am–4:30 pm CT, Monday-Friday); 314-534-5070 fax

info@post-polio.org (Inquiries should include name and mailing address.)

www.post-polio.org

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 (ventinfo@post-polio.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 (CO₂) 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

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- ◆ shallow breathing or pauses in breathing
- ◆ 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.post-polio.org/ivun/d.html).

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 H₂O)
- ◆ MEP — maximum expiratory pressure (<60 cm H₂O)
- ◆ peak expiratory cough flow (<300 L/min)
- ◆ end-tidal CO₂ (>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 ventilation may eventually fail, and invasive tracheostomy positive pressure may be necessary.

Treating underventilation with oxygen therapy instead of assisted ventilation can lead to respiratory failure and death because supplemental oxygen

Question: *Why would my physician add oxygen to bilevel positive pressure ventilation, such as BiPAP®, if there is no underlying lung problem?*

Answer: It would be extremely worthwhile to request that PHI members who use a ventilator due to post-polio breathing problems ask that their physicians explain their oxygen advice so we can all benefit, or at the very least develop a list of justifications that can be reviewed. The question is simple and can be stated, "The use of oxygen for people with neuromuscular disease without any lung disease or pneumonia is a subject of considerable interest, and some controversy. Please explain why oxygen is advised as part of my post-polio treatment plan." Send your physician's comments to PHI (editor@post-polio.org).

A physician might advise adding oxygen to BiPAP® when there is no underlying lung problem, if the person is traveling by air, where the air has a lesser concentration of oxygen. Another possibility is that the bilevel device is not satisfactorily set up and not adjusted from time to time. If that is the case, the oximetry or ABG oxygen saturation might be below 95% and the physician might prescribe oxygen. The advised response to this, of course, would be to increase the IPAP (inspiratory positive airway pressure) to improve ventilation, and then to re-check the oxygen level until it stayed at 95% or better while using ventilation.

Reliable small portable oximeters, such as the Nonin Onyx® 9500, can now be purchased on the Internet without a doctor's prescription. Having one at home to monitor assisted ventilation would allow minor adjustments of the IPAP as needed — if the treating physician agrees. Prices vary considerably on the Internet so search carefully. Most often an oximeter is not covered by health insurance.

Edward Anthony Oppenheimer, MD, FCCP, Member of PHI's Medical Advisory Committee
Pulmonary Medicine (Retired, consultation only), Los Angeles, California (eaopp@ucla.edu)

Question: *I am a polio survivor who uses a ventilator during the night. My physician wants me to undergo a colonoscopy, but I am worried about anesthesia for this procedure. Should I proceed?*

Answer: A colonoscopy is an important test that can be performed safely on polio survivors who use assisted ventilation. In your case, I suggest a pulmonary evaluation before the procedure to document your respiratory reserve and a candid discussion with whomever is performing the colonoscopy. Sedation is needed because this procedure is uncomfortable. Usually a gastroenterologist does the colonoscopy with a nurse giving the sedation and supposedly monitoring the patient.

The colonoscopy should be done in a hospital (not an outpatient surgery center) with an anesthesiologist in attendance and administering the sedation. The procedure can be in the hospital's GI lab or in an operating room. The GI lab has adequate monitors; someone (the anesthesiologist) needs to watch you closely and to be careful with sedation. Afterward, you can be observed for respiratory problems in the regular recovery room and, if necessary, go to a "monitored" bed for an overnight stay — one night should be enough. You can bring and use your own home ventilator, just be sure this is discussed with the hospital staff ahead of time. I have received this question several times and after dispensing the above advice, I have not heard of any problems.

Selma Harrison Calmes, MD, Member of PHI's Medical Advisory Committee
Chair, Department of Anesthesiology, Olive View/UCLA Medical Center (shcmd@ucla.edu)

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, 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. ●



Finding causes of and managing fatigue in PPS

Frans Nollet, MD, PhD

Professor, Chair Dept. Physical Medicine and Rehabilitation

Academic Medical Center, University of Amsterdam, The Netherlands

Daria A. Trojan, MD

Assistant Professor, Physical Medicine and Rehabilitation

Montreal Neurological Institute and Hospital, Montreal, Quebec, Canada

Presented at Post-Polio Health International's 10th International Conference:

Living with Polio in the 21st Century (April 2009). (www.post-polio.org)

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 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 muscle to generate force. Several factors have been identified that may play a role in this: 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;

- 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;

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 active 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.

Modafinil, a drug used in narcolepsy, was recently demonstrated as not effective in reducing fatigue in a study by Vasconcelos OM, Neurology 2008 confirming the negative results reported earlier by Chan KM in Muscle and Nerve in 2006.

Intravenous Immunoglobulines (Ivlg) have been studied in two trials by Borg K, in Lancet Neurology in 2006 and by Farbu E, European Journal of Neurology in 2007. The study by Borg found effect for muscle strength and for 'vitality'. The study by Farbu found an effect for pain. Both studies however found no effect for fatigue.

Pyridostigmine, a drug that improves neuromuscular transmission was demonstrated not effective in two studies, one by Trojan DA in Neurology in 1999 and one study by Horemans HL in Journal of Neurology Neurosurgery and Psychiatry in 2003.

Other drugs were investigated in only one study involving limited numbers of patients. Negative results were found by Dinsmore S for high-dose *prednisone*, and by Stein DP, for *amantadine*, an anti-inflammatory drug, both published in Annals of New York Academy of Sciences in 1995. A study in 2005 by On AY, demonstrated a significant effect of *lamotrigine*, an antiepileptic drug, supposed to have neuroprotective properties, on fatigue. So far confirmative studies have not been published. Finally, a recent pilot study by Skough K, in 2008, found no effects for coenzyme Q10.

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 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 co-morbidities. What is the physical burden of activities such as standing, walking, transfers, stair climbing, and the individuals 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 in 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 cognitions. 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 known 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 fatigued 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 individual or in group therapy programs. On the other hand regular physical activity is advised to maintain physical functioning. This implies an individual non-fatiguing exercise 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 be needed 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.

*Presented at Post-Polio Health International's 10th International Conference:
Living with Polio in the 21st Century (April 2009). (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 Confer 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.)

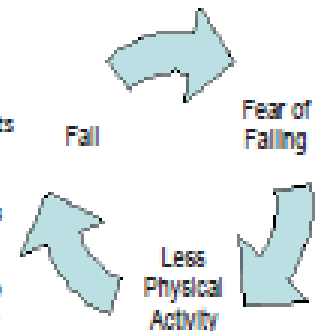
In addition to these suggestions, Ms. Molsen also noted that some individuals can reduce swallowing problems by turning the head to the right or left, or tucking the chin down when swallowing. Finally, Ms. Molsen cautioned that swallowing difficulty is a symptom, not a disease. Any persistent or unusual 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.

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New Jersey Polio Network Newsletter, Fall 1995

Aging Well with Post-Polio Syndrome: Don't Let Fall Prevention Fall through the Cracks

Researchers at the University of Washington's Aging Rehabilitation Research and Training Center,
agertrc@u.washington.edu

Falling in older adults is a big public health problem. Injuries that result from falling in older adults are serious, life-changing, costly, potentially fatal. In the United States, deaths from falls is the leading cause of injury-related deaths in adults over the age of 65.¹ In 2000, the incidence of falling injuries was estimated to be 10,300 for fatal and 2.6 million for non-fatal injuries in adults over the age of 65.² Both fatal and non-fatal injuries from falling increase with age among older adults.⁶ The direct medical care costs of treating injuries from falling in the elderly is estimated to be \$0.2 billion for fatal injuries and \$19 billion for non-fatal injuries.² The economic cost for rehabilitation after falling is even greater when stays in a nursing home, assistive devices (canes, walkers, etc.) and physical therapy are considered. Once an initial fall occurs, it can lead to a fear-of-falling, which is associated with avoiding daily activities as well as physical activity.⁴ This, in turn, becomes a troubled cycle as lack of physical activity increases the risk of falling.⁵



Polio survivors have a variety of symptoms that are known risk factors for falls in older adults and people with neuromuscular diseases such as muscle weakness, joint pain and fatigue. One study showed that the rate of polio survivors who fell at least once in the past year was four times that of other adults over 55.⁶ This study also found polio survivors report falling more often in the afternoon and inside the home.⁶ Three important predictors of falling were identified for polio survivors – a) Problems maintaining balance, b) Weakness in knee extension in the weakest leg, “knee buckling” and c) Fear of falling.⁶

Polio Survivor Data from our Survey

Many Post-Polio Health International readers participated in our survey that asked some questions about falling. Here are the responses of people with post polio syndrome:

- 242 (54%) reported a fall within the last 6 months.
- 385 (86%) are concerned about falling.
- 366 (82%) reported not doing things because of fear of falling.

What can you do to prevent falls?

Knowledge is half the battle. Falls inside the home have been linked to stairs with four or more steps, slippery floors, sliding rugs, low lighting levels, missing handrails, uneven flooring and obstructive walkways. Falls outdoors are often linked to walking on uneven or cracked sidewalks, curbs or streets. Other fall prevention tips include:

- Have your vision and hearing checked regularly.

- Talk to your doctor about side effects of medication that could affect coordination and balance or increase weakness.
- Wear rubber-soled and low-heeled shoes that fit well and fully support your feet, and replace worn cane and crutch tips.
- Avoid wearing socks when walking inside on hardwood or linoleum flooring. Socks with the grippers on the bottom or wearing Crocs while inside help prevent indoor falls.
- Be careful when walking outdoors on wet or icy sidewalks. Carry your cell phone on walks. Try to anticipate fatigue and bring what you might need for more support (cane, walker, etc.) or even a friend or family member.
- Ask your doctor what exercises you can do regularly to maintain strong bones, strength and flexibility. Exercise that improves bal-

ance and coordination (Tai Chi or Yoga) are most helpful.

- Keep your home safe – remove things you can trip over (shoes, papers, books, clothes) from stairs and high traffic areas. Keep clutter down!
- Install handrails or grab bars in your bathroom or other frequently used areas where you may need extra support (stairs and hallways).
- Improve the lighting in your home. As you age, you need brighter lights to see well.

The U.S. Centers for Disease Control and Prevention has produced brochures titled “What YOU can do to prevent falls” and “Check for Safety: A Home Falls Prevention Checklist for Older Adults” available in English, Spanish and Chinese. www.cdc.gov/ncipc/duip/spotlite/falls.htm

Thank you

For recognizing your friends and loved ones with contributions to support the unique mission of PHI and IVUM. PHI strives to publish an accurate list. Please contact us if we made an error.

Contributions to PHI's education, advocacy and networking activities ...

In Memory of

Carol Allmandinger's sister, Ellen

Sue Cheney

Jean DeJong

Catherine "Kay" McMullin

Moet Rubenstein

Arthur E Siegfried, Esq.

Lawrence Turilli

In Honor of

Burt Zucker

Contributions to The Research Fund ...

In Memory of

Jean DeJong

Virginia L. Harris

Lawrence Turilli

Contributions to the Gilbert Goldenhersh Memorial Tribute Fund ...

Marcia & Howard Denarholz's brother-in-law, Jack

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To Review Falls:



Changes in Your Body as You Age

Common Medical Conditions

Problematic Medications:

- The best medicine: An evaluation and physical activity
- Keep moving: Physical activity helps
- Lifestyle changes: Simple Steps to keep you in step
- Wearing sensible shoes

Get Rid of Tripping and Slipping Hazards

Light up Your Living Space

Modify Your Home

- Grab bars inside and outside of shower or tub
- Liquid soap dispensers in shower
- Replace Glass Shower with shatter proof material
- Use raised toilet seat or one with armrests to steady yourself
- Place a sturdy plastic seat in your tub if you can't lower yourself to the floor
- Install handrails on both sides and across the entire length of the stairways
- Put no slip treads on each bare-wood step
- Remove raised doorway thresholds in all rooms



Have a Back-Up Plan

By getting a medical evaluation, you can identify your most important risk factors for falling and take steps to correct them. A physical activity program, lifestyle changes and home improvements may further reduce your risk. But if you do find yourself falling, you can still take steps to reduce your risk of serious injury. If possible, fall forward on your hands or land on your buttocks.

If you live alone, and are afraid no one will be there to help you if you fall, ask someone to check on you once a day. Or consider paying for an emergency-monitoring company that responds to your call for help 24 hours a day.



Polio Feet

***There's a reason you have cold feet -
but you can keep warm and stay cool***

Richard Bruno, Ph.D.

