

Articles:

- Managing Medications
- Caregivers: Setting Goals
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- Recognizing Members' Efforts
- Sleep Apnea & PH
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Did you know?

- Obstructive sleep apnea was first reported in medical literature in 1965.
- In 1981 Colin Sullivan & associates from Sydney, AU first described CPAP machines.
- Sleep apnea sufferers have a 30% higher risk of heart attack or premature death than those unaffected.

SEVEN STEPS TO PROPER PRESCRIPTION DRUG USE

Pulmonary Hypertension patients take a lot of medications: to help manage their disease, to prevent the disease from worsening, and to treat side effects from some of their unique PH drugs. **Taking ownership of your medication regimen is the most important step in preventing drug mishaps.** Here's how:

1. Make a List and Check it Twice: list all of your medications, current doses, allergies, medical/surgical history, physicians, insurance, etc. and keep the list with you at all times – write it on a card and carry it in your wallet. Keep it current! Include over the counter medications and all nutritional supplements. With this valuable information at hand, particularly in emergencies, you may avoid delay in receiving adequate treatment or facing harmful treatment.

2. Share and Share Alike: many PH patients have several physicians. Be vigilant about sharing information with **everyone**. This includes all of your physicians and specialists, nurses, pharmacists, local EMS services and family members. Remember that doctors, hospitals and pharmacies generally do not share information. Don't assume your PH physician knows, for instance, that your family doctor just added a new sinus medicine to your regimen. Notify him or her immediately and ask questions before you fill the prescription or take the first dose.

3. Do Your Homework: knowledge is power. Educate yourself about all your medications, their side effects and interactions. Some websites even allow you to check for potentially harmful drug interactions. Try www.drugs.com for this feature. Try to become as knowledgeable about your medications

as your physicians and pharmacists are. In fact, with the unique features and potency of many of the PH medications, you should be the expert, too. Doing so can prevent many medication mishaps.

4. Ask. Ask. Then Ask Again: there are no stupid questions. Medical professionals are educated and knowledgeable about medications, but they are often busy and can become distracted. Don't be afraid to repeatedly ask questions until you are comfortable that they've been answered adequately.

5. Establish a Ringleader: For most PH patients, the ringleader is the PH specialist. PAH is rare and different from other diseases in many ways – especially medicines. Your "ringleader" is the physician that possesses the greatest overall knowledge of your condition(s) and treatments.

6. Buy Some Jewelry: purchasing a Medic Alert bracelet or necklace can be a lifesaver. Don't underestimate the value of fast assessments by healthcare personnel in the event of an emergency. The presence of the jewelry is an indicator to the practitioner to search deeper for the other information they need to treat you adequately. Minutes make a difference. Medic Alerts can be purchased at www.medicalert.com

7. Gossip: talk to other PH patients to find other creative ideas and to ask what has worked for them. Two (or more) heads are always better than one.

Source: *Pathlight*, Summer 2008, page 11.

CAREGIVERS: THE IMPORTANCE OF SETTING GOALS

It's hard to know where emotional needs stop and physical needs begin for a caregiver.

Taking control doesn't mean "doing it all." It simply means choosing what is important and letting go of what is not. To a caregiver choices never come easy. Many caregivers face an uphill battle with an unreasonable spouse, parent, or relative, often reaching the point where obstacles can no longer be successfully managed.

In setting goals, caregivers need to learn to put themselves first - NOT at the exclusion of loved ones, but at the inclusion of the caregiver. Past history has proven that caregivers generally put themselves last in any given situation; thus, their health is poorer and their mortality rate is higher.

Setting goals or deciding what you would like to accomplish in the next three to six months is an important tool for taking care of yourself. Here are some sample goals:

- Take a break from caregiving.
- Get help with caregiving tasks like bathing or preparing meals.
- Feel healthier.

Goals are generally too big to work on all at once. Once you have set a goal, ask yourself, "What steps do I take to reach my goal?" Make an action and then get started!

Example: Goal and Action Steps

Goal: Feel healthier.

Possible action steps:

1. Make an appointment for a physical check-up.
2. Take a half-hour break once during the week.
3. Walk three times a week for 10 minutes.

Analyze what outside sources could hinder your success. Attitude is a vital asset, and if you are truly "in control" then only YOU have the power to change that positive attitude. Don't give away that power-not to a family member, a neighbor, a well-meaning spouse, and especially not to the patient. Make the positive attitude a part of your life that is unshakable, and there won't be a hurdle you can't jump.

