

## Articles:

- Caregivers Need Care & Support
- Caregivers: Managing Stress
- From the Mailbox
- Pursed-lip breathing
- Scleroderma & PH
- 2009 Meeting Schedule
- Sudoku Puzzle

### Did you know?

More than 50 million people, provide care for a chronically ill, disabled or aged family member or friend during any given year

17% of family caregivers are providing 40 hours of care a week or more.

## CAREGIVERS NEED CARE & SUPPORT, TOO

The doctor enters the exam room and utters the words, "It's pulmonary hypertension," and with those words the world is turned upside down for the patient and for the caregiver. Nothing in a caregiver's life prepares him/her for what will follow. They feel nervous and overwhelmed about what is expected, and they feel *alone*.

Hopefully, the tips provided in this and future issues will help eliminate or lessen the stress of caregiving and provide some helpful resources.

On an airplane, the first rule is to put on your own oxygen mask before you assist others because only when we first help ourselves, can we effectively help others. Caring for self is one of the most important and one of the most often ignored things that a caregiver can do. Yet, when the caregiver's needs are met, the patient will benefit, as well.

Caregiving can be an emotional roller coaster. On one hand, caring for a family member demonstrates love and commitment and can be a rewarding personal experience; however, exhaustion, worry, inadequate resources are enormously stressful and all too common.

Despite all their efforts, the caregivers cannot stop the impact of a chronic or progressive illness on their loved one. But they can do a great deal for their own personal well-being and meet their own needs.

Yes, caregivers need to identify their own personal barriers. They may feel selfish for putting their needs first or feel inadequate if they ask for help, but it is necessary. They often fall into a pattern of negative "self-talk" which can cause unnecessary anxiety. Behavior is based on our thoughts and beliefs, attitudes and misconceptions, and these can cause caregivers to continually attempt to do what cannot be done and to control what cannot be controlled. Feelings of continued failure and frustration often result, and these feelings are followed by the inclination to ignore their own needs.

Ignoring those needs puts the caregivers' own health at risk. Family caregivers are less likely than noncaregivers to practice preventative healthcare and self-care behavior, and this can result in sleep deprivation, poor eating habits, failure to exercise, failure to stay in bed when they are ill, and postponement of or failure to make their own medical appointments. The combination of prolonged stress, and the physical and emotional demands of caregiving place the caregiver at risk for significant health problems. Studies show that an estimated 46 percent to 59 percent of caregivers are clinically depressed.

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

## CAREGIVERS (PART ONE): MANAGING STRESS

How we perceive and respond to an event is a significant factor in how we adjust and cope with it. The stress that caregivers feel is not only the result of the caregiving situation but also the result of their perception of it. It is important to realize that they are not alone in their experiences.

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*The stress that caregivers feel is not only the result of the caregiving situation but also the result of their perception of it.*

A caregiver's stress level is influenced by many factors, including:

- *Whether the caregiving is voluntary.* If you feel you had no choice in taking on the responsibilities, the chances are greater that you will experience strain, distress and resentment.
- *Your relationship with the care recipient.* Sometimes people care for another with the hope of healing a relationship. If healing does not occur, you may feel regret and discouragement.
- *Your coping abilities.* How you coped with stress in the past predicts how you will cope now. Identify your coping strengths so that you can build on them.
- *Whether support is available.*

**Recognize warning signs early.** These may include irritability, sleep problems, and forgetfulness. Know your own warning signs, and act to make changes. Don't wait until you are overwhelmed.

**Identify sources of stress.** Ask yourself, "What is causing this stress for me?" Sources of stress might be too much to do, family disagreements, feeling of inadequacy, inability to say no.

**Identify what you can and cannot change.** Remember we can only change ourselves; we cannot change another person. When you try to change things over which you have no control, you will only increase your sense of frustration. Ask yourself, "What do I have some control over? What can I change?" Even a small change can make a big difference. The challenge faced as caregivers is well expressed in words from the Serenity Prayer: . . . *Grant me the serenity to Accept the thing I cannot change, Courage to change the things I can, and the Wisdom to know the difference.*

**Take action.** Taking some action to reduce stress gives back the sense of control. Stress reducers can be simple activities like walking and other forms of exercise, gardening, meditation, having coffee with a friend. Identify some stress reducers that work for you.

Next month: Caregivers: Setting Goals

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

## MEMBERS SHARE EXERCISE & COOKING TIPS



### **EXERCISE FOR PEOPLE OVER 50**

Begin by standing on a comfortable surface, where you have plenty of room at each side. With a 5-lb potato sack in each hand, extend your arms straight out from your sides, and hold them there as long as you can.

Try to reach a full minute, and then relax. Each day you'll find that you can hold this position for just a bit longer.

After a couple of weeks, move up to 10-lb potato sacks.

Then try 50-lb potato sacks, and then eventually try to get to where you can lift a 100-lb potato sack in each hand, and

hold your arms straight for more than a full minute. (I'm at this level.)

After you feel confident at that level, put a potato in each sack.

*Submitted by Jeanette M. - Rock Springs*

*Lora K, - Green River* shares the following website, listing dozens of crock pot recipes, categorized by Main Ingredients: MEAT: Beef, Pork, Chicken, Fish, Seafood Soups: Stews, Chili's, BBQ, Side Dishes, Misc., and even Desserts. Once you see this list of recipes, you may want to get the crock pot out of the cupboard. <http://www.50plusfriends.com/cookbook/crockpot/index-5b.html>

## PURSED LIP BREATHING CONTROLS BREATHLESSNESS

Pursed lip breathing is one of the simplest ways to control shortness of breath. It provides a quick and easy way to slow your pace of breathing, making each breath more effective.

Pursed lip breathing:

- Improves ventilation
- Releases trapped air in the lungs
- Keeps the airways open longer and decreases the work of breathing
- Prolongs exhalation to slow the breathing rate
- Improves breathing patterns by moving old air out of the lungs and allowing for new air to enter the lungs
- Relieves shortness of breath
- Causes general relaxation

### When should I use this technique?

Use this technique during the difficult part of any activity, such as bending, lifting or stair climbing.

Practice this technique 4-5 times a day

at first so you can get the correct breathing pattern.

