

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, etc.)

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, (carpal tunnel, tendonitis, etc.)
- 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 (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 ABOUT BREATHING PROBLEMS?

Polio survivors may experience new breathing problems; even though the lungs were not originally thought to be affected by the acute polio virus.

SYMPTOMS:

- The need to sleep sitting up
- Insomnia
- Morning headaches
- Excessive daytime fatigue/sleepiness
- Night sweats and interrupted sleep
- Unproductive cough and increase in respiratory infections

APPROPRIATE ACTIONS:

- See your Healthcare provider and/or a pulmonologist immediately
- Be wary of oxygen therapy if your lungs are not damaged. (You cannot assume that polio damages the lungs)
- Tracheostomy tubes should be avoided
- Possible need for sleep study

7. WHAT TO DO WHEN SURGERY IS REQUIRED.

- Talk to your healthcare provider about the planned procedure and post-polio concerns
- Set up a consultation with the anesthesiologist during the pre-admission process about concerns with post-polio and curare types of anesthesia
- Review your previous medication reactions with surgeon
- Assess with Healthcare provider your need for in-patient vs. out-patient surgery:
 - Body positioning during procedure

- Cold intolerance
- Additional post-operative recovery time may be required
- Additional anesthesia and/or pain medicine may be required
- Assess level of fatigue to determine your ability to tolerate out-patient or in-patient procedures

8. 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 (ibuprofen, Celebrex, Vicodin, Percocet, Oxycontin, etc.) as prescribed by your Healthcare provider
- Try alternative type treatments (acupuncture, yoga, myofascial release, Reiki, Watsu, etc.)

9. WHAT ABOUT MEDICATION?

It is your responsibility to know all your prescriptions, over-the-counter (OTC) drugs, and supplements. Inform your health care provider with:

- Name
- Purpose
- Dosage
- Interaction with other medications
- Side effects and risks
- Previous medication reactions
- Change your lifestyle before turning to pain medications
- Avoid stimulants that cause increased fatigue

10. HOW IS PPS DIAGNOSED?

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

11. HOW TO COMMUNICATE WITH YOUR HEALTHCARE PROVIDER?

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, (tiredness, fatigue, exhaustion, etc.)
- From journal, make a list of questions and concerns to present to your Healthcare provider

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, (normal aging, heart disease, diabetes, etc.)

AFTER your Health care provider’s visit

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

12. 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. Develop programs to 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

13. WHERE DO YOU FIND MORE INFORMATION?

- **Polio Epic, Inc.**
P.O. Box 17556
Tucson, AZ 85731-7556
(520) 750-8608 (message)
www.polioepic.org
- **Polio Echo, Inc.**
P.O. BOX 61024
Phoenix, AZ 85082-1024
(480) 545-1147
www.polioecho.org
- **Post-polio Health International (PHI)** including International Ventilator Users Network
St. Louis, MO
(314) 534-0475
www.post-polio.org



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 - Revised August 2007