[New Mobility](#), March 1996

The process that cause "Polio Feet" to turn blue and cold and become difficult to move when it's only cool is the same process that caused paralysis after the original polio

The Polio virus got into the spinal chord and either destroyed or damaged the anterior horn cell motor neurons that transmit the message to move from the brain to a muscle. When those neurons were damaged, or especially when they died, they disintegrated and the muscle fibers that used to be turned on by those cells no longer were.

There is another kind of motor neuron that was affected by the virus - the motor nerve that controls the muscle around your blood vessels. When these muscles died, there were no motor nerves to tell the blood vessel to contract; if the blood vessel cannot contract, blood 'pools,' especially in the veins. When the blood pools in the veins, it is going to be blue, because venous blood is not oxygenated.

Polio feet are caused by warm blood that should be in the center of your body, flowing out into the hands, arms, and especially the legs (since gravity is pulling the blood down). The warm blood pools in the surface of your skin, and because the blood vessels cannot contract, the result is "polio feet." The venous pooling causes your blood to radiate heat into the environment. People who had polio keep the world warm, unfortunately at their own expense. The price of this is a thorough cooling of the limbs and all tissues of the limbs.

When heat leaves the veins, the motor nerves that lie near the surface of the skin start to cool. The muscles that lie just a bit below the surface start to cool. The connective tissue that connects muscle to muscle, and muscle to bone starts to cool and stops being elastic so it is harder for it to move.

When the motor nerves aren't functioning well, the muscles aren't going to function well; if the muscles don't function well, there is going to be muscle weakness. We think that muscle weakness and the loss of body heat are causing fatigue; and we think that people who lose all their body heat into the environment are burning calories to maintain their body temperature, so there are fewer calories to keep moving.

People who had polio should dress as if it is 20 degrees colder than it actually is, but you should dress in layers so you can control your body temperature and not pass out from a rapid flow of blood away from your head as your arteries warm

The bottom line is to keep warm, stay cool and:

- ♦ Use polypropylene socks and underwear by Gortex Thinsulate.
- ♦ Dress in layers.
- ♦ Never wear a skirt after Labor Day (first Monday in September) or before Memorial Day (last Monday in May).

Autumn is comin' in on purple feet. Remember that Polio Survivors are 15 degrees colder inside their bodies than the outside temperature. So expect muscle spasm pain. More fatigue and muscle weakness. Keep your feet, legs and hands warm and always keep our neck covered!

Its turtle necks and scarf's 'til April!

Polio Feet

***There's a reason you have cold feet -
but you can keep warm and stay cool***

Richard Bruno, Ph.D.

New Mobility, March 1996

LEG EXERCISES FOR POLIO SURVIVORS

Jun 9, 2011 | By Jim Thomas

Jim Thomas has been a freelance writer since 1978. He wrote a book about professional golfers and has written magazine articles about sports, politics, legal issues, travel and business for national and Northwest publications. He received a Juris Doctor from Duke Law School and a Bachelor of Science in political science from Whitman College.

Read more: <http://www.livestrong.com/article/467193-leg-exercises-for-polio-survivors/#ixzz1f1HTq49D>

Leg exercises for polio survivors are a controversial subject. On the one hand, there is a school of thought that polio survivors must exercise their polio-damaged legs to keep them from further deterioration. On the other hand, there are some advocates who strongly debunk a 2005 Mayo Clinic study that concluded people "who survive polio in childhood will not suffer further effects later in life." There seems to be an emerging middle ground that recommends exercise for polio survivors, as long as it is carefully monitored, especially leg exercises that may further weaken or kill motor neurons already damaged by polio.

POLIO

According to Dr. Richard Bruno, director of the Post-Polio Institute, it was discovered in 1949 that the polio virus kills, on the average, 50 percent of motor neurons. This results in fatigue, pain and muscle weakness, particularly in the legs. Leg exercises that strengthen the limbs of most people can do further damage to polio survivors if the exercises are too vigorous, since the remaining muscle neurons may already be overworked in day-to-day activities.

RECOMMENDATIONS

According to research cited by Dr. Bruno, polio survivors with muscle weakness lose some 7 percent of their motor neurons each year. The researchers concluded that "polio survivors should not engage in fatiguing exercise or activities that further stress metabolically damaged neurons that are already overworking." Post-polio survivor expert and UCLA neurologist Dr. Susan Perlman writes, "The least fatiguing way for a polio survivor to exercise is in the pool. There are many published studies that show that polio survivors can exercise safely and gain better strength and endurance with non-fatiguing exercises." Other activities include cross-training and a mix of exercises that include strengthening and motion exercises.

CONSIDERATIONS

Dr. Bruno advises polio survivors to exercise their heart, which is not damaged by polio, in an appropriate fashion. He writes, "there is no benefit to running on a treadmill or riding a bicycle to exercise the heart if you thereby stress and kill off poliovirus-damaged motor neurons."

Instead of overworking the legs, Dr. Bruno suggests to improve cardio fitness with machines that work the arms, and also notes that it is critical for polio survivors to eat well and consume plenty of protein, especially at breakfast. Couple with non-carb snacks throughout the day, most of Dr. Bruno's polio survivors reported a sharp decrease in fatigue and other post-polio symptoms. Finally, all of the experts say that it is critical to develop an exercise program with your doctor that will fit you as an individual. Such a program should consist of low-to-moderate intensity exercise, at a slowly increasing pace, utilizing a range of activities. Pain or undue fatigue during exercise is a sign to stop exercising until you have spoken to your doctor.

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[T'N'T: Tips and Techniques for Polio Survivors Exercise: Use It and Lose It; Dr. Richard L. Bruno](#)

[Polio Today; Ask the Expert; UCLA Neurologist and PPS Expert Dr. Susan Perlman Answers Your Questions](#)

[San Antonio Polio Survivors Association: Exercise and Polio](#)

Article reviewed by Roman Tsivkin Last updated on: Jun 9, 2011

Read more: <http://www.livestrong.com/article/467193-leg-exercises-for-polio-survivors/#ixzz1f1GLI34n>

A STATEMENT ABOUT EXERCISE FOR SURVIVORS OF POLIO

Advising all polio survivors not to exercise is as irresponsible as advising all polio survivors to exercise.

Current evidence suggests that exercises are often beneficial for many polio survivors provided that the exercise program is designed for the individual following a thorough assessment and is supervised initially by knowledgeable health professionals. Polio survivors and their health professionals who are knowledgeable about the complete health status of the individual survivor should make the ultimate decision on the advisability of exercise and the protocol of the exercise program.

Clinical research studies support exercise programs that are prescribed and supervised by a professional for many polio survivors, including those with the symptoms of post-polio syndrome. (See [References](#).)

Acute paralytic polio can result in permanent muscular weakness when the viral infection leads to death of anterior horn cells (AHCs) in the spinal cord. Recovery from paralysis is thought to be due to the re-sprouting of nerve endings to orphaned muscle fibers creating enlarged motor units. Recovery is also attributed to exercise that facilitates the enlargement of innervated muscle fibers. For example, some polio survivors regained the use of their arms and have walked for years with crutches. Others regained the ability to walk without the aid of braces, crutches, etc., and have continued to walk for decades.

The increased muscle weakness recognized in those with post-polio syndrome is believed to occur from the degeneration of the sprouts of the enlarged motor units. The premature death of some of the AHCs affected by the poliovirus is speculated to also cause new weakness, and some new weakness is caused by disuse, or a decline in activity or exercise.

There is agreement that repetitive overuse can cause damage to joints and muscles, but can repeated overuse and excessive physical activity accelerate nerve degeneration or nerve death? This is the crux of the physical activity/exercise debate.

Physical activity is movement occurring during daily activities. Exercise is defined as planned, structured and repetitive body movement.

Therapeutic exercise is conducted for a health benefit, generally to reduce pain, to increase strength, to increase endurance and/or to increase the capacity for physical activity.

Polio survivors who over-exercise their muscles experience excessive fatigue that is best understood as depletion of the supply of muscle energy. But, some polio survivors' weakness can be explained by the lack of exercise and physical activity that clearly leads to muscle fiber wasting and cardiovascular deconditioning.

The research supports the fact that many survivors can enhance their optimal health, their range of motion and their capacity for activity by embarking on a judicious exercise program that is distinct from the typical day-to-day physical activities. These same polio survivors need not fear "killing off" nerve cells, but do need to acknowledge that the deterioration and possible death of some nerve cells may be a part of normal post-polio aging.

Exercise programs should be designed and supervised by physicians, physical therapists and/or other health care professionals who are familiar with the unique pathophysiology of post-polio syndrome and the risks of excessive exercise. Professionals typically create a custom-tailored individualized exercise program that is supervised for two-four months. During this period, they will monitor an individual's pain, fatigue and weakness and make adjustments to the protocol, as needed, to determine an exercise program that a polio survivor can follow independent of a professional.

When designing a program, these general principles are followed to achieve specific goals and/or maintenance levels.

- The intensity of the exercise is low to moderate.
- The progression of the exercise is slow, particularly in muscles that have not been exercised for a period of time and/or have obvious chronic weakness from acute poliomyelitis.
- Pacing is incorporated into the detailed program.
- The plan should include a rotation of exercise types, such as stretching, general (aerobic) conditioning, strengthening, endurance or joint range of motion exercises.

Polio survivors who experience marked pain or fatigue following any exercise should hold that exercise until contacting their health professional.

Researchers and clinicians cannot make a more definite statement until additional studies on the long-term effects of exercise and the effects of exercise on function and quality of life are undertaken.

CRITERIA FOR DIAGNOSIS OF POST-POLIO SYNDROME

Prior paralytic poliomyelitis with evidence of motor neuron loss, as confirmed by history of the 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 fatigability (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 symptoms.

SOURCE: [Post-Polio Syndrome: Identifying Best Practices in Diagnosis & Care. March of Dimes, 2001.](#)

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T'N'T: Tips and Techniques for Polio Survivors Exercise: Use it and Lose it

by Dr. Richard L. Bruno Chairperson of the International Post-Polio Task Force ,Director of The Post-Polio Institute and International Centre for Post-Polio Education and Research at Englewood (NJ) Hospital and Medical Center.

Q. I read that you don't recommend exercise for polio survivors who are getting weaker. But if I stop exercising and do nothing, won't I lose muscle tone, get flabby and become de-conditioned and become weaker still?

You're asking a good question but are using buzz words that Americans hear on infomercials. It's vital that polio survivors understand what the research really says about exercise for newly-weakened muscles and know the definitions of "muscle tone" and "de-conditioned".

We never tell polio survivors to "do nothing". Both The Post-Polio Institute and Warm Springs long-term follow-up studies find the same thing. All PPS symptoms, fatigue, pain and muscle weakness, decrease when polio survivors stop exercising and follow **The Golden Rule:**

If anything causes fatigue, weakness or pain, DON'T DO IT! (or do much less of it.)

Unfortunately, those who recommend strengthening exercise to polio survivors quote from the conclusions of a half-dozen small studies of leg muscle strengthening, apparently without having read them critically. The studies' conclusions say that exercise programs "lead to significant gains in strength." However, when you look at the responses of individual subjects the "significant gains in strength" are hard to find. Just over half of the studies' subjects had an increase in upper leg muscle strength of about 26%. One quarter had no change in strength while 21% actually had a decrease in strength of about 10%. **So almost as often as not exercise either had no effect or actually decreased muscle strength.**

What's more, **only two studies asked whether exercise affected polio survivors' fatigue and their ability to function in their daily lives.** In one study, strength increased by 36% but muscle fatigue also increased by 21%. In the other study, although muscle strength increased by 30%, there was no improvement in polio survivors' ability to do daily activities, and muscle fatigue increased as much as 300%! You have to ask what good comes from any small percentage increase in muscle strength that is not related to improved functional ability and that actually increases muscle fatigue more than strength.

And what of "muscle tone"? Most people think that muscle tone means muscles that are firm and have a nice shape. **Muscle tone actually means that muscle fibers are ready to contract.** Muscle tone is lost when motor neurons are damaged and

can't turn on muscle fibers. **Loss of tone can happen when polio survivors exercise too much and muscles become weaker when poliovirus-damaged motor neurons fail.** Remember, PPS researcher Alan McComas found that polio survivors who have muscle weakness lose at least 7% of their motor neurons each year (see PPS Forum June 2001). This is why he concluded that ***"polio survivors should not engage in fatiguing exercise or activities that further stress metabolically damaged neurons that are already overworking."***

Polio survivors' muscles get smaller and lose tone if they're overused and the motor neurons that turn on the muscle fibers die. Arms and legs get flabby because of increased fat deposits, not a loss of muscle tone. Exercise does burn fat and at first causes muscles to increase in size. But polio survivors don't want bigger muscle fibers because they *"further stress metabolically damaged neurons that are already overworking."*

The best way to prevent flabby arms and legs is to stop overusing and abusing your motor neurons and to follow the higher protein, low fat and lower carb Post-Polio Diet (see PPS Forum July, 2002).