Once you feel the positive attitude, it will be much easier to maintain. Negativity will have

no room in your life, nor will blaming others for things that happen to you. You still have the power, and to blame means you've surrendered that power. Without negativity or blame in your life, doesn't it seem logical that your "quality" of life will improve automatically?

It's hard to know where emotional needs stop and physical needs begin for a caregiver. The positive attitude can apply to both, and it's so very important for all caregivers to take back whatever power has been given away in order to maintain full control of their lives. However, physical needs are also vital to the mental and physical health of a caregiver. We've all been told to "take time and read a book" or "take a long walk to clear your mind," but this is simply not possible for all of us. One of the basic needs for a caregiver is relaxation, which will provide tranquility in an already-stressful environment.

Caregivers **do** need to spend time alone, even if for only a few minutes a day. To think. To feel. To reflect. And perhaps to reassess goals. Time alone allows you to get to know yourself better, which should be an ongoing, eternal process.

Caregivers also need to get outside for both physical and emotional benefits. Mother Nature has a way of providing healing that no television or CD player ever could. It's also a perfect environment for exercise, which is another essential to a caregiver.

Most importantly, caregivers must find the time to do something for themselves on a regular basis. Even those who care on a 24/7 basis can take a few minutes to soak in a hot bubble bath, speak to a friend by phone or read a few chapters in a favorite book. "Little Things Mean a Lot"...and they do especially to today's caregiver.

Next month: Caregivers: Communicating Constructively

Source: Family Caregiver Alliance Fact Sheet: "Taking Care of YOU: Self-care for Family Caregivers," 2003.

"It's Time to Take Control of Our Own Lives," Empowering caregivers.com, 2001.

REMODULIN THERAPY ASSISTANCE PROGRAM

Elisha McKim, a RTA, spoke at the April support group meeting. Since a spring snowstorm prohibited several members from attending, the following information should briefly explain the RTA program.

The Remodulin Therapy Assistance (RTA) Program is a free service provided by United Therapeutics to patients on Remodulin therapy. The program complements the existing medical team by adding a dedicated Remodulin Therapy Assistant to answer your non-medical questions. These questions do not have to relate to your Remodulin therapy, and you may call your RTA any time and as often as you like. In addition, your RTA will call you periodically and ask some general questions about your Remodulin therapy and how you are feeling.

Your RTA does not replace any member of your medical team. Instead, he or she should be viewed as an additional team member who can provide broader, more general support.

Examples of questions asked by RTA participants:

- What patient support groups are in my area?
- I am no longer able to clean my house. Can you find a housecleaning agency in my area?

- Where can I obtain additional information about financial assistance to help cover the cost of my medical bills?
- Do other Remodulin patients live in my area? Would they be willing to speak with me about their experiences?

Additional information can be found on the Remodulin web site, www.REMODULIN.com This site contains detailed information about Remodulin therapy and distribution information.

To enroll in the Remodulin Therapy Assistance program, call toll-free 1-877-864-8437, send an email to RTA@unither.com, or complete a form online at www.unither.com/utcpatients.asp

Additional Remodulin patient resources:

- **PEER network** – 1-866-505-7337
www.peernetwork.net
- **PAP (Patient Assistance Program)**
1-888-485-8350

Source: Patient Support – RTA brochure (REM_RTABrochure_JUL08v.3), United Therapeutics Corporation.

RECOGNIZING OUR MEMBERS' EFFORTS

National Home Oxygen Patients Association March newsletter featured Pulmonary Hypertension thanks to the suggestion of Jeanette M. (Rock Springs). Because of Jeanette's actions, NHOPA members throughout the United States have a better understanding of pulmonary hypertension.

Pat H. (Cheyenne) offered to provide snacks for the special meeting in Cheyenne on May 27, 2009. Pat works at a local Cheyenne restaurant. The meeting will be held at the Laramie County Public Library (Sage Room) from 3 – 5 PM. Elisabeth Ravazzolo, Accredio will speak about PH and its therapies.



SLEEP APNEA AND PULMONARY HYPERTENSION

About 12 million Americans have *sleep apnea*: they stop breathing several or many times an hour while they sleep. This disease wasn't well known until recently, and most people who have it are unaware that they do.



Sleep apnea, if left untreated, may lead to serious medical problems. These include irregular heart rate, heart disease, heart attack, high blood pressure, and stroke.

Sleep apnea is not a condition to be taken lightly.

