

Founded in 1989
Post-Polio Support Group of Orange County
15231 Marne Circle Irvine CA 92604

WEBSITE: ppsupportoc.org

January 2018 Newsletter

Finger food Pot Luck

and discussions on topics of interest to those attending

Saturday

January 14, 2018

2-4 pm

Villa Park City Council Chambers

Sleep and Respiratory Care Part 2 **Summary of September 2017 Presentation** **Diana Guth, BA, RRT** **Sleep Associated Hypoventilation (Continued)**

Diagnosing Hypoventilation

- Pulmonary Function Tests are required to diagnose Hypoventilation
- Problems with Sleep Studies
 1. Designed to diagnose sleep apnea not hypoventilation
 2. Sometimes hypoventilation presents itself as Central Sleep Apnea (because of weak respiratory effort)
 3. They rarely monitor ventilation; sometimes they monitor carbon dioxide levels but...
 4. They are not prepared to titrate effective ventilator settings
 5. Poses a hardship for some patients with severe neuromuscular disorders
- **Pulmonary Function Test (PFT):**

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1. A group of tests that measure how well your lungs & respiratory muscles function
2. Spirometry: Measures a person's breathing capacity; air volumes, the speed of breathing compared to predicted
3. Recommendation: Do the PFT both upright and lying down (if possible). Gravity aides a weakened diaphragm to breathe. By lying down, gravity can't help the diaphragm descend

4. There are two important test results. Assuming the diagnosis of PPS, only one is needed to qualify for Medicare coverage of a BiPAP S/T. These test result are not needed for Medicare coverage of a ventilator but it is an objective proof of respiratory weakness.
 - Forced Vital Capacity (FVC): The volume of air expelled after a maximal inhalation
 - If it is less than 50% predicted (based on age, height, weight & smoking history), it proves a need for ventilatory support
 - Maximal Inspiratory Pressure (MIP): Measures the strength of the diaphragm by the negative pressure generated by sucking in as hard as possible. It's a simple, easy & sensitive test.
 - MIP should be less than -60 cm H₂O (If **close** to that, a re-measurement must be done lying down!)
- **Arterial Blood Gas Test**
 1. Measures the partial pressure of oxygen & carbon dioxide plus the acid base balance in the arterial blood (vs the much more common venous blood tests)
 2. It is not usually done unless someone is in the hospital in acute respiratory failure. Taking arterial blood is more traumatic and difficult.
 3. Normal PCO₂ (partial pressure of carbon dioxide) is 38-42 mm Hg.
 4. A PCO₂ of 45 mm Hg for Medicare Coverage of a BiPAP S/T & is one proof of hypoventilation

Treatment of Hypoventilation: Noninvasive (Positive Pressure) Ventilation (NIV)

- **Noninvasive Ventilation (NIV)**
 1. Provides noninvasive ventilatory support; provides relief from Shortness of Breath (SOB)
 2. Provides larger, pressure supported, or volume supported effective breaths to maintain a normal PCO₂ and PO₂
 3. Easy to use, portable (some have built-in batteries)
 4. Sleep peacefully
 5. Feel better, more energetic & maintain an active lifestyle
- **Respiratory Disease Management by a Respiratory Therapist**
 1. Expert Respiratory Care is essential for the proper treatment of people who require respiratory support.
 2. Preferred Prescription: "Titrate to patient comfort". Many companies will not accept this type of order. MD cannot know what the ideal settings are. They can give parameters.
 3. Assessment & Reassessment of the Patient
 4. Be able to administer different phases of treatment, perhaps starting out slow then adjusting as the patient becomes acclimated, stable times monitoring, take action with acute changes.
 5. Expert mask fitting with a wide selection of masks.
 6. Good communication with MD, family & others
- **Two Classes of NIV: Respironics "BiPAP" AVAPS or ResMed iVAPS & Volume Ventilator**
 1. Connected to the person via a wide choice of masks. Masks for Bilevel PAPs &

- CPAPs have Exhalation Ports – many choices
2. Volume Ventilator can be used via mouthpiece (“sip & puff”)
 3. Some can be remotely monitored & settings changed with built-in wireless modems
- Respironics AVAPS BiPAP (Trademark of Philips Respironics) or ResMed Ivaps
 1. Provides Bilevel Positive Airway Pressure Support Ventilation
 2. Set **IPAP: Inspiratory PAP** Set **EPAP: Expiratory PAP**
 3. The difference between the IPAP & EPAP determines the size of each breath
 4. Can program the size of each breath (Tidal Volume)
 5. They have **Timed Backup Rates: S/T**
 - “S”: Spontaneous: The user can trigger each breath
 - “T”: Timed: If the user doesn’t trigger a breath, the machine will deliver a timed breath
 6. **DO NOT** order Bilevel PAP S!!!! NO B/U Rate! Don’t let the insurance companies switch!
 7. Advantages:
 - Entry level, small, less intimidating device
 - Less expensive
 8. Disadvantages:
 - Can’t choose the company you want under Medicare
 - No built-in or detachable battery
 - Can’t do mouthpiece ventilation
 - Under Medicare, unit becomes owned after 13 months so DME company with the respiratory care have no obligation to see the patient. They don’t get paid for their time.
 - No Medicare coverage for a 2nd unit