And what does *"de-conditioned"* mean? Many polio survivors believe that there are only two ways to live: overusing and abusing, or being a couch potato and becoming *"de-conditioned"*. De-conditioning is something that happens when astronauts live in space or you put someone to bed for weeks, removing the pull of gravity and causing a decrease in blood volume and blood pressure. De-conditioning can only happen if polio survivors never leave the couch, not if they take two daily rest breaks on the couch, take a ninety minute nap, stop strengthening exercising or use a power wheelchair.

However, there is no benefit to running on a treadmill or riding a bicycle to exercise the heart if you thereby stress and kill off poliovirus-damaged motor neurons.

However, polio survivors may need to *"condition"* their hearts, especially if they have had a heart attack. *"Cardiopulmonary conditioning"* uses exercise to strengthen the heart muscle (which was not affected by polio) and make it work more efficiently.

Many polio survivors can do heart conditioning by using their less affected limbs, usually their arms, in a carefully monitored program of paced and non-fatiguing exercise (see PPS Forum May 2001).

Post Polio Wellness

Information in this section was provided from a presentation from Dr. Fredrick Maynard of Marquette, MI, entitled Post Polio Syndrome 101 and Wellness

There are many controversies about exercise for those who suffer with Post Polio or Post Polio Syndrome (PPS). Is it good or bad? What types and intensities are the best? What methods should be avoided? What muscle groups should be concentrated on? There seem to be as many questions as there are people asking them. Most importantly one needs to remember there are three essential components to a healthy body. They are: Nutrition, Activity, and Rest. We will be looking at activity and exercise.

There are different types of exercises. They include flexibility, strength, and conditioning. All three are important.

Flexibility exercises help one to maintain optimal lengths of our muscles as well as full range of motion for ones joints. These are important for pain management and functional activities. It is crucial to ensure that stretches are done correctly, taking the muscles to the point of tightness and avoiding over stretching weak muscles. If over stretching occurs, you could further damage the muscle you are trying to rehabilitate. This in turn means more time in physical therapy or rehab or both.

After you are loosened up, you are ready to start strengthening activities. There are a lot of different types of strengthening exercises. You need to consult your physician or physical therapist to learn which ones would be the best for your condition. Remember not to over do it. The key principals for safe and effective strengthening exercises for post-polios are:

- Use low Reps : 5-8 to start

- Use high Resistance :approximately 60% of 3 reps MAX

- Advance Slowly 2 reps every 3-4 days

Always follow Dr. J. Perry Rule

**** If pain or fatigue occur, reduce by ½ ****

Therapeutic exercises regimens should be monitored by a physician or a physical therapist that is versed in the general principals of exercise prescriptions and has an understanding of the effects of exercise on post-polios.

There are many methods of exercise and strength training available today. You and your provider should review your need to see which method would

work the best. Some of the options available to choose from are:

- Free Weights
- Thera Bands
- Machines
- Body Weight (floor mat exercises or in water)
- Targeted Movement (Yoga/Tai Chi)

Although there are no universal guidelines for exercise and PPS, exercise needs to be approached thoughtfully, just as for any one else. The best rule of thumb is to be careful and limit your intensity until the exercises have been done without any negative side effects (pain or fatigue). If you are honest with yourself and your provider, you can work hand in hand to build your strength and endurance. Do not ignore what your body is telling you. Be honest and communicate your pain and fatigue to your provider. If you over exert, you could end up doing more harm than good.

Endurance training exercises are designed to increase your ability to sustain activities for longer periods of time. In other words, doing what you want to do for as long as desired. After consulting with your provider on an approved regimen of exercise regarding type, intensity, frequency, and duration, a feasible method of exercise will need to be selected. Some of the common methods are:

- Treadmill or Walking Routine
- Stationary Bike or Rowing Machine
- Elliptical
- Aerodyne Bike
- Arm Ergometer
- Mat/ floor exercises
- Water exercises
- Free Weights

You may start out training 3-4 times a week to reach your goal. Then train 2-3 times a week to maintain your achieved goals.

As mentioned before, there is standardized regimen for those who have PPS. It is a matter of working with your providers on the details of an optimal program and maintaining good communication.

You may find your provider approaches your physical training the same as he does with anyone else. If so, you both need to remember that while there are no universal rules or definitions for treating patients with PPS, establishing exercise programs for them must be done more carefully and may need to be more modest in regard to amount of improvement expected and the time frames for achieving desired goals. Good, clear, and honest communication is necessary between you and your provider. Before beginning any exercise/endurance program, habits that may be contributing to any perceived new weakness need to be honestly explored by you and your provider. This will lead the two of you to agree on realistic goals and the most effective and safe exercise regime for you for you to achieve them.

Possible factors leading to the perception of the loss of strength for Post-Polios, not necessarily due to PPS (new nerve losses), are:

- Poor awareness of changes in strength
- Aging Process
- Poor Nutrition: Weight Gain
- Under Activity
- Over Activity
- Poor Pacing Skills

Again, knowing yourself and your body and having good, honest communication with your providers are the best ways to clarify reasons for experiencing any new weakness.

Post Polio Health International has established Guidelines for Exercise for Post-Polio People. They recommend working with your providers to develop an *individualized exercise program* (IEP). An IEP can enhance your overall health and functional activity tolerance. By doing this you may improve your life by regaining sufficient strength and endurance for the things you want to do or start doing again. Professionals with the knowledge of PPS and exercise should be designing and supervising you and your progress. IEP can be tricky to set up. You and your provider need to work together to find out what work's the best for you. Any good IEP requires a commitment on your part. You will need to dedicate two months, at a minimum, to your provider and your IEP, before you will be able to transition into an independent program. For the best success just keep in mind a couple of simple rules:

- Good communication with your provider
- Following general principles of low to moderate intensity
- Slow progression and pacing
- Rotating your exercise type
- Using frequent rest periods and longer total durations of exercise bouts, if necessary, to achieve your overall goal

There maybe some pain after exercise, but it should be modest. One important thing to know is the difference between muscle and joint pain. This can tricky, and you need to ensure that you communicate clearly with your provider. Pain can occur as a result of strain or mild injury during daily activity and may require some modestly painful strengthening exercises to resolve. Do not attempt to do exercises on your own to resolve a pain problem; only begin them under provider supervision. Pain can result in a vicious cycle. Typically what happens is you develop a pain in a region of your body. You then coddle that area until it begins to feel better. During this time of decreased use, muscles become weaker. So to re-strengthen that area you focus your training on the area, or you begin trying to use it again for typical daily activities. Again the pain increases and you stop; then more disuse weakness develops. You see where I am going with this. Unfortunately, the old saying of “*No pain, No gain*” comes into play here, even for those with PPS. It is extremely important that any IEP is under provider supervision.

Acute or chronic stress and strain syndromes that develop during an IEP can affect one small area or your entire body and can't turn on muscle fibers.

You need to remember to note any new pain, swelling, or discomfort and report it to your provider at your next appointment. This will aid your provider in adjusting your IEP to best suit you and your specific needs. You may find adaptive equipment needs to be used temporarily or routinely in order to resolve a pain problem and you must ensure it is being used correctly. You and your provider will also want to set realistic and achievable goals.

Just to review, you can improve your over all well being with regular exercise and greater activity. You will need to consult with your provider to setup the most effective IEP for you and your condition. Some of your muscles may benefit from strength training and some will benefit from endurance training or stretching exercises. This will be up to you and your provider to explore.

Don't be discouraged if you do not improve your fitness level. Only some PPS patients are able to accomplish this. Dedication is not the question, it is a question of what your body is able to adapt to with your PPS. Interval training and pacing are essential to your success. These activities will increase your stamina for daily activities and the occasional extra activity. Finally, your provider and you need to have a good, and clear understanding of what your goals are and what you want your desired outcome to be. Remember they need to be realistic. Please also ensure you have good, clear, open lines of communication with your providers. This is essential for you to move forward in your treatment. Granted this advice may seem like a bit of different thinking for PPS patients, but please remember nothing ventured, nothing gained when trying to improve your health and function.

ASSESSMENT TOOLS

ASSESSMENT

The assessment of an individual with a history of polio who is experiencing new health problems, presents a challenge to the health professional. This is due to the number, complexity and diversity of symptoms, the absence of special diagnostic tests, the uncertainty of the underlying cause and the lack of curative medications or treatments. In this section, the diagnosis of PPS, including differential diagnosis of the primary symptoms will be reviewed.

Diagnosis of Post-Polio Syndrome

The diagnosis of PPS is one of exclusion and is clinically based. There are no serologic, enzymatic, electro diagnostic or muscle biopsy tests that can diagnose PPS. Therefore, it is essential that each patient receives a careful history and physical examination along with appropriate laboratory, radiological and diagnostic studies to rule out other medical, neurological or orthopedic conditions that may be producing or aggravating the symptoms the patient may be experiencing. Halstead (1991)⁸⁶ has developed the following criteria for the diagnosis of PPS:

1. **A prior episode of paralytic polio with residual motor neuron loss confirmed by history, physical examination, and typical findings on electromyography (EMG).** The diagnosis of paralytic polio usually can be confirmed by:
 - Eliciting a credible history of an acute, febrile illness resulting in motor loss and not sensory deficit. Memory is often not a reliable tool when determining the location and extent of the original paralysis. Although most patients appear to remember the location of severe weakness, they may not have any recollection of extremities that incurred only mild weakness;¹¹⁴
 - Noting whether other members of the patient's family or neighbors had a similar illness;
 - Observing the presence of focal, asymmetric weakness and/or atrophy on examination;
 - Examining whenever possible the original medical records; and
 - Changes on EMG of chronic denervation with re-innervation compatible with prior anterior horn cell disease.

Non-Paralytic Polio

There is significant debate in the literature whether people with a history of non-paralytic polio (NPP) are at risk of the development of PPS. Several studies have shown that individuals with non-paralytic polio do have late onset symptoms.^{47,115} Falconer and Bollenbach (2000)¹³ have suggested a number of reasons why people with a history of NPP should not be automatically excluded from a diagnosis of PPS. These include:

- The person had non-paralytic (or abortive) polio. At the time of the acute illness there was no obvious damage to the nervous system although unobserved damage was likely. There are no established figures for the minimum amount of neuronal damage which can result in PPS symptoms. Several studies have shown that neuronal damage occurred in all non-paralytic cases of polio. For neuronal damage to be visible, at least 50-60 percent of the motor neurons must be damaged or destroyed.¹¹⁶ When fewer motor neurons are involved the patient will present with no specific muscle weakness, although neuronal damage can be present.
- The person had paralytic polio during their initial illness, but was misdiagnosed. Symptoms of paralysis and/or weakness may have been missed or the symptoms may have manifested for a short period of time. The patient recovered (apparently) fully within a matter of weeks. This type of polio often was labeled as “non-paralytic”. PPS will occur in these individuals with the same frequency as in paralytic polio cases. Diagnosis of PPS on the same basis as for a patient with a history of paralytic polio is merited.
- The person did not have polio but had another disease with clinical symptoms similar or identical to polio and currently presents with PPS symptoms. Some evidence supports the hypothesis that non-polio enter viruses can have late, post-viral effects.
- The person may have had undiagnosed polio. PPS should not be excluded and further tests may be required.

Halstead and Silver (2000)¹¹⁷ have suggested that the diagnostic criteria for PPS syndrome should be modified to include, “a history of remote paralytic polio

POST-POLIO 101

WHAT YOU NEED TO KNOW

1. DID YOU HAVE POLIO?

- ☐ Spinal tap?
- ☐ Unexplained fever?
- ☐ Flu like symptoms?
- ☐ Paralysis?
- ☐ Severe neck pain and/or headache?
- ☐ A disease that severely affected the nervous and muscular systems?

