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

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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.)

AFTER your Healthcare 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

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YOU KNOW YOUR OWN BODY BEST!