Volume Ventilators: Volume Ventilators and Hybrid Volume Ventilators

- **Volume Ventilators:** Volume of each breath (Tidal Volume) is set
 1. Uses an Active Closed Circuit that has an Exhalation Valve that closes during inhalation so all the volume is delivered to the user and opens during exhalation to let the air out.
 2. Must use a mask without an Exhalation Port – there are few portless mask choices
- **Hybrid Volume Ventilators:** Can deliver above Bilevel modes OR Volume
 1. Uses a Passive Open Circuit for Bilevel modes via wide selection of masks with Exhalation Ports
 2. Can also use Active Closed Circuits for Volume modes
- Advantages
 1. Can choose the company you want under Medicare so receive better Respiratory Care Service
 2. Has built-in & switchable batteries
 3. Has Mouthpiece Ventilation Mode
 4. Separate Daytime and Night time settings
 5. Medicare covers 2nd ventilator if used with a wheelchair
- Disadvantages (under Medicare)

1. Far more expensive: only rented but includes supplies and RT visits
2. They are larger

Initiating NIV Treatment: The Window of Opportunity

- It's better to start too early than too late. Many advantages!
 1. When symptoms first appear: DON'T be in denial!
 2. Improved Quality of Life
 3. Rest weak diaphragm
 4. Correct hypoventilation during sleep
 5. Provide stability to the upper airway
 6. Provide time to learn needed skills
- DON'T let it become an EMERGENCY
 1. Recognize the early, chronic signs while you can make careful, informed decisions!
 2. Start before symptoms are severe & an emergency situation occurs!
 - Respiratory failure leading to intubation, leading to tracheostomy
 - Let your decision makers know your wishes! Have a Detailed Advanced Directive for Healthcare
 - If you use NIV have four documents ready from "Take Charge, Not Chances" should you need to be hospitalized

Masks: The Key to Successful NIV Treatment

- Three general mask classifications
 1. Nasal Pillow – Fits into the nose
 2. Nasal Mask – Fits around the nose
 3. Full Face Mask – Fits over the nose & mouth
- Mask Fitting Goals
 1. Comfortable
 2. Easy to use
 3. Effective
- There are many choices. Choose a company that has a wide mask selection and

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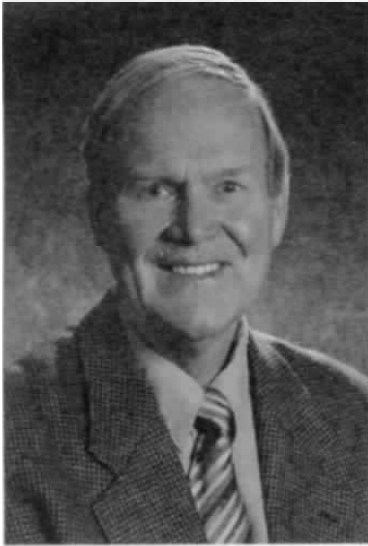
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Author: Frederick M Maynard, MD Page (s)/column location: 10,11

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Ask Dr. Maynard



Frederick M. Maynard, MD

Question: *After several weeks when my polio-affected right leg began to swell, beginning at the foot and now up into the knee, a vascular physician diagnosed the condition as lymphedema and referred me to physical therapy. The swelling decreases only slightly after sleeping all night, even with my legs elevated. My ability to exercise (walk) is not practical having great instability and imbalance. I also have symptoms of neuropathy in both feet contributing to lack of balance. I do use a cane.*

In 1949, my right ankle underwent a triple arthrodesis with a tendon transfer, which really was a great help although I have had to go to a supportive in-shoe ankle/foot brace to avoid tripping. My question becomes, is the diagnosis of lymphedema something to be expected and what treatment or medication protocol would be appropriate?

A: Lymphedema is a fairly common complication in a paralyzed lower limb, particularly as people age, if there are any open sores on the feet/ankles from minor/major traumas, and/or there is dependent swelling from at least some degree of venous

insufficiency.

It is important to treat lymphedema vigorously after it is first diagnosed, because further complications can occur and the longer it is present, the harder it is to treat and sometimes resolve.

Vigorous treatment involves “elevation with specific massage” as a one-to-three times per day regimen that can be taught by a “lymphedema therapist specialist” (usually a PT or OT) to a family member or friend.

Additionally, the limb must be wrapped with specialized materials between treatments. Sometimes the therapists must also utilize Jobst pumping sleeves as a specific frequent treatment until the limb circumferences measurements stabilize. Then, one must order custom-sized compression garments that are worn when one will be sitting up with legs dependent.

The vigorous treatment regimens can be time consuming and expensive but are worth it in the long run, and usually aren’t too intrusive of time after one-to-three months. Feel free to share these thoughts with your doctors or therapists.

Question: *I am 66, had polio in 1951 or '52, and to my knowledge the only part of my body impacted was my left leg with paralysis in the quadriceps. I have always been physically active.*

Even now, I exercise four to five days a week and play golf when weather permits.