2. WHAT IS POST-POLIO SYNDROME? (PPS) (late effects of polio)

TRUTHS:

- ☐ A secondary condition to having had polio
- ☐ New symptoms approximately 10-40 years after recovery from polio
- ☐ Not everyone who had polio develops PPS
- ☐ Other conditions have been ruled out including normal aging

MYTHS:

- ☐ It doesn't exist
- ☐ The virus has returned
- ☐ You can't do anything about it
- ☐ Everyone gets the same symptoms
- ☐ PPS is life threatening
- ☐ All polio survivors have atrophied limbs

3. WHAT CAUSES POST-POLIO SYNDROME? (PPS)

- ☐ Decades of "overuse and abuse" of the body
- ☐ Polio damaged the nervous system, including the brain
- ☐ Motor neurons, that move muscles, weakened by polio are beginning to fail
- ☐ Triggered by a trauma (surgery, accident, immobilization, death of a loved one)

4. WHAT ARE SOME OF THE SYMPTOMS?

- ☐ Unaccustomed fatigue – either rapid muscle tiring or feeling of total body exhaustion
- ☐ New weakness in muscles – both those originally affected and those unaffected by the virus
- ☐ Pain/burning sensations in muscle and/or joints
- ☐ Breathing difficulties and/or sleep problems
- ☐ Swallowing problems
- ☐ Functional decline
- ☐ Depression and/or anxiety
- ☐ Weakness and muscle atrophy
- ☐ Muscle spasms, twitching and tingling
- ☐ Nerve compression problems, (i.e. carpal tunnel and tendonitis)
- ☐ Hypoglycemia
- ☐ Hypothyroidism

5. WHAT CAN BE DONE?

To **PREVENT** new symptoms from occurring

- ☐ Awareness of type “A” behavior
- ☐ Plan frequent rest periods
- ☐ Pace daily activities
- ☐ Limit exposure to cold
- ☐ Increase protein and decrease added sugars in diet.
- ☐ Gentle exercise program as prescribed by a professional familiar with PPS

To **PRESERVE** remaining strength

- ☐ Conserve energy, “Conserve to Preserve”
- ☐ Stop overusing and abusing
- ☐ Be active, but STOP short of fatigue and pain
- ☐ Use assistive devices (i.e. braces, canes, wheelchairs, etc.)
- ☐ Use quality nutritional supplements as advised by a nutritionist
- ☐ Control your weight
- ☐ Maintain a positive attitude
- ☐ Join a post-polio support group

6. WHAT TO DO ABOUT PAIN?

Tips that have worked

- ☐ Use moist heat and/or ice packs to the painful area
- ☐ Get light massages
- ☐ Try warm water therapy
- ☐ Get tested for sleeping and/or breathing problems. Use assistive and adaptive aids, as necessary to reduce stress to muscles and joints
- ☐ Check into need for anti-depressant prescription drugs
- ☐ Use pain medication, (i.e. ibuprofen, Celebrex, Vicodin, Percocet, Oxycontin) as prescribed by your Healthcare provider
- ☐ Try alternative type treatments, (i.e. acupuncture, yoga, myofascial release, Reiki, Watsu, etc.)

7. HOW IS PPS DIAGNOSED?

Having a physician exclude all other possible causes for new symptoms, (i.e. normal aging, ALS, MS, MD, Guillen-Barre, etc.)

8. HOW TO COMMUNICATE WITH YOUR HEALTHCARE PROVIDER?

A. BEFORE you visit your Healthcare provider

- ☐ Keep a journal of progression of symptoms, making simple entries concerning:
 - ☒ Daily living
 - ☒ Physical
 - ☒ Emotional
 - ☒ Time of day most affected
 - ☒ Positive and negative changes
- ☐ Note current symptoms, (i.e. tired, fatigue, exhaustion)
- ☐ From journal, make a list of questions and concerns to present to your healthcare provider

B. DURING the visit with your Healthcare Provider

- ☐ Describe all current symptoms and when/how they have changed over time.
- ☐ Be specific about what you need, if known
- ☐ Avoid giving “Yes” and “No” answers

- ☐ Describe HOW: (i.e. much, long, in what way). (“I can climb 3 steps in 5 minutes with assistance.”)
- ☐ Clarify what you hear by asking, “Did you say...?”
- ☐ Bring written post-polio information
- ☐ Build a relationship with your Healthcare provider
- ☐ REMEMBER, some symptoms are not PPS related, (i.e. normal aging, heart disease, diabetes, etc.)

C. AFTER your Health care provider’s visit

- ☐ Request copies of all reports and test results
- ☐ Call if you have further questions

9. DID YOU KNOW?

- ☐ There are Post-polio Clinics and support groups all over the world
- ☐ Rotary International goals are to:
 1. Eradicate polio worldwide
 2. Assist polio survivors
- ☐ People still get polio
- ☐ Polio survivors are likely to develop post-polio symptoms
- ☐ “No Pain – No Gain” DOES NOT apply to post-polio syndrome
- ☐ Many resources are available

10. WHERE DO YOU FIND MORE INFORMATION?

- | | |
|--|---|
| <ul style="list-style-type: none"> <input type="checkbox"/> Polio Epic, Inc.
P.O. Box 17556
Tucson, AZ 85731-7556
(520) 750-8608 (message)
<u>www.polioepic.org</u> <input type="checkbox"/> Post-polio Health International
(314) 534-0475
<u>www.post-polio.org</u> | <ul style="list-style-type: none"> <input type="checkbox"/> Polio Echo, Inc. Phoenix, AZ
P.O. BOX 61024
Phoenix, AZ 85082-1024
(480) 545-1147
<u>www.polioecho.org</u> <input type="checkbox"/> International Centre for Post-Polio Education and Research
Dr. Richard Bruno, Ph.D.
(201) 894-3000
<u>www.postpolioinfo.com</u> |
|--|---|

□ International Rehabilitation Center

Julie Silver, M.D.

(508) 872-2200

www.polioclinic.com

□ The Lincolnshire Post-Polio Network

www.ott.zynet.co.uk/polio/lincolnshire

TAKE CHARGE OF YOUR MEDICAL CARE.

YOU KNOW YOUR OWN BODY BEST!

Permission to copy with credit given to Polio Epic, Inc. of Tucson, Arizona

For Friends and Family: Another Golden Rule

See no evil, hear no evil and help only when asked.

Polio survivors have spent their lives trying to look and act "normal." Using a brace they discarded 30 years ago and reducing their super-active daily schedule is both frightening and difficult for them. Consequently, you need to be supportive of lifestyle changes and accept survivors' physical limitations and new assistive devices. Most important, you should be willing to do the physical tasks a polio survivor should not do, but only do them when the polio survivor asks. You need to know everything about PPS but say nothing; neither gentle reminders nor well-meant nagging will force survivors to use a new brace, sit while preparing dinner or rest between activities. If survivors take responsibility for taking care of themselves, and ask for help, they will slow down ... instead of just fight with you about your "nagging."

After 15 years of digging, archaeologists from The Post-Polio Institute have unearthed 10 definitive "commandments" for treating post-polio squeal.

By Richard L. Bruno and Nancy M. Frick



Listen to Your Body

Polio survivors often turned themselves off from the neck down after they got polio. The first step in treating PPS is to listen to yourself: to what you feel, physically and emotionally, when you feel it and why. Our most powerful tool in treating PPS is the daily logs our patients keep that relate activities to their symptoms. Sometimes, however, you can listen too much: to salesmen who say some herb or supplement will "cure" PPS, to fellow survivors who warn that you will eventually have every possible PPS symptom, and to friends and family members--and the voices in your own head--saying you're getting lazy. Polio survivors need to listen to their own bodies, not to busybodies.

Work Smarter, Not Harder

Many polio survivors believe that if they walk around the block five times a day, spend an hour on the exercise bike and take extra trips up and down stairs, their muscle weakness will go away. The opposite is true: The more you overuse your muscles, the more strength you lose. Muscles affected by polio lost at least 60 percent of their motor neurons; even limbs you thought were not affected by polio lost about 40 percent. Most disturbing is that polio survivors with new muscle weakness lose on average seven percent of their motor neurons per year, while survivors with severe weakness can lose up to 50 percent per year! Forget about "use it or lose it." You need to "conserve it to preserve it." Stretching may help pain, and non-fatiguing exercise for specific muscles can prevent you from losing the strength you have after you get a brace. But polio survivors need to work smarter, not harder. Remember the Golden Rule for polio survivors: If anything causes fatigue, weakness or pain, don't do it. Or do lots less of it.

Go Slow and Stead

The follow-up study of our patients showed that taking two 15-minute rest breaks per day--that's doing absolutely nothing for 15 minutes--is the single most effective treatment for PPS symptoms. Another study showed that polio survivors who pace activity--that is, who work and then rest for an equal amount of time--can do 240 percent more work than if they push straight through. Our patients who take rest breaks, pace activities and conserve energy have up to 22 percent less pain, weakness and fatigue. But polio survivors who quit or refuse therapy have 21 percent more fatigue and 76 percent more weakness. For polio survivors, slow and steady wins the race.



Be Kind to Your Neurons

Using crutches or braces are not signs of failure or of "giving up." You use one third of the energy--and look better walking--using a short leg brace on a weakened leg. Muscles and joints hurt and nerves die after decades of doing too much work with too few motor neurons. So why not use a brace, cane, crutches--dare we say even a wheelchair or scooter--if they decrease your symptoms and make it possible to finally take that trip to Disney World? We know, you'll slow down and take care of yourself "when you're ready." And you'll use a wheelchair "when there's no other choice." Well, you don't drive your car until it's out of gas. Why drive your body until it's out of

Say No to Drugs, Unless ...

Five studies have failed to find any drug that treats PPS. And no studies show that herbal remedies or magnets reduce symptoms. Don't think that you can apply a magnet or pop a pill to make your PPS disappear. Pain, weakness and fatigue are not-so-subtle messages from your body telling you that damage is being done. Masking symptoms--with magnets or morphine--will not cure the damage. However, two studies have shown that polio survivors are twice as sensitive to pain as everyone else and usually need more pain medication for a longer time after surgery or an injury.

Sleep Right All Night

The majority of polio survivors have disturbed sleep due to pain, anxiety or sleep disorders such as sleep apnea or twitching muscles. However, you may not be aware that you stop breathing or twitch. If you awaken at night with your heart pounding, anxiety, shortness of breath, choking or twitching, or if you awaken in the morning with a headache or not feeling rested, you need a sleep study. "Post-polio fatigue" may be due to a treatable sleep disorder.

Turn Up the Heat

Polio survivors have cold and purple "polio feet" because the nerves that control the size of blood vessels were killed by the poliovirus. Actually, your nerves and muscles function as if it's 20 degrees colder than the actual outside temperature! Cold is the second most commonly reported cause of muscle weakness and is the easiest to treat. Dress in layers and wear socks made of synthetic fabrics like breathable fiber polypropylene that hold in your body heat.





Eat Breakfast or Else

Mom was right. Many polio survivors eat a Type A diet: no breakfast, coffee for lunch and cold pizza for dinner. A recent study shows that the less protein polio survivors have at breakfast the more severe their fatigue and muscle weakness during the day. When our patients follow a "hypoglycemia diet" (16 grams of low-fat protein at breakfast and small, non-carbohydrate snacks throughout the day) they have a remarkable reduction in fatigue. Protein in the morning does stop your midday yawning.

Anesthetize with Care

Polio survivors are easily anesthetized because the part of the brain that keeps them awake was damaged by the poliovirus. They also stay anesthetized longer and can have breathing trouble during and after anesthesia. Even nerve blocks using local anesthetics can cause problems. You should have lung function tests before having a general anesthetic. Your complete polio history and any new problems with breathing, sleeping and swallowing should be brought to the attention of your surgeon or dentist--and especially your anesthesiologist--long before you go under the knife. You should never have same-day surgery or outpatient tests (like an endoscopy) that require an anesthetic.

Do Unto Yourself as You Have Been Doing for Others

Many polio survivors were verbally abused, slapped or even beaten by therapists or family members after they had polio to "motivate" them to get up and walk. So polio survivors took control, becoming Type A super-achievers, doing everything for everyone except themselves. Many polio survivors do for others and don't ask for help because they are afraid of being abused again. Isn't it time you got something back for all you've done for others? Accepting assistance is what can keep you independent. Appearing "disabled" by not doing for others and asking for help may be frightening, but they are also the best ways to manage your PPS.

Richard L. Bruno is Director of The Post-Polio Institute at New Jersey's Englewood Hospital and Medical Center, and Chairperson of the International Post-Polio Task Force. Nancy M. Frick is Executive Director of Harvest Center in Hackensack, N.J. Articles describing the research mentioned above can be found in the online PPS Library: members.aol.com/harvestctr/pps/polio.html





RESOURCES

NATIONAL

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 book lists.

