

ALS Support Bulletin

Advising, Learning & Sharing

A PUBLICATION FOR ALS PATIENTS,
FAMILIES AND CAREGIVERS

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Information and Treatment Links

www.als.mda.org

www.als-link.org

www.neurology.emory.edu/ALS

www.clinicaltrials.gov

www.alscenter.org

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SUPPORT GROUPS

Athens - Oconee Veterans
Park. 3500A Hog Mountain
Rd, Watkinsville, GA 30677

Fayetteville - Senior Services
Center. 4 Center Drive,
Fayetteville, GA 30214

Macon - Central Georgia
Rehab. 3351 Northside Drive,
Macon, GA 31210

Marietta - First United
Methodist Church.56
Whitlock Avenue, Marietta,
GA 30064

New Patient - ALS
Association of GA. 1955
Cliff Valley Way, #116,
Atlanta, GA 30329

Issue: # 3

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Welcome to the June 2012 issue of the ALS Support Bulletin. This is a quarterly publication from HisGrip Home Care in close collaboration with professionals, patients and caregivers of Amyotrophic Lateral Sclerosis(ALS - Lou Gehrig's) disease. The goal is to Advise, Learn and Share information to patients and caregivers of the disease.

"It was my turn to give back..." A Caregiver's Perspective By Phyllis Mathis

I would like to tell you about how ALS affected the life of my husband Leonard Todd Mathis Sr. and I. In 2006, we were both excited about life because it was almost time for us to be empty nesters and we couldn't wait to have the house to ourselves. Guess what? Amyotrophic Lateral Sclerosis (ALS) often referred to as Lou Gehrig's disease had different plans for us.

Leonard was diagnosed with ALS on December 12, 2006. When we found out what ALS was, we both felt as though our hearts had been ripped out of our bodies. We were in disbelief that this was happening to him. We cried and prayed together.

After Leonard's diagnosis, he was tested and became a good candidate for one of the ALS trial drugs, Certrixone. As his caregiver, I had to be trained on how to maintain the port, administer the trial drug twice a day and make sure the area stayed clean and free from infections. As Leonard started to lose a lot of weight, he had to get a PEG (feeding) tube to help keep his weight up. As his disease progressed, his body got weaker. When it became too hard to do a lot of tasks including his job as a tax auditor, he decided to stop work.

Leonard was hospitalized with aspiration pneumonia which led to him being put on a ventilator. I visited Leonard in Rehab every day. I decorated his room with family photos and made sure he had his favorite thing - music. Despite all

For additional information about the support groups including dates and time of meetings, please contact the ALS Association of GA at 404-636-9909 or visit the website www.alsaga.org

We all know about raised toilet seats but.....what do you do when visiting a friend's home, a restaurant, or other public place? Did you know there is a 5-inch portable toilet seat (like a plastic doughnut) available for about \$25.00 in many pharmacies? Just keep it in a drawstring bag and "don't leave home without it".

he was going through, Leonard always had a great smile and a personality to match it. Unfortunately, he was not able to be weaned off the vent and we brought him home.

It was a very scary time in my life because Leonard had always been a great husband and my soul mate and now he was dependant on me. *I decided it was my time to give back to Leonard.* I learned how to use all the equipment that was associated with keeping my husband alive. I put his hospital bed downstairs in our home and the sofa next to it became my bed. My mom made sure the house stayed clean and the clothes were washed. My sons came home every weekend to help out. I decorated the room with all our family pictures. It looked cluttered but Leonard loved it and that was all that mattered. As the disease progressed, I became Leonard's physical, occupational and respiratory therapist. I was also his wife, advocate and best friend.

Leonard kept getting infections in his trach and pneumonia in his lungs. When his organs started to fail, Leonard was at peace and left us to be with the Lord on March 27, 2010. I miss him each day, but knowing he is in heaven makes it easier to accept his death. I thank God for His grace, peace and mercy during this trying time.

Here are some helpful hints to caregivers:

1. Accept help. Let other people that you and the patient trust help you out. Do not try to be a super person.
2. Use other resources. Take advantage of support groups, respite care, in-service training, education, research and volunteer support.
3. Be well informed of your loved one's wishes (Last Will and Testament) and make sure everyone knows as well.
4. Provide a pleasing environment. Make sure the room where your loved one spends most of their time is pleasing to them.
5. Be proactive. Don't wait till the last minute to get what you need. If a patient is falling a lot, get a walker. If they are having problems speaking, research communication devices.
6. Communicate adequately to medical staff. When you go to the hospital, do not forget to tell the staff if your loved one has an easy stick, or has rolling or small veins. Provide information about PEG tube, vent points and trach size.

7. Communicate with your loved one. It is imperative that you let everyone know that your loved one may not be able to communicate but they can still hear so all communication must be directed to them.

8. If your loved one is on a ventilator, contact your electric and telephone company to inform them. Ask your doctor to write a letter. This will place you as high priority when there are power problems. Always keep backup batteries charged. Let your local fire department know to log you in their system for priority response and to send special trained vent staff when needed.

Phyllis Mathis is a loving caregiver and wife of Leonard Todd Mathis, Jr. She currently lives in Lithonia, GA and remembers her husband fondly every day.

Equipment Educator - Cough Assist

The Cough Assist Machine helps to clear secretions from the lungs by helping you with your breathing. When you breathe in (inspiration), the machine gives you air (positive pressure) to help expand your lungs. When you blow out (expiration), the machine creates a sucking force (negative pressure) that pulls the air out of your lungs. This rapid change in pressure during the different phases of breathing (inspiration and expiration) helps make your cough stronger and more effective.

Maintenance

Machine Cleaning

Replace disposable filters monthly or per manufacturer manual. Clean non-disposable filters weekly and replace when needed.

Use warm soapy water and let air dry before inserting back into machine.

Headgear

Wash as needed.

Hand wash in mild detergent (i.e. Woolite) and air dry.

Can be placed in dryer on 'air' setting. **DO NOT** machine wash headgear.

Masks & Nasal Pillows

Wash daily with mild detergent (i.e. Ivory); rinse thoroughly to remove all detergent and residue; air dry.

Use detergent that is free of perfumes, dyes, and moisturizers. They can shorten the useful life of your mask or pillow.

Tubing

Wash bi-monthly with mild detergent and air dry.

Humidifier

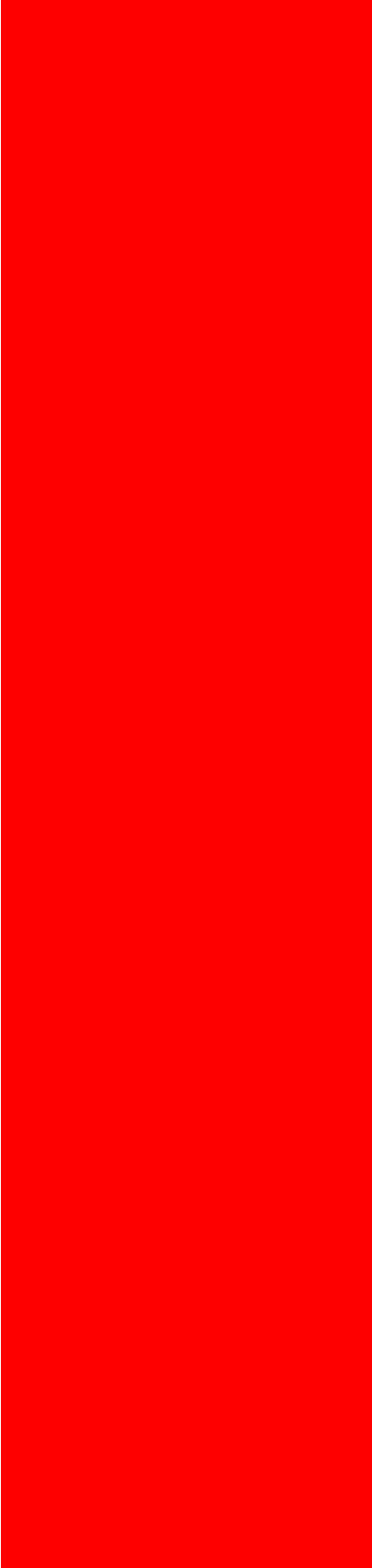
Change distilled water daily right before bed. It is best to put the distilled water in right before bed.

Clean chamber daily and let air dry.

Some heated humidifier chambers can go into top rack of the dishwasher.

Soak all other humidifier chambers for 30 minutes in a solution of equal parts white vinegar & water. This solution can remain in refrigerator for one week.

A few other things about the Cough Assist Machine



The machine is very easy to learn once you understand what each knob controls.

- **Power Switch:** 'I' symbol means ON. 'O' symbol means OFF
- **Inhale:** Determines how long the positive pressure will be blowing air into the lungs.
- **Exhale:** Determines how long the negative pressure will be sucking or forcing the air out of the lungs.
- **Pause:** Determines the time between the last negative pressure and next positive pressure.
- **Inhale Flow:** Sets the amount of flow needed during inspiration (taking a breath in). There are two settings: FULL or REDUCED. If REDUCED flow is used, there is a small reduction in inhale pressure.
- **Inhale Pressure:** Adjusts the inhale pressure to be less than the exhale pressure.
- **Manual/Auto:** Controls whether you want the machine to be automatically switching between pressures or if you want to do it by hand (manually).
- **Manual Control:** Allows you to toggle between inhale and exhale when you are using the manual setting.

The Use of Oxygen in the Comfort Care Setting: Yes, No, Maybe? By Jackie Marcum, RRT, RCT, CPFT

Now, more than ever, ALS patients are acquiring respiratory care equipment for use in the home setting and adapting to the use of this equipment for the treatment of respiratory insufficiency and failure during the disease process. NIPPV, CoughAssist™ and suctioning equipment are common place in the home setting. Patients, family members and caregivers are given instructions in equipment use, maintenance, and cleaning of the equipment. Reinstruction, coaching and encouragement are a major portion of the subsequent respiratory assessments. The use and effectiveness of this equipment is the topic of many ALS Support Group meetings and Conferences. FVC and NIF measurements are made during clinic appointments resulting in recommendations for the initiation or changes to NIPPV settings and CoughAssist™ use. A great deal of emphasis is placed on the value of both of these devices.

Supplemental oxygen is not a primary treatment for shortness of breath in this population. The majorities of neuromuscular patients have normal oxygen saturation and do not require supplemental oxygen. Unfortunately, there are ALS patients with coexisting problems and diseases which do require additional oxygen, especially lung and heart disease. Pneumonia, pulmonary embolism and DVT are examples that may require temporary or long term use of supplemental oxygen which may be used in ADDITION to the use of NIPPV and CoughAssist™.

Oxygen is a drug that requires a physician prescription and is administered at a flow prescribed by a physician. Oxygen can be added to NIPPV or a ventilator using an adaptor when prescribed but administered alone does not "inflate" the lungs, cure a disease or remove fluid buildup. Oxygen may increase the oxygen level of the blood, but does not lower the carbon dioxide level. ALS patients who have been compliant users of NIPPV and CoughAssist™ should continue to use these devices as prescribed throughout the disease. Low dose oxygen, as prescribed by the physician or hospice advisor, can be added if the patient's oxygen saturation drops below normal. Oxygen at the prescribed setting may be used for breaks and for those patients who have either decided to remove their NIPPV device or have not begun their use. Care must be taken not to exceed the

prescribed oxygen liter
flow. As every

ALS patient is different, so can be the differences in comfort care. At the discretion of the healthcare provider team and patient, pharmacologic agents that lessen the feeling of shortness of breath can be used. Continuing to provide NIPPV, suctioning as needed, supplemental oxygen, continued mucous clearance with the CoughAssist™, optimal positioning in the bed or wheelchair are all options that can be used together or separately to help achieve a level of comfort for both the patient and the caregivers.

Jackie Marcum is a Registered Respiratory Therapist who has worked with ALS patients in a clinic setting for the past 14 years. Jackie has spoken at numerous ALS association meetings and is a sought after resource on the use of Respiratory Care Equipment for the ALS patient.