



As the number of polio survivors gradually decreases in the US, finding medical providers familiar with post-polio syndrome is becoming more difficult. An individual provider is not able to develop expertise when experience is limited to a few patients per year. This necessitates that the polio survivor become an “expert patient.”

The term “expert patient” originated in England and refers to patients who have the confidence, skills, information and knowledge to play a central role in the management of life with chronic diseases. This concept has become part of medical education in the United States. Medical

students are trained to provide more patient education and rely on the patient as part of the medical treatment team to contribute to decision making regarding their care. To be an effective “expert patient” it is important to keep expectations realistic. Do not expect a primary physician to know much about post-polio syndrome. Be able to provide concise, scientifically based information for your physician. The Post-Polio Health International website (www.post-polio.org) has information for medical providers that can provide basic medical information and serve as a resource for specific conditions. Do not bring stacks of unreferenced information from the internet to your provider!

Establishing a good relationship with your primary doctor is key to accessing the medical care you need for the symptoms related to aging with polio sequelae. Medical management of post-polio syndrome includes management of the primary symptoms, treatment of underlying or associated conditions and optimizing health and wellness. Individual treatment plans include a detailed medical history and exam to identify problems, potential problems or health risks and goals. Identifying associated medical, neurological, musculoskeletal and psychological conditions are part of the process. Evaluation may require consultation with a specialist such as a physiatrist, neurologist, orthopedic surgeon, pulmonologist, or otolaryngologist. Interventions may include referral to a physical therapist, occupational therapist, speech language pathologist, orthotist or psychologist.

It is important for providers to recognize the unique physiologic aspects of residual paralysis due to polio. Polio survivors have a number of muscles that have lost some percentage of the normal innervation. These muscles cannot strengthen like normal muscles and lose proportionally more strength with aging. If polio occurred in childhood, bone and joint development were affected in the involved limbs. Muscle imbalances and joint deformities alter body mechanics and put increased stress on the musculoskeletal system, resulting in early degeneration. Body composition, or the ratio of muscle, fat and bone may be significantly altered and affect metabolism. Many of the symptoms of post-polio syndrome are like those of aging but accelerated and more complicated. Goals of treatment are to minimize symptoms of post-polio syndrome, optimize body mechanics, protect weak muscles and joints, decrease physical demands on the body, treat associated conditions and optimize wellness.

The primary symptoms of post-polio syndrome are excessive fatigue, muscle and/or joint pain, new weakness, cold intolerance and dysphagia or respiratory changes. Each of these symptoms may be exacerbated by other factors that should be addressed as part of the medical management.

Fatigue is a very non-specific symptom with many potential causes and contributing factors. Fatigue is exacerbated by poor sleep, deconditioning, obesity, poorly controlled chronic illness and depression in addition to the fatigue associated with overuse of weak muscles and

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post-polio syndrome. Managing fatigue involves optimizing body mechanics and cardiovascular health in addition to conserving energy. Pacing activities with intermittent rest periods is key.

This may require a change in lifestyle or work schedule. Sleep must be optimized by identifying and treating sleep apnea or hypoventilation at night, pain that interrupts sleep, or anxiety that may prevent sleep.

Muscle and joint pain associated with post-polio syndrome is often a result of overuse or excess stress on the body. Muscle pain commonly occurs in polio-affected muscles that have functional strength, putting them at risk of overuse. The pain may be associated with cramping, twitching or crawling sensation and is typically worse at the end of the day. Post-polio muscle pain is a warning sign of overuse and muscle tissue damage. Preventing the pain by modifying activity and stress on a muscle is an essential part of treatment. Using pain medication to simply mask symptoms may ultimately lead to further damage and loss of function.

Joint pain may be due to degeneration and inflammation in the joint or stress on the connective tissue surrounding the joint. It may occur in a polio affected limb where there is excess stress on a joint due to joint deformity, altered body mechanics, or poor protection due to weak muscles and ligaments or in a “strong limb” which has been subjected to years of overuse. Treatment of joint and soft-tissue pain must include evaluation and modification of body mechanics. This may require weight loss, physical therapy, bracing, assistive devices or mobility aids. Treatment may also include modalities, medication, injections and, at times, surgical intervention.

New weakness in polio survivors may manifest in muscles known to be affected by polio or in muscles thought to be unaffected. Most likely the “unaffected” muscles had sub-clinical motor neuron loss at the time of the acute polio infection. Loss of motor units and degeneration of the axon sprouts developed when muscles were [reinnervated](#) results in the weakness associated with post-polio syndrome. Medication has not been shown to be effective in preventing loss of strength unless other factors such as low testosterone or neuromuscular transmission defects are also present. Avoidance of overuse of “at risk” muscles and appropriate exercise to strengthen deconditioned muscles can delay loss of function. Identifying which muscles are weakening due to overuse and which have become deconditioned by changes in mobility requires very careful muscle testing and monitoring.

Cold intolerance, like fatigue, is a non-specific symptom common to polio survivors. Limbs with significant muscle atrophy related to polio have reduced blood flow and microcirculation due to minimal oxygen demand. Individual basal metabolic rate, related to amount and percentage of muscle tissue, is reduced in a polio survivor. Cold intolerance can be managed by improving cardiovascular circulation, insulating with layers of appropriate breathable clothing and ensuring availability of environmental control and external heat sources. Dysphagia and respiratory problems are related to a history of bulbar polio with residual weakness of upper airway, swallowing and respiratory muscles. A history of choking or coughing when eating or difficulty swallowing certain foods may warrant a swallowing evaluation and training in compensatory swallowing techniques. Reduced respiratory function may be a result of upper airway obstruction (weakness of muscles in the throat) or poor ventilation due to chest wall or diaphragm muscle weakness. Pulmonary function tests and sleep studies can identify the etiology of symptoms and indicate appropriate interventions. Assisted ventilation, assisted cough, breathing exercises and pulmonary rehabilitation may be utilized to optimize pulmonary function. Significant illness may be prevented through regular vaccinations and exposure precautions.

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Optimizing wellness contributes to overall health and sense of well-being. A good relationship with a primary care provider is essential to monitoring health and managing chronic conditions. Good nutrition, restful sleep and regular exercise help maintain vitality.

Preventing injury and illness and modifying lifestyle to minimize risks are key to preserving function. Psychosocial support lends security and purpose to life. Although post-polio syndrome can be a complicated condition to live with, finding the needed medical management and living well is still possible.

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You can find access to these informative video(s):

“Components of Post-Polio Management”

“Aging with Post-Polio Syndrome”

And more listed under Dr. Vandenakker-Albanese on the [Living with Post-Polio Syndrome](#) page of our website.