<http://groups.yahoo.com/group/ippsobulletinboardchat>

Is a decision forum and resource for current trends and research relating to polio and post-polio syndrome. Must join the group on Yahoo to participate.

www.eastersealscolorado.org

At Easter Seals Colorado, there is a link to news about polio survivors in Colorado as well as a link to the latest issue of the Colorado Post –Polio Connections Newsletter.

BOOKS

The Polio Paradox

By Richard Bruno Published 2002

Managing Post-Polio: A Guide to Living Well with Polio

By Lauro Halstead Published 2006

**Halstead is the most recent and complete resource for polio survivors.*

Post-Polio Syndrome: A Guide for Polio Survivors and Their Families

By Julia Silver, MD Published 2001

Anne Gawne, MD

The late Effects of Poliomyelitis; For Physicians and Survivors

By Fredrick Maynard, MD Published 1999

Joan Headley, MS



POLIO SURVIVORS OF MONTANA



205 9TH AVE SOUTH, SUITE 101

GREAT FALLS, MT 59405-4001

406.454.7715

WWW.POLIOSURVIVORSOFMONTANA.CLUB.OFFICELIVE.COM

E-MAIL: PPSOM@OFFICELIVEUSERS.COM

OFFICE HOURS

MONDAY 12:45-2:30

THURSDAY 2:45-5:00

FRIDAY 1:30-3:15

MEETINGS

DATE: 3RD SATURDAY ON THE MONTH

TIME: 10:00-NOON

LOCATION: 4400 CENTRAL AVE, GREAT FALLS
POT LUCK (BRING YOUR FAVORITE DISH)

CONTACTS

ANN TUSS, COORDINATOR

406.452.0722

JUANITA TSCHETTERS

406.761.6737





Statewide Resources

Action for Eastern Montana

2030 North Merrill

PO Box 1309

Glendive, MT 59330-1309

(406) 377-3564

(800) 227-0703

District VII HRDC

7 North 31st Street

PO Box 2016

Billings, MT 59103-2016

(406) 247-4732

800-433-1411

District IV HRDC

2229 Fifth Avenue

Havre, MT 5501

(406) 265-6743

Rocky Mountain Development Council

3108 McHugh Drive

Helena, MT 59602

(406) 447-1625

(800) 356-6544

Opportunities, Inc.

905 First Avenue North

PO Box 2289

Great Falls, MT 59403-2289

(406) 761-0310

(800) 927-2270

District IX HRDC

32 South Tracy

Bozeman, MT 59715

(406) 587-4486

PO Box 1530

District VI HRDC

Centennial Plaza, Room 203

300 First Avenue North

Lewistown, MT 59457

(406) 535-7488

800-766-3018

Livingston, MT 59047-1530

(406) 222-0896

(800) 289-0896

Community Action Partnership of Northwest Montana

214 Main Street

PO Box 8300

Kalispell, MT 59904-1300

Roundup Office

(406) 323-3857

(406) 752-6565

(800) 344-5979

District XI HRC

1801 South Higgins
Missoula, MT 59801
(406) 728-3710

District XII HRC

700 Casey Street
PO Box 3486
Butte, MT 59702-3486
(406) 496-4975
(800) 382-1325

Independent Living Centers

Summit Independent



Living Center

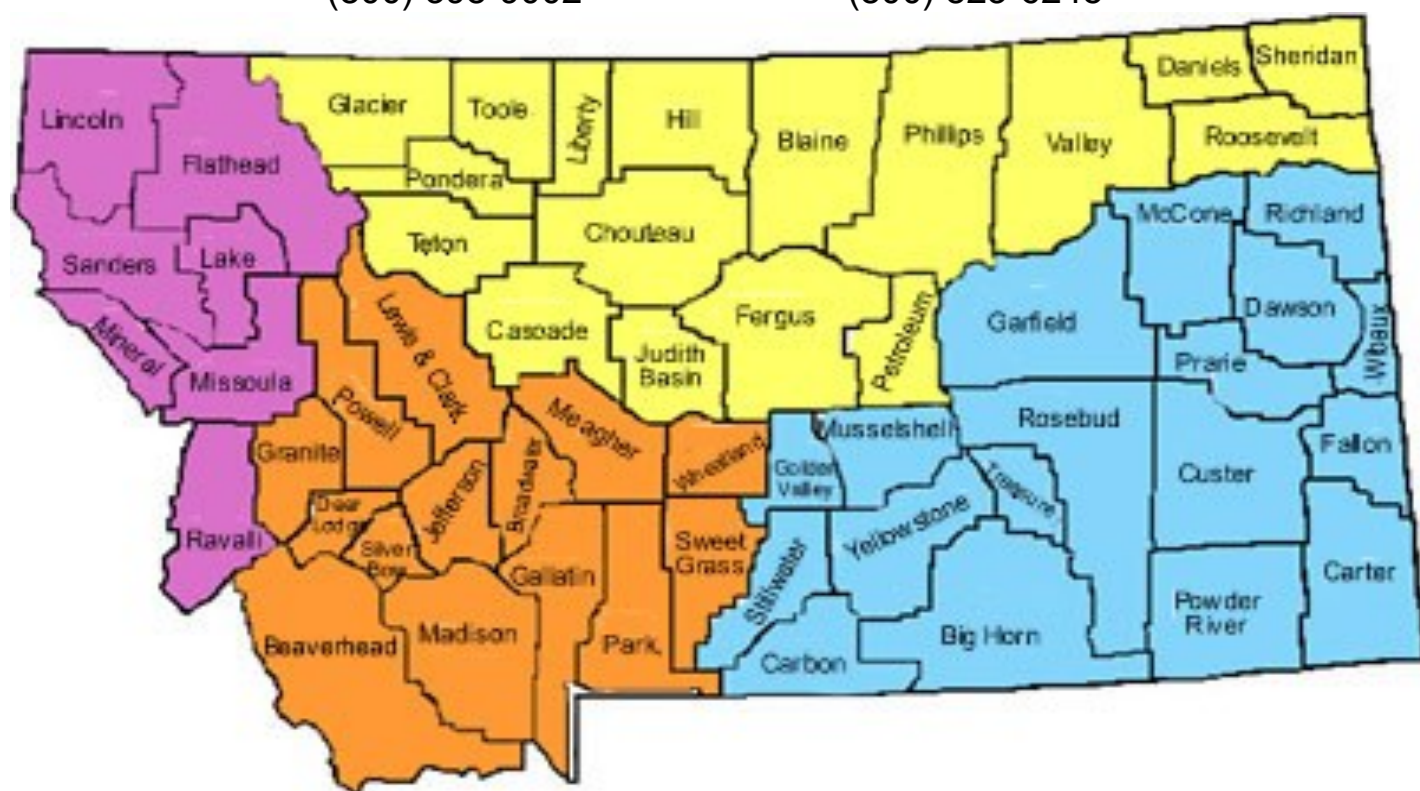
(800) 398-9002

North Central Independent



Living Services

(800) 823-6245



Montana Independent



Living Project

(800) 735-6457

Living Independently



for Today & Tomorrow

(800) 669-6319

Living Independently for Today and Tomorrow (LIFTT)

Located in Billings and provides services to southeastern Montana. They have branch offices set up in Miles City and Glendive.

Living Independently for Today and Tomorrow

Bobbie Becker, Director

3333 2nd Ave N, Suite 100

Billings, MT 59101

(406) 259-5181

(800) 669-6319 (toll free)

(406) 259-5259 fax

(406) 245-1225 TTY

bobbieb@liff.org

LIFTT - Glendive Branch

Pam Mitchell and Jen Hawkinson

115 W Valentine

Glendive MT 59330

(406) 377-4062 voice/TTY

(406) 377-4064 fax

(888) 502-9700 voice/TTY (toll-free)

pamm@liff.org and jenh@liff.org

LIFTT - Northern Cheyenne Branch

Mark Small

PO Box 1146

Ashland MT 59003

(406) 679-0063 voice

marksmall@rangeweb.net

LIFTT - Hardin Branch

Linda Henry, CWIC

210 2nd Ave S

Hardin MT 59034

(406) 665-4074

MILP - Montana Independent Living Project

Located in Helena and provides services to southwestern Montana. They have branch offices set up in Butte and Bozeman.

Main Office

Bob Maffit, Director

34 N Last Chance Gulch, Suite 500

Helena MT 59601

(406) 442-5755 voice/TTY (800) 735-6457 (toll-free)

(406) 442-1612 fax

bmaffit@milp.us

MILP - Bozeman Branch Office

Alison Cole

1165 N 14th AVE Suite 4

Bozeman MT 59715

(406) 522-7300 voice/TTY (406) 522-7302 fax

acole@milp.us

MILP - Butte Branch Office

Tami Hoar

1941 Harrison Ave

Butte MT 59701

(406) 782-4834 voice/TTY (406) 782-4835 fax

thoar@milp.us

MILP - Dillon Branch Office

Jeannette Prodgors

435 S Atlantic St, #2

Dillon, MT 59725

(406) 925-5005

NCILS - North Central Independent Living Services

North Central Independent Living Services is located in Great Falls and provides services from Glacier County across the Hi-Line to the North Dakota border. A branch office is set up in Glasgow.

Main Office

Tom Osborn, Director

1120 25th Avenue NE

Black Eagle MT 59414

(406) 452-9834 voice/TTY

(800) 823-6245 (toll-free)

(406) 453-3940 fax

ncils.osborn@bresnan.net

NCILS - Glasgow Branch

Colleen Forrester

334 W Court

Glasgow MT 59230

(406) 228-2075 voice/TTY

ncils2@nemon.net

NCILS - Poplar Branch

Debra Mason

PO Box 53

Poplar MT 59255

(406) 768-3040

ncils3@nemon.net

Summit Independent Living Center

Summit Independent Living Center's main office is located in Missoula and has branches in Kalispell, Ronan, and Hamilton. Summit serves northwestern Montana.

Main Office

Mike Mayer, Director
700 SW Higgins, Suite 101
Missoula MT 59803
(406) 728-1630 voice/TTY
(800) 398-9002 (toll-free)
(406) 829-3309 fax
mmayer@summitilc.org

Summit - Ronan Branch

Michelle and Scott Williamson
111 2nd Ave SW
Ronan MT 59864
(406) 676-0190 voice/TTY
(866) 230-6936 (toll free)
mwilliamson@summitilc.org
scottwilliamson@summitilc.org

Summit - Hamilton Branch

Joanne Verwolf
316 N 3rd Suite 113
Hamilton MT 59840
(406) 363-5242 voice/TTY/fax
(800) 398-9013 (toll free)
jverwolf@summitilc.org

Summit - Kalispell Branch

Flo Kiewel
1203 US Highway 2 W, Suite 35
Kalispell MT 59901
(406) 257-0048 voice/TTY/fax
(800) 995-0029 (toll-free)
flok@summitilc.org

* * *

If there is not a center in your community, an outreach worker from the main center will come to you.

* * *

HUMAN RESOURCE DEVELOPMENT COUNCILS

Ten Human Resource Development Councils (HRDCs) across the state help connect low-income, elderly, minority, and disabled Montanans with programs aimed at alleviating poverty and providing educational and training opportunities. HRDCs are nonprofit corporations first established in 1965 as part of the federal government's "War on Poverty." They are governed by volunteer boards of directors representing the private, public and low-income sectors of their communities. They work to accomplish their goals by providing a better focus on all available local, state, federal, and private resources.

Action for Eastern Montana

2030 North Merrill
PO Box 1309
Glendive, MT 59330-1309
(406) 377-3564
(800) 227-0703

District IV HRDC

2229 Fifth Avenue
Havre, MT 5501
(406) 265-6743

Opportunities, Inc.

905 First Avenue North
PO Box 2289
Great Falls, MT 59403-2289
(406) 761-0310
(800) 927-2270

District VI HRDC

Centennial Plaza, Room 203
300 First Avenue North
Lewistown, MT 59457
(406) 535-7488
800-766-3018

Roundup Office

(406) 323-3857

District VII HRDC

7 North 31st Street
PO Box 2016
Billings, MT 59103-2016

(406) 247-4732

800-433-1411

Rocky Mountain Development Council

3108 McHugh Drive
Helena, MT 59602
(406) 447-1625
(800) 356-6544

District IX HRDC

32 South Tracy
Bozeman, MT 59715
(406) 587-4486

PO Box 1530

Livingston, MT 59047-1530
(406) 222-0896
(800) 289-0896

Community Action Partnership of Northwest Montana

214 Main Street
PO Box 8300
Kalispell, MT 59904-1300
(406) 752-6565
(800) 344-5979

District XI HRC

1801 South Higgins
Missoula, MT 59801
(406) 728-3710

District XII HRC

700 Casey Street
PO Box 3486
Butte, MT 59702-3486
(406) 496-4975
(800) 382-1325

HUMAN RESOURCE DEVELOPMENT COUNCILS

ACTION FOR EASTERN MONTANA

2030 North Merrill
PO Box 1309
Glendive, MT 59330-1309
(406)-377-3564
(800)-227-0703

SERVES COUNTIES:

Carter	Prairie
Custer	Richland
Daniels	Roosevelt
Dawson	Rosebud
Fallon	Sheridan
Garfield	Treasure
McCone	Valley
Phillips	Wibaux
Powder River	

DISTRICT IV HRDC

2229 Fifth Avenue
Havre, MT 59501
(406)-265-6743
(800)-640-6743

SERVES COUNTIES:

Blaine
Hill
Liberty

OPPORTUNITIES, INC.

905 First Avenue North
PO Box 2289
Great Falls, MT 59403-2289
(406)-761-0310
(800)-326-0955

SERVES COUNTIES:

Cascade
Chouteau
Glacier

DISTRICT VI HRDC

Centennial Plaza
300 First Avenue North
Rm 203
Lewistown, MT 59457
(406)-535-7488
(800)-766-3018
(406)-323-3857 Roundup Office

SERVES COUNTIES:

Fergus
Golden Valley
Judith Basin
Musselshell
Petroleum
Wheatland

DISTRICT VII HRDC

7 North 31st Street
PO Box 2016
Billings, MT 59103-2016
(406)-247-4732
(800)-433-1411

SERVES COUNTIES:

Big Horn
Carbon
Stillwater
Sweet Grass
Yellowstone

ROCKY MOUNTAIN DEVELOPMENT COUNCIL

SERVES COUNTIES:

LIEAP Office
648 North Jackson
P O Box 1717
Helena, MT 59624
(406)-447-1625
(800)-356-6544

Broadwater
Jefferson
Lewis & Clark

DISTRICT IX HRDC

Serves counties:

32 South Tracy
Bozeman, MT 59715
(406)-587-4486
(800)-332-2796

Gallatin
Meagher
Park

COMMUNITY ACTION PARTNERSHIP OF NORTHWEST MONTANA

Serves counties:

214 Main Street
PO Box 8300
Kalispell, MT 59904-1300
(406)-758-5433
(800)-344-5979

Flathead
Lake
Lincoln
Sanders

DISTRICT XI HRC

SERVES COUNTIES:

1801 South Higgins
Missoula, MT 59801
(406)-728-3710

Mineral
Missoula
Ravalli

DISTRICT XII HRC

SERVES COUNTIES:

700 Casey Street
PO Box 3486
Butte, MT 59702-3486
(406)-496-4975
800-382-1325

Beaverhead
Deer Lodge
Granite
Madison
Powell

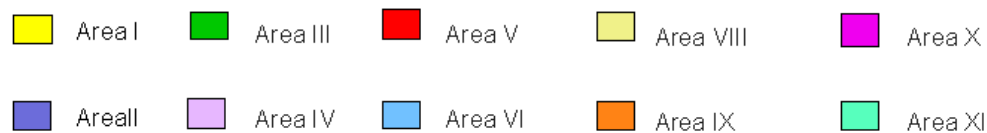
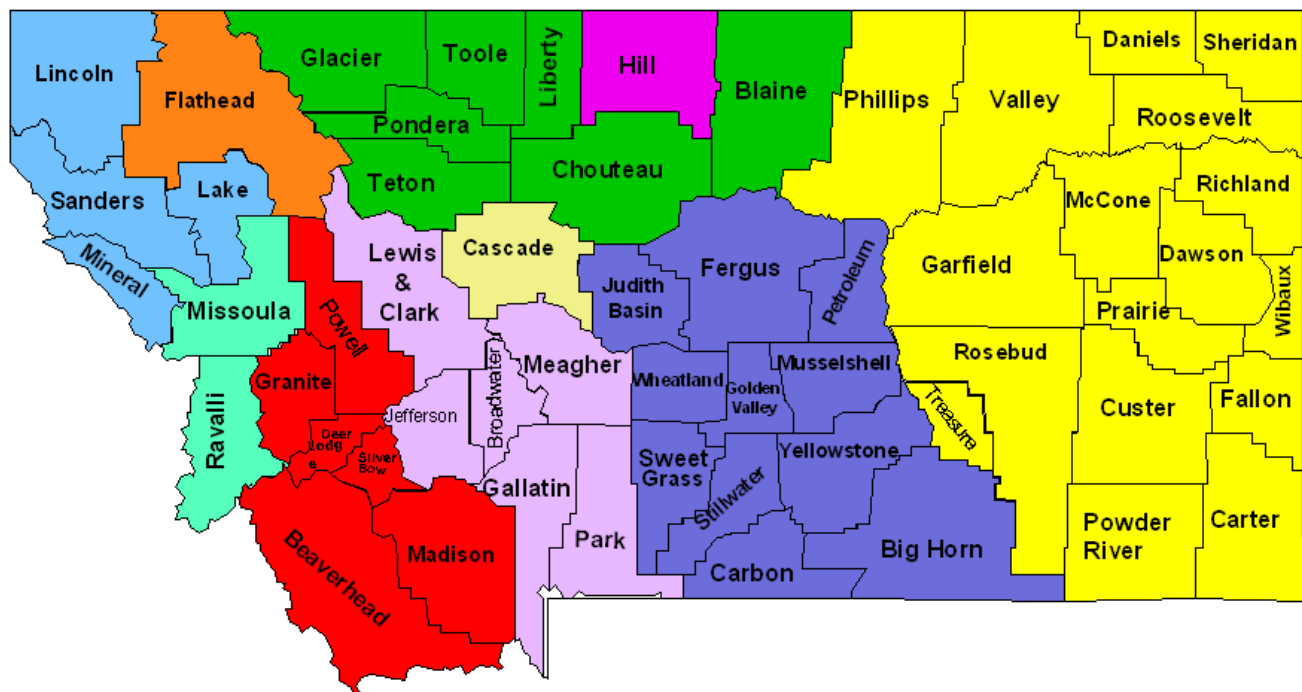
NORTH CENTRAL AREA AGENCY ON AGING

NORTH CENTRAL AREA AGENCY ON AGING SERVES COUNTIES:

Pondera Village Shopping Center
600 South Main, Suite 4
Conrad, MT 59425
(406) 271-7553

Pondera
Teton
Toole

Montana Area Agencies on Aging



AREA AGENCIES ON AGING

Congress enacted the 1965 "Older Americans Act" as a response to the challenges a rapidly increasing older population imposed on our country's systems of health care, retirement, housing, employment, and community services. The Older Americans Act created structures at the federal, State, and local level to administer programs that help our nation's elderly maintain their health and independence in their homes and communities.

Today, the National Network on Aging includes the Administration on Aging, a part of the U.S. Department of Health and Human Services. Montana's 10 Area Agencies on Aging are under contract to the Aging Services Bureau, Department of Public Health and Human Services; the designated State Agency on Aging responsible to administer Older Americans Act programs.

Montana's Area Agencies on Aging are public or private non-profit agencies, designated by the Aging Services Bureau, to address the needs and concerns of older Montanans at the local level. Every Area Agency on Aging is required to have an advisory council, comprised primarily of older persons, to review and comment on all programs affecting the elderly at the community level. More than 100 advisory council members work in partnership with Montana's Area Agencies on Aging.

In Montana, there is one toll free telephone number to call that will ring into your local Area Agency on Aging, that number is 1-800-551-3191.

Area Agencies on Aging

1-800-551-3191

Updated 3/23/11

Area I Agency On Aging

Lori Brengle, Director

Action For Eastern MT

Po Box 1309 - 2030 N. Merrill

Glendive MT 59330

377-3564 Fax: 377-3570

l.brengle@aemt.org

Area II Agency On Aging

Karen Erdie, Director

Po Box 127

Roundup MT 59072-0127

323-1320 Fax: 323-3859

areatwo@midrivers.com

Area III Agency On Aging**Karin Roehm, Director**

North Central AAA

600 S Main St Suite 4

Conrad MT 59425-2335

271-7553 Fax: 271-2769ncaaafin@3rivers.net**Area IV Agency On Aging****Charles Aagenes, Director**

Po Box 1717 - 648 Jackson St.

Helena MT 59624-1717

447-1680 Fax: 447-1629caagenes@rmdc.net**Area V Agency On Aging****Joe Gilboy, Director**

P.O. Box 459

1015 S Montana St

Butte MT 59703

782-5555 Fax: 782-5662joeareav@qwestoffice.net**Area VI Agency On Aging****Duane Lutke, Director**

Western MT AAA

110 Main Street Suite #5

Polson MT 59860-2316

883-7284 Fax: 883-7363aging6@area6aging.org**Area VIII Agency On Aging****Rob Rung, Director**

1801 Benefis Court

Great Falls MT 59405

454-6990 Fax: 454-6991rrung@cascadecountymt.gov**Area IX Agency On Aging****Jim Atkinson, Director**

160 Kelly Road

Kalispell MT 59901-5143

758-5730 Fax: 758-5732jatkinson@Flathead.mt.gov**Area X Agency On Aging****Evelyn Havskjold, Director**

2 W Second Street

Havre MT 59501-3434

265-5464 Fax: 265-3611evelyn@havre.mt.us**Area XI Agency On Aging****Missoula Aging Services****Susan Kohler, Director**

337 Stephens

Missoula MT 59801

728-7682 Fax: 728-7687skohler@missoulaagingservices.org



CONTACT US

Benefis Health System values your questions and feedback. Please contact us using the email address listed below if you have any questions or comments about our services. For specific departments, see the Directory of Services below.

Benefis Health System
1101 26th Street South
Great Falls, Montana 59405

Phone: (406) 455.5000

Email: benefis@benefis.org

For patient issues and concerns contact:

Deb Nader, Patient Advocate

(406) 455.5838 or DebNader@benefis.org

Benefis Health System Directory of Services

Switchboard, Patient Rooms (406) 455.5000
Mercy Flight (800) 972.4000

Addiction Medicine (406) 455.2367

Bariatric Institute (406) 455.2814

Behavioral Health (406) 455.2380

Benefis Birth Center (406) 731.8750

Benefis Healthcare Foundation (406) 455.5840

Benefis Medical Group (406) 455.2900

Breast Center (406) 731.8405

Cancer Programs & Services (406) 731.8200

Cardiac Rehab (406) 455.2180

Diabetes Education (406) 455.5516

Dialysis (406) 455.3960

Peace Hospice of Montana (406) 455.3040

Emergency & Trauma II Center (406) 455.5200

Employment/Jobs (406) 455.5175

Endoscopy (406) 455.5224

Extended Care Center/Senior Services (406) 455.5903

Foot Clinics (406) 727.0414

Gift of Life Housing (406) 731.8180

Heart & Vascular Institute (406) 731.8500

Injury Center (406) 731.8989

Lifeline Personal Emergency Response System (406) 455.5839

Med Spa and Vein Center (406) 455.2845

Native American Welcoming Center (406) 455.5197

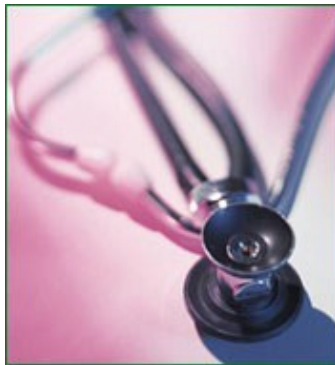
Benefis Health System Directory of Services

Orthopedic Center of Montana	(406) 731.8900	Spectrum Medical, Inc.	(406) 727.9322
Parkinson's Disease Information & Referral Center	(406) 455.2964	Spine Institute	(406) 731.8925
Patient Advocate	(406) 455.5838	Spirit of Women	(406) 455.5545
Plastic/Reconstructive Surgery	(406) 455.2821	Sports Medicine	(406) 731.8961
Quick Care	(406) 455.2130	Therapy Center	(406) 731.8930
Radiology	(406) 731.8400	Total Joint Program	(406) 731.8051
Rehabilitation Services	(406) 455.2293	Women's & Children's Services	(406) 731.8750
Sletten Cancer Institute	(406) 731.8200	Wound Care & Hyperbaric Medicine	(406) 455.2680



Sisters of Charity of Leavenworth Health System

1233 North 30th Street
Billings, MT 59101
406.657.7000



Patricia A LaHaie, MD

Appointments by Physician Referral ONLY

Words of Wisdom

*If muscles are weak, tired or painful
more than 2 hours after an activity, that activity is
probably too intensive for the polio survivor.*

Specialty	Physical Medicine/Rehab; Electrodiagnostic Medicine
Facility	St. Vincent Physician Network-Physiatry
Address	2900 12th Ave N Suite 400E, Billings, MT, 59101
Phone	(406) 237-7125
Fax	(406) 237-7190
Certification	American Board of Electrodiagnostic Medicine - Physical Medicine/Rehab
Medical School	University of Michigan Medical School
Residency	University of Michigan Medical Center- Physical Medicine & Rehabilitation



CONTACT US

GENERAL CONTACT

Billings Clinic

801 North 29th Street
PO Box 35100
Billings, MT 59107-7000
406-238-2500 or
1-800-332-7156

Billings Clinic Hospital

2800 10th Avenue North
PO Box 37000
Billings, MT 59107-7000
406-238-2500 or
1-800-332-7156

Billings Clinic Foundation

2917 10th Avenue North
PO Box 31031
Billings, MT 59107-1031
406-657-4670 or
1-800-332-7156

Billings Clinic Research Center

1045 North 30th St.
Billings, MT 59101
406-255-8470 or
1-800-996-2663

Aspen Meadows Assisted Living and Rehab Center

3155 Avenue C
Billings, MT 59102
406-656-8818

SPECIALIZED SERVICES

Behavioral Health

1020 North 27th Street-4th Floor
PO Box 37000
Billings, MT 59107-7000
406-255-8550

Cardiovascular Services

1020 North 27th Street-2nd Floor
PO Box 37000
Billings, MT 59107-7000
406-238-2000

Home Oxygen and Durable Medical Equipment

801 North 27th Street
Billings, MT 59101
406-657-4999

Orthopedic & Sports Medicine

2702 8th Avenue North
PO Box 37000
Billings, MT 59107-7000
406-238-5200

BRANCH LOCATIONS

Billings Clinic Heights

760 Wicks Lane
Billings, MT 59105
406-238-2575 or
1-800-332-7156

Billings Clinic West

2675 Central Avenue
Lamplighter Square
Billings, MT 59102
406-238-2900 or
1-800-332-7156

Billings Clinic Cody

201 W. Yellowstone Avenue
Cody, WY 82414
307-527-7561

Billings Clinic Columbus

407 North A Street
Columbus, MT 59019
406-322-4542

Billings Clinic Miles City

620 South Haynes Avenue
Miles City, MT 59301
406-233-7000

Billings Clinic Red Lodge

10 South Oakes Street
Red Lodge, MT 59068
406-446-2412

Bozeman OB/GYN

Highland Park Medical Office
Building 1
Suites 1210 & 1220
Bozeman, MT 59715
(Connected to Bozeman Deaconess Hospital)
Mailing Address
925 Highland Boulevard
Suite 1210
Bozeman, MT 59715
406-587-9202 or
406-587-5000
Toll Free 1-866-587-9202

AFFILIATE LOCATIONS

Beartooth Hospital and Health Center

600 West 21st Street
PO Box 590
Red Lodge, MT 59068
406-446-2345

Colstrip Medical Center

6230 Main Street
PO Box 1858
Colstrip, MT 59323
406-748-3600

Daniels Memorial Hospital

105 5th Ave. East
PO Box 400
Scobey, MT 59263
406-487-2296

Livingston Memorial Hospital

504 S 13th Street
Livingston, MT 59047
406-222-3541

North Big Horn Hospital

1115 Lane 12
Lovell, WY 82431
307-548-5200

Pioneer Medical Center

301 W. 7th Avenue
PO Box 1228
Big Timber, MT 59011
406-932-4603

Stillwater Community Hospital

44 W. 4th Ave. North
Box 959
Columbus, MT 59019
406-322-5316



Phone: 406-543-7271

Address:

St. Patrick Hospital
500 West Broadway
Missoula, MT 59802

Email: info@saintpatrick.org

HEALTH SERVICES

[Acute Inpatient Rehab](#)

[Back and Neck Pain](#)

[Clinical & Lab Resources](#)

[Clinics Near You](#)

[da Vinci Surgery](#)

[Diabetes Care Center](#)

[Diagnostic Imaging](#)

[Dialysis](#)

[Emergency Services](#)

[International Heart Institute](#)

[Joint Replacement](#)

[Life Flight](#)

[Montana Cancer Center](#)

[Montana Spine & Pain Center](#)

[Neurobehavioral Medicine](#)

[Primary Stroke Center](#)

[Sleep Center](#)

[St. Pat's Associated Providers](#)

[Trauma Program](#)

[Treatment of Obesity](#)

[Weight Loss Services](#)

[Women's Care Center](#)

[Wound Care Center](#)



From Day One
2827 Fort Missoula Road
Missoula, Montana 59804

Phone: (406) 728-4100

Email: contatus@communitymed.org

Contacting Careflight: 1-888-487-8635 or (406) 327-4726

PHONE DIRECTORY

Endoscopy	327-4297	Foundation	327-4149
Outreach	327-4167	Rehabilitation Institute of Montana	327-4321
Physician Billing	327-4284	Care Management Services	327-4062
Diagnostic Imaging	327-4042	Organizational Development	327-4027
Health Information Management	327-4155	Patient Financial Services	327-4188
IT, Applications	327-4270	Women & Children Services	327-4043
Telecommunications	327-4095	Physician Services	327-4377
Respiratory Services	327-4268	Emergency Department	327-4185
Surgical Services	327-4281	Fiscal Services	327-4018
Community Physician Group	327-4377	Clinical Lab	327-4611
Pharmacy/Pain Management	327-4190	Operations	327-4004
Administration	327-4004	CMC Foundation	327-4150
Community Physician Group	327-7368	Community Physician Group - Stevensville	777-2775
Patient Access Services	327-4203	ICU	327-4147
Nutrition Services	327-4164	Montana Heart Center	327-4658

Lab Services	327-4028	Environmental & Facility Services	327-4137
Community Relations	327-4152	ICU & Heart Center	327-4235
Pediatric Services	327-4302	Strategic Planning	327-4030
Environmental Services	327-4231	Strategic Planning	327-4449
Pharmacy	327-4041	Surgery	327-4013
Patient Financial Services	327-4311		
Education	327-4038		
Outpatient Therapy	327-4617		
Marketing & Public Relations	327-4024		
Patient Care Resources	327-4004		
Medical Affairs	327-4134		
Health Information Management	327-4040		
Fiscal Services	327-4083		
Oncology	327-3914		
NICU	327-4239		
IT, Operations	327-4198		
Human Resources	327-4016		
Quality & Risk Management	327-4259		
Patient Care Resources	327-4154		
Obstetrics	327-4057		
Community Physician Group	327-4754		
Information Technology	327-4073		
Materials Management	327-4034		
Bridges	327-4592		
Mail & Transportation Services	327-4511		
Medical Staff	327-4004		
Med/Surg	327-4213		
Polio Survivors of Montana	80		



915 Highland Boulevard
Bozeman, MT 59715

(406) 585-5000

- [Cancer Center](#)
- [Diabetes Center](#)
- [Emergency Medicine](#)
- [Heart Center](#)
- [Hospice](#)
- [Hospital Medicine](#)
- [Hyperbaric Medicine](#)
- [Interventional Radiology](#)
- [Labor and Delivery](#)
- [Laboratory Services](#)
- [Lifeline Medical Alert System](#)
- [Nutrition Specialists](#)
- [Palliative Medicine](#)
- [Perioperative Services](#)
- [Pharmacy Services](#)
- [Radiology \(Diagnostic Imaging\)](#)
- [Rehabilitation Services](#)
- [Respiratory Services](#)
- [Sleep Disorders Center](#)
- [Surgical Services](#)
- [Synergy Medical Spa](#)
- [Women's Center](#)
- [Wound Clinic](#)



400 S Clark St Butte, MT 59701

(406) 723-2621

- Obstetrical Services
- Linear Accelerator
- Hospitalist
- Trauma Center/Level III
- MRI (Magnetic Res Imaging)
- Sleep Disorders
- Reconstructive/Plastic Surgery
- Pediatric Services
- Orthopedic Surgery
- Ultrasound
- Sports Medicine
- Psychiatric Services/Geriatric
- Oncology Services
- Wellness Center
- Birthing Room
- Physical Therapy
- Alcohol-Chemical Depend/In-Patient
- CT Scan
- Labor/Delivery/Recovery/Post Partum
- Intensive Care/General
- Neurological Services
- PET Scan (Positron Emission Tomography)
- Respiratory/Pulmonary Services
- Auxiliary Services
- Emergency Services
- Nuclear Medicine
- Intensive Care/Neonatal
- Cardiac Catheterization Lab
- Hemodialysis (Dialysis)
- Intensive Care/Cardiac
- Laser Surgery (Ophthalmology)
- Lithotripsy
- Occupational Therapy Services
- Radiation Therapy
- Skilled Nursing Facility
- Ambulatory Surgery Services
- Blood Bank
- Histopathology Lab
- Cardiology/Non-Invasive
- Gastroenterology



St. Peter's Hospital



HELENA and SURROUNDING AREA

Adult Day Care

Gottfried House.....	(406) 458-6159
Masonic Home.....	(406) 458-5431

Alcohol & Drugs

Alcoholics Anonymous.....	(406) 443-0438
Boyd Andrew Center.....	(406) 443-2343
Crisis Line.....	(406) 443-5353
Helena Indian Alliance Substance Abuse.....	(406) 443-7780
Narcotics Anonymous.....	1-(800) 990-6262

Assisted Living Homes

Country Life, LLC (Montana City).....	(406) 443-1288
Connie's Country Cottage.....	(406) 458-5773
Golden Garden, Whitehall.....	(406) 287-2223
Homestead Personal Care (Townsend).....	(406) 266-3669
June's House.....	(406) 442-4628
Masonic Home.....	(406) 458-5431
Our House.....	(406) 443-3364
Aspen Gardens.....	(406) 457-0092
Rosetta Assisted Living & Respite Care.....	(406) 449-7587
Sharon's Sunshine Care.....	(406) 458-5535
Shelby's House.....	(406) 475-3621
Son Heaven Personal Care.....	(406) 449-0229
Talbert House.....	(406) 457-0220
Tiffany's and Linda's Care (TLC).....	(406) 266-4453
Townsend Personal Care.....	(406) 266-3711
Waterford Retirement and Assisted Living.....	(406) 449-4900
Wendy's House.....	(406) 458-6277

Adult Independent Living

Aspen Village.....	(406) 449-1226
Eagle's Manor.....	(406) 442-0610
East Park Villas.....	(406) 449-9795
Helena Housing Authority.....	(406) 442-7970
Hunter's Pointe.....	(406) 443-4222
Queen City Estates.....	(406) 449-7165
Sunset Apartments.....	(406) 442-2970
Waterford Retirement Home.....	(406) 449-4900

Economic Assistance

Big Sky RX.....	(406) 444-1233
Cheryl Taylor, Payee Services.....	(406) 431-6333
Department of Public Health & Human Services.....	(406) 444-4473
Energy Assistance.....	(406) 447-1680
Helena Housing Authority, Section 8 and Public Housing.....	(406) 442-7970
Office of Public Assistance (Medicaid, Food Stamps, AFDC):	
Lewis & Clark County.....	(406) 444-1700
Broadwater County.....	(406) 266-3157
Jefferson County.....	(406) 225-4045
Social Security Administration	1-(866) 563-9496
Veterans' Administration.....	(406) 442-6410
Weatherization & Energy Assistance.....	(406) 447-1625
Montana Payee Services.....	1-(800) 725-0755

Emergency Housing

Friendship Center.....	(406) 442-6800
God's Love Shelter.....	(406) 442-7000
YWCA.....	(406) 442-8774

Food and Meal Assistance

Boulder Senior Center.....	(406) 225-3656
Daily Dinner Club (Helena).....	(406) 447-1680
E. Helena Daily Dinner Club.....	(406) 227-9959
Food Stamp Assistance.....	(406) 444-1700
God's Love Shelter.....	(406) 442-7000
Good Samaritan.....	(406) 442-0780
Helena Food Share.....	(406) 443-3663
Lincoln Dinner Club.....	(406) 362-4504
Meals on Wheels.....	(406) 447-1680
Salvation Army.....	(406) 442-8244
Townsend Daily Dinner Club.....	(406) 226-3995

Grocery Delivery

Heritage IGA.....	(406) 227-5304
Van's Thriftway.....	(406) 442-8645

Handicapped Services

Developmentally Disabled Division.....	(406) 444-2995
Family Outreach.....	(406) 443-7370
Helena Industries.....	(406) 442-8632
Lewis & Clark County:	
Health Department.....	(406) 443-2584
Human Services.....	(406) 444-1700
Library for the Blind.....	1-(800) 332-3400
Montana Independent Living Project.....	(406) 442-5755
Montana Telecommunication Access Program (MTAP).....	1-(800) 833-8503

Handicapped Services continued:

Social Security Administration	1-(866) 563-9496
Spring Meadow Resources	(406) 443-2376
Visual Services.....	(406) 444-4012
Westmont.....	(406) 447-3100
Big Sky Handicapped Services.....	1-(800) 630-8267

Health Education

Lewis & Clark County Health Department.....	(406) 443-2584
Planned Parenthood.....	(406) 443-7676
St. Peter's Hospital: Education Department.....	(406) 444-2130

Home Health Care Agencies

Frontier Home Health Care.....	(406) 443-4140
Homelink of St. Peter's Home Health.....	(406) 444-2244
Mountain View Medical Center Home Health, White Sulfur Springs.....	(406) 547-3321

Hospice

Frontier Home Health Care.....	(406) 443-4140
HomeLink of St. Peter's Hospital.....	(406) 444-2244

Hospitals

Broadwater Health Center.....	(406) 266-3186
Ft. Harrison Veterans'.....	(406) 442-6410
Mountain View Medical Center, White Sulfur Springs.....	(406) 547-3321
Shodair Hospital.....	(406) 444-7500
St. Peter's Hospital.....	(406) 442-2480

Information and Referral Systems

Area IV Agency on Aging.....	(406) 447-1680
End-of-Life Registry.....	(406) 444-0660

Infusion and Enteral Therapies

Statewide list provided on request; Contact Case Management..	(406) 444-2285
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In-Home Assistance (Private Pay & Medicaid)

ADL of Helena.....	(406) 443-0322
North West Home Care.....	(406) 442-6755
A to Z Personnel.....	(406) 443-7664
Nightingale Nursing & Caregiving.....	1-(800) 357-4799
Nightingale Local.....	(406) 443-1036
A Plus.....	(406) 443-3866

Insurance

Insurance Commissioner.....	1-(800) 332-6148 -or- (406) 444-2040
Medicare Eligibility Information:	
Social Security Office.....	1-(800) 772-1213 -or 1-(866) 563-9496

Insurance continued:

Claims Information.....	(406) 444-8350
Mountain Pacific Quality Health Foundation.....	(406) 443-4020

Legal

Adult Protective Services.....	(406) 444-2030
Area IV Agency on Aging.....	(406) 447-1680
Child Protective Services.....	1-(866) 820-5437
Montana Legal Services Association.....	(406)442-9830
Office on Aging.....	(406) 444-4676

Library and Resources

Lewis & Clark County: City/County Library.....	(406) 447-1690
Montana Talking Book Library.....	1-(800) 332-3400
Sr. Citizens' Library.....	(406) 447-1680
St. Peter's Medical Library.....	(406) 447-2462

Long-term Care Facilities

Big Sky Care Center.....	(406) 442-1350
Broadwater Health Center (Townsend).....	(406) 266-3186
Cooney Convalescent Home.....	(406) 447-1651
Deer Lodge:	
Powell County Medical Center.....	(406) 846-2212
Colonial Manor.....	(406) 846-1655
Elk Horn Health and Rehabilitation Center, Clancy.....	(406) 933-8311
Mountain View Medical Center Home Health, White Sulfur Springs.....	(406) 547-3321
Nursing Home Ombudsman	(406) 444-4676
Rocky Mountain Care Center.....	(406) 443-5880

Medical Equipment and Supplies

Clarks.....	(406) 442-6069
Community Home Oxygen and Equipment.....	(406) 443-3716
Harrington's (Butte).....	1-(800) 345-9517
Home Ox.....	(406) 449-4777 or (406) 459-9534

Medical Information and Other Healthcare Resources

AIDS Hotline.....	1-(800) 233-6668
Alzheimer's Association.....	(406) 447-1680
American Diabetes Association.....	1-(800) 766-8596
American Lung Association.....	(406) 442-6556
Area IV Agency on Aging Info & Referral.....	(406) 447-1680
Cancer Resource (Mens/Women's Support Groups).....	(406) 447-2435
Cancer Treatment Center of St. Peter's Hospital.....	(406) 444-2381
Cooperative Health Clinic.....	(406)443-2584
Helena Indian Alliance.....	(406) 442-9244
Leo Pocha Health Clinic.....	(406) 449-5796

Medical Information and Other Healthcare Resources continued:

Lewis & Clark County Health Department.....	(406) 443-2584
LIFELINE of St. Peter's Hospital.....	(406) 447-2739
Montana Heart Association.....	1-(800) 325-1774
St. Peter's Hospital Care Management.....	(406) 444-2284
Vocational Rehabilitation.....	(406) 444-1710
Capital City Case Management.....	(406) 431-2184 or (406) 431-2185

Mental Health

Crisis Line.....	(406) 443-5353
Center for Mental Health.....	(406) 443-7151
Montana Advocacy Program.....	(406) 449-2344
St. Peter's Hospital Care Management.....	(406) 444-2284
Cooperative Health Clinic.....	(406) 443-2584
St. Peter's Hospital Behavioral Health.....	(406) 495-6560
AWARE.....	(406) 449-3120
National Alliance for the Mentally Ill (NAMI).....	(406) 443-7871
WARM Line.....	1-(877) 688-3377
Suicide Prevention.....	1-(800) 273-8255
Mental Health Ombudsman.....	(406) 444-9669 or 1-(888) 444-9669

Nursing Home Alternative

Medicaid Waiver Program:

Lewis & Clark Case Management.....	(406) 443-2584
Rocky Mountain Case Management.....	(406) 447-1680

Oxygen and Supplies

Apria.....	(406) 457-1282
APEX: Home Oxygen & Equipment.....	(406) 447-2739
Community Home Oxygen & Equipment.....	(406) 443-3716
CPAP Solutions.....	(406) 442-7700
Home OX.....	(406) 449-4777 or (406) 459-9534
Lincare.....	(406) 449-2253

Pharmacy Delivery

Bergum Drug.....	(406) 443-0506
CVS West.....	(406) 442-2196
Tiger Express.....	(406) 410-0127

Public Health Agencies

Broadwater County Public Health.....	(406) 266-5209
Lewis & Clark County Health Dept.....	(406) 443-2584

Social Activities & Lectures

Senior Center (for information on all activities).....	(406) 447-1680
Senior Companion Program.....	(406) 447-1680

Call for a list of lectures and activities or visit www.stpetes.org

Support Groups

For the Support Group you are interested in, please check the local newspaper, call St. Peter's Hospital at 444-2363, refer to the Bulletin Board of the Helena *Independent Record*, or visit www.stpetes.org.

Thrift Stores

Good Samaritan..... (406) 442-0780
Goodwill Store..... (406) 457-1325

Transportation

HATS..... (406) 447-1580
Integrated Transportation Management
(for approval of Medicaid covered transportation)..... 1-(800) 292-7114
Capitol Taxi..... (406) 449-5525
Rimrock Trailways..... (406) 442-5860
Eagle Ambulance..... (406) 441-9111

Urgent Care

Helena Urgent Care..... (406) 443-5354
St. Peter's Urgent Care..... (406) 444-2343



KALISPELL REGIONAL MEDICAL CENTER

MEDICAL PRACTICES

Northwest Healthcare sponsors many primary care and specialty care medical practices in the region. As integrated members of Northwest Healthcare facilities, these practices work in conjunction with the hospital to provide area residents with access to quality medical services close to home.

PRIMARY CARE

<u>Big Sky Family Medicine</u> 752-8433	<u>Eureka Health</u> 297-3145	<u>Northwest Family Medicine</u> 752-8877
<u>Bigfork Medical Clinic</u> 837-5541	<u>Family Health Care</u> 752-8120 (Kalispell) 892-3206 (Columbia Falls Clinic)	<u>Polson Health</u> 883-3200
<u>The Clinic at Walmart</u> 751-6533	<u>Flathead Valley Women's Center</u> 752-0303	<u>Woodland Clinic</u> 755-7366



KALISPELL REGIONAL MEDICAL CENTER

Kalispell Regional Medical Center
310 Sunnyview Lane
Kalispell, MT 59901

(406) 752-5111 (Switchboard)

Information Desk

(406) 752-5111, Extension 2504

Direct Dial Patient Room

(406) 751-6700 + Room Number

For Emergencies Call

911

A.L.E.R.T. Program Information

(406) 751-5775

Admitting Telephone Pre-Registration

(406) 751-6745

Admitting/Registration

(406) 752-1719

Big Sky Family Medicine

(406) 752-8433

Birthing Center

(406) 752-1745

Cancer Center

(406) 752-1790

Community Health Education

(406) 751-4500

Corporate Compliance Officer

(406) 752-1774

Customer Relations

(406) 751-5434

Gift Shop

(406) 751-6791

Volunteer Office

(406) 752-1781

Medical Library

(406) 752-1739

Diabetes Resource Center

(406) 751-5454

Home Options

(406) 751-4200

HR Job Line

(406) 756-4405

Human Resources

(406) 752-1760

Laboratory

(406) 752-1737

Medical Records

(406) 752-1740

Orthopedics Program

(406) 751-6769

Pathways Treatment Center

(406) 756-3950

Patient Accounts - Financial Counselor

(406) 756-4761

Patient Accounts (Billing)

(406) 756-4408 (automated)

Performance Improvement

(406) 752-1768

Radiology (Diagnostic Imaging)

(406) 752-1766

Rehabilitation - Outpatient

(406) 751-4520

Rehabilitation - Inpatient

(406) 756-4720

Respiratory Care

(406) 752-1772

Risk Manager

(406) 751-5760

Same Day Surgery

(406) 752-1780

Spiritual Care

(406) 752-1776



DIRECTORY OF FACILITIES & SERVICES

Brendan House

350 Conway Drive
Kalispell, MT 59901
(406) 751-6500

Kalispell Regional Medical Center

310 Sunyview Lane
Kalispell, MT 59901
(406) 752-5111 (Switchboard)

Clinical Pharmacy

200 Conway Drive
Kalispell, MT 59901
(406) 751-7600

Medical Office Management Services

202 Conway Drive
Kalispell, MT 59901
(406) 752-5656

Dino-Sore

66 Claremont Street
Kalispell, MT 59901
(406) 756-9551

Northwest Healthcare Foundation

310 Sunyview Lane
Kalispell, MT 59901
(406) 751-6930

The Healthcenter

320 Sunnyview Lane
Kalispell, MT 59901
(406) 751-7500

Occupational Health Services

205 Sunnyview Lane
Kalispell, MT 59901
(406) 751-4508

Kalispell Medical Equipment

53 Third Avenue E.N.
Kalispell, MT 59901
(406) 752-6111

Behavioral Health Services Pathways Treatment Center

200 Heritage Way
Kalispell, MT 59901
(406) 756-3950

Regional Support Services

310 Sunnyview Lane
Kalispell, MT 59901
(406) 752-1724

Turtle Bay/Northwest Behavioral Health

7325 Hwy 93 S STE A
Lakeside Mt 59922
(406) 844-2890

The Summit Medical Fitness Center

205 Sunnyview Lane
Kalispell, MT 59901
(406) 751-4100

Special Thanks To:

Great Fall Rotary Club

Benefis Healthcare Foundation

Sletten Cancer Institute

NCILS

Rural Institute of Montana

University of Montana

Easter Seals of Montana

Dr. Patricia LaHaie

St. Vincent Healthcare Foundation

New Jersey Polio Network

New Mobility Magazine

Post Polio Health

Palmyra Post Polio Clinic

Polio Epic, Inc.

Post-Polio International

Post Polio of Montana

POLIO THE LIFE AFTER



Post-Polio Syndrome Awareness

RECOVERY AND REHABILITATION

SURGERY AND BRACES

POSSIBLE NORMAL LIFE

RELAPSE AND WEAKENING OF MUSCLES

BRACES

FATIGUE

POSSIBLE JOB LOSS

DISABILITY

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