

When a Post-Polio Clinic Is Not an Option

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A. You must start with a good primary care physician.

1. Keys to finding a good doctor:

- a. Look for a physician you trust and can communicate with.
- b. Identify the best hospitals in your area and try to find a physician on staff there. The best hospitals attract the best doctors.
- c. Get recommendations from trusted sources: hospital referral service, health plan directory, another physician or nurse, friends and neighbors.
- d. Find out if the doctor is Board Certified.
- e. Access your state's website for information.
- f. Your insurance choice may dictate what physicians you can see.

2. You will be an "expert patient":

- a. Good and bad connotations.
- b. Provide a brief summary of PPS:
 - 1) NINDS Post-Polio Syndrome Information Page
 - 2) March of Dimes Quick Reference and Fact Sheets — Post-Polio Syndrome
 - 3) Post-Polio Health International —
Polio and Post-Polio Fact Sheet or The Late Effects of Polio-An Overview
- c. Do not expect that the doctor will know much about polio.

3. Do NOT overwhelm a new physician.

- a. Let the physician get to know you and evaluate your overall medical condition and health issues.
- b. Do not go in with a shopping list of equipment needs or a stack of disability forms.
- c. Be familiar with the summaries and provide the one most appropriate for your needs.
- d. Give the doctor a chance to learn about you and PPS.

4. The first step to managing symptoms of Post-Polio Syndrome is optimizing health.

(Any good doctor can help you with this step.)

- a. Other conditions must be diagnosed and treated. "Diagnosis of exclusion"
- b. Monitoring for osteoporosis (strong limb/weak limb), hypertension, anemia, sleep apnea, thyroid dysfunction
- c. Aging changes should be discussed.
- d. Health promotion through:
 - 1) Nutrition — calories and weight control
 - 2) Exercise — stretching, strengthening and aerobic conditioning
(See Guidelines for polio survivors)
 - 3) Stress management — psychosocial, emotional health

B. Symptoms should dictate diagnostic testing and/or referrals. A variety of specialists may be able to identify and treat problems. You may find one of your specialists most receptive to your needs.

1. Pain may be classified into different categories:

a. Post-polio muscle pain — caused by overuse of weak muscles

- 1) Occurs in polio muscles
- 2) Similar to pain of acute polio
- 3) Associated with cramps, twitching, crawling sensation
- 4) Increased at end of day
- 5) Aggravated by activity, stress, cold

b. Soft tissue pain

- 1) Injury or inflammation of muscles, tendons, ligaments, bursae
- 2) Common examples: rotator cuff tendonitis, "tennis elbow", bursitis of the hip
- 3) Often affects the "strong" limb
- 4) Related to body mechanics

c. Joint pain from degenerative changes

- 1) Affects joints in strong limbs due to normal or excessive "wear and tear"
- 2) Joints in polio - affected limbs may have force changes resulting in ligament tears, joint deformity
- 3) Joints with mild degeneration may be symptomatic because of abnormal body mechanics.

d. Spine pain

- 1) May be in spine or referred into extremities
- 2) Increased scoliosis increases risk of spine problems
- 3) Spinal stenosis may mimic PPS

e. Nerve pain

- 1) Severe pain often associated with sensory changes or shooting/electrical symptoms
- 2) May result from diffuse disease or localized nerve compression (carpal tunnel syndrome)

f. Bone pain

- 1) Osteoporosis with small compression fractures
- 2) Traumatic fractures/bruising

2. Fatigue

a. Evaluation of causes/aggravating factors

- 1) Sleep pattern
- 2) Other medical illnesses: thyroid, CAD, obesity, anemia
- 3) Deconditioning
- 4) Depression
- 5) Overuse
- 6) PPS

3. New weakness

a. Evaluation of possible causes:

- 1) New superimposed neurologic condition
- 2) Disuse atrophy/ deconditioning
- 3) Weight gain
- 4) Medical condition
- 5) PPS

4. Respiratory/Pulmonary problems

- a. Decreased muscle strength from polio causes restrictive lung disease similar to that seen with other neuromuscular diseases.
 - b. Polio survivors may have obstructive disease as well, especially with h/o smoking or allergies.
5. Swallowing difficulties
- a. Should be assessed by a speech therapist and appropriate studies ordered as indicated

C. Basic principles of treatment:

1. Identify goals
 - a. Improve body mechanics
 - b. Correct or minimize postural and gait changes
 - c. Protect weak muscles and joints
 - d. Adjust the workload on muscles and joints to match their capacity
 - e. Control inflammation (sign of poor body mechanics)
 - f. Control muscle spasm (sign of overstress of muscle)
 - g. Alleviate nerve impingements
 - h. Promote healthy lifestyle modifications
2. Determine appropriate treatment modalities:
 - a. Behavior modification/pacing
 - b. Physical therapy (provide resources)
 - c. Occupational therapy
 - d. Bracing
 - e. Assistive devices
 - f. Weight loss
 - g. Joint/spine injections
 - h. Medications
 - i. Psychological counseling
3. Educate those who work with you
 - a. Provide resources (not stacks of printed material)
 - b. Let your feelings and needs be known without becoming overbearing or too demanding
 - c. Treatment plan should result from discussion between you and your health care provider - not one or the other giving orders!

Pain and Specialists Listing:

Bone Pain:

Specialists: Endocrinology, Orthopedics

Treatment: Treatment of osteoporosis, immobilization of fracture, bone stimulation

Joint Pain:

Specialists: Orthopedics, PM&R, Rheumatology

Treatment: Bracing, assistive devices, therapy, medications

Polio Muscle Pain:

Specialists: PM&R, Orthopedics, Neurology- YOURSELF!

Treatment: Protection of muscles, activity modification, pacing

Nerve Pain:

Specialists: Neurology, PM&R, Orthopedics

Treatment: Activity modification, splints, therapy, medications, injections, surgery

Respiratory or Pulmonary Specialists:

Specialist: Pulmonologist, referral to local muscular dystrophy clinic pulmonary specialist may be most helpful.

Soft Tissue Pain:

Specialists: Orthopedics, PM&R, Rheumatology

Treatment: Correct/adapt body mechanics; protect affected areas, rest, ice, NSAIDS, injections, therapy

Spine Pain:

Specialists: Orthopedic Spine, PM&R

Treatment: Therapy, injections, bracing, surgery

New Muscle Weakness:

Specialists: Most of the assessment can be done by the primary MD, with assistance from PM&R, neurology, and possibly psychologist, sleep specialist, physical therapist

Treatment: Treat all contributing factors, appropriate pacing, limited exercise program, protecting weak limb

If you are unable to find satisfactory treatment locally, I recommend a visit to a post-polio clinic for assessment and recommendations.

Post-polio Fact Sheets Available on the Internet:

www.ninds.nih.gov/disorders/post_polio/post_polio.htm

www.post-polio.org/ipn/fact.html

www.post-polio.org/ipn/lep.html

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