I wore a brace - KFO - in high school to straighten out my left knee, and until about ten years ago, basically used the brace only to play golf, as it locked the knee and permitted me to follow through on my golf swing and to walk golf courses. Without the brace, I probably could walk about a quarter of a mile before extreme fatigue set in.

With the advent of hip issues in the past, my physical therapist suggested I use the

brace more frequently as it gave me better posture/alignment and it took pressure off of my good (right) leg.

Eleven years ago I had hip replacement surgery on my right side, and my recovery was excellent. Since using the brace I have noticed an improvement in my back pain - practically non-existent - all of which is great. BUT, I can't walk without the brace without having to hold in my knee to keep it from buckling. (I seem to be able to ride the exercise bike as well as before the hip surgery and walking distances with the brace is still not a problem.)

Here is the question: Is the increased inability to walk without the brace due to a dependence on the brace or simply due to increased age and post-polio issues? Pain isn't an issue - never really has been (other than my good hip before the surgery). Most muscle pain that I have is usually resolved through exercise, and I seldom take anything other than an occasional ibuprofen.

If it is due to increased dependence on the brace, is there something I can do to retrain myself so that I can walk some without the brace? I miss the freedom of not having to wear the brace all the time.

A: Your question brings up several recurring issues for aging active polio survivors. It is common that arthritis develops in a polio survivor's stronger leg. You were wise to take your therapist's advice and use the KFO regularly during and after your recovery from the hip surgery.

If you now have a safe, pain-free and functional walking ability, albeit with the KFO, your primary goals have been met.

Your concern that your ability to walk without the KFO is now worse is understandable, but probably can't be significantly altered (at least not without a lot of time and effort and with questionable results, particularly lasting results).

What has most likely happened is that your "post-polio syndrome" weakness in the right quadriceps (the muscle most involved from your original polio infection) has worsened, both as a result of time and age as well as by several months of only walking with the brace which led to less vigorous regular contractions of that muscle.

Once a chronically weak post-polio muscle, particularly the quadriceps reaches the point that it cannot stabilize the knee joint, it cannot regain sufficient strength to do this function again, at least not without assistance, such as pushing on the thigh with your hand during stance on that leg.

My advice would be to "count your blessings" and go on with your life using the KFO and having it become part of you and being sure it is well-maintained and modified as needed to be maximally comfortable and minimally intrusive.

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Some readers who responded to the call for financial help

Mary Louise Hinshaw, Larry Dornacker, Hal Hichborn, Janice Palmer, Anita Cano, Margo Wilson, Helen Gonzalez, Winifred Hyson, Winifred Hyson, Karen Berquist, Didi Dodson, Mary Armenta, Lois Jackman, Barbara Mackinnon, Gail Williams, Nancy Norwood, Catherine Lyon, Sally Shaw,



Rancho Los Amigos Meeting

Saturday 27th
2018

2-4 PM

How to contact Rancho Support Group:

The Rancho Los Amigos Post-Polio Newsletter is published as a joint venture with the Polio Survivors Association. For Additional information please call Richard at 562-862-4508.

Or email: Rancho@hotmail.com

Agenda ideas for PPSG of OC?

Please call Aleta at 949-559-7102
or email Priscilla at prisofoc@aol.com
WEBSITE: ppsupportoc.org

Orange County Meetings

- Saturday January 13th 2-4 PM
Finger Food Potluck and lively discussion
- Saturday March 10th 2-4 PM
Disaster Preparedness for the disabled
by Jerry Couchman, Red Cross Volunteer
- Sunday May 6th 2-4 PM (tentative)
Dr Perlman on latest in PPS research and care *** Note this is 1st Sunday**
- Saturday July 14 2-4 PM (tentative)
Travel designed for the disabled
- Saturday September 8th 2-4 PM
Sharing ideas for home modifications and "gadgets" to live better with PPS.
- Saturday November 10th 2-4 PM
HICAP on Changes in Medicare

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The OC Group usually meets 2nd Saturdays of odd numbered months. Its newsletter is published more or less quarterly. The Rancho Los Amigo PPS Support Group meets most months and publishes on even months. We share the same mailing list. All donations are shared equally. **Recent donors:**

More readers who responded to the call for financial help

Kathleen Grams, Betty Thompson, Mary Correia, Carol Hall-Condon, Denis Hunter, Barbara Driggs, Kathryn Hooper, Marcia Leitner, Astrid Gallagher, Sally Ann Adams, Barbara Arczynski, Linda Klinkert, Janice Palmer, Sidney Israel, Lou Bradley-Sapp, Rose Mary Yarak, Conrad Villanueva, Edward Doyle, Judith Martasin, Kenneth Coulson, Paul Williamson, William Bevan, Sue Haskins, Sharon Gover, Linda Groth, Selma Calmes, MD, Betty McFarland, Rowland Rice, Rebecca Coyne, Patricia Hogate, Norma Olivares, Helen Gonzalez, Carole Ashby, J. Caruso, Sharon Rockwell, Mary Hicks, Mary Darmody, Raul Esparza *(More will be listed next newsletter)*

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