Obstructive sleep apnea (OSA) is a condition with frequent episodes of apnea (breath holding). This is due to collapse of the upper airways during sleep. During sleep, episodes of loud snoring may alternate with periods of silence. Breathing stops for several seconds to over a minute, and levels of blood oxygen may drop during these episodes. This lack of oxygen can cause pulmonary vasoconstriction and a resulting rise in pulmonary artery pressures (PAPs). Each episode causes the person to awaken and then go back to sleep. As the person awakens, he or she may grunt loudly, gasp, choke, or move the body. These events recur throughout the night and may result in daytime sleepiness.

OSA tends to affect middle-age people. People with OSA are often overweight, and OSA seen more often in men than women. However, it can affect children and persons with normal weight as well.

PH is moderately prevalent, but mild, in OSA patients. The incidence of sleep apnea among PH patients is probably low, but this isn't known for certain. It appears more often when other risk factors for PH are present, such as obstructed airways and obesity with hypoxemia.

A few sketchy studies suggest that sleep apnea alone might cause PH, but most studies point to daytime hypoxemia (due to other pulmonary problems) as the cause of PH in sleep apnea patients. Severe PH is probably not caused by sleep apnea alone although apnea could worsen it.

When the hypoxemia that sleep apnea causes is prevented, the changes in the pulmonary vessels appear to be reversible. Sleep apnea is a rare situation where it is possible that

supplemental oxygen might actually "cure" PH.

Because there is evidence that treating OSA with continuous positive airway pressure (CPAP) lowers PAPs, some PH doctors order a polysomnogram (sleep study). During the study, you sleep will be monitored through the night. Breathing, heart rate, oxygen level, eye movement and brain waves are monitored. The sleep study is often performed in a sleep lab, which is a specialized unit, usually in a hospital.

Sleep apnea can be controlled: by maintaining an ideal weight, changing sleeping position, using CPAP or dental devices, and sometimes surgery.

More severe cases of OSA (which can lead to PH) may require using CPAP, the most effective treatment for apnea. It provides pressure to the person's airway by a machine that blows air. The airflow from the CPAP machine is delivered by a mask, which covers the nose or the nose and the mouth. The air flowing through the mask acts as a splint or support to hold back the tongue and soft tissue from the back of the throat, allowing the airway to remain open during sleep. This allows breathing to become more regular, snoring stops, and restful sleep is restored. The patient's quality of life often improves as the individual becomes less tired and may have more energy.

Supplemental oxygen is frequently prescribed to PH patients with OSA. The oxygen is used in conjunction with the CPAP.

Sleep apnea, if left untreated, may lead to serious medical problems. These include irregular heart rate, heart disease, heart attack, high blood pressure, and stroke. Sleep apnea is not a condition to be taken lightly. Ask your doctor for more information especially if someone has witnessed your breathing stop during your sleep.

Sources: Pulmonary Hypertension: a Patient's Survival Guide, pgs 53-54 and Natl. Jewish Medical & Research Center.

Answers for Brain Power on page 5: 1. right between the eyes 2. banana split 3. screen pass 4. lemon drop 5. give a big hand 6. all hands on deck

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Disclaimer

We encourage readers to discuss their healthcare with their doctors. This newsletter is intended only to provide information on PH/PPH and not to provide medical advice on personal health matters, which should be obtained directly from a physician.

PHA and WY PH Support Group will not be responsible for readers' actions taken as a result of their interpretation of information contained in this newsletter.

**WY PULMONARY HYPERTENSION
SUPPORT GROUP
2009 MEETING SCHEDULE**

Unless specifically indicated, all meetings will be held at the
Riverton Public Library (1330 W. Park Ave., Riverton, WY)
from 1 PM – 3 PM (specific room locations may vary)

- May 27th** Special Meeting in Cheyenne @ Laramie Co. Public Library
3 – 5 PM (Sage Room)
PH and its therapies – Elisabeth Ravazzolo, RN
Accredo Health Group
- June 13th** PH and its therapies – Elisabeth Ravazzolo, RN
Accredo Health Group
- August 8th** Clinical PH Research – David Badesch, M.D.
University of Colorado Hospital
- October 10th** Not yet determined
Gilead Services
- December 12th** Not yet determined

Boost your brainpower by solving these puzzles. See if you can uncover the meaning in these words, letters, symbols and their positions. Each puzzle represents a common word, phrase, expression, person, place or event.

1		2		3	
4		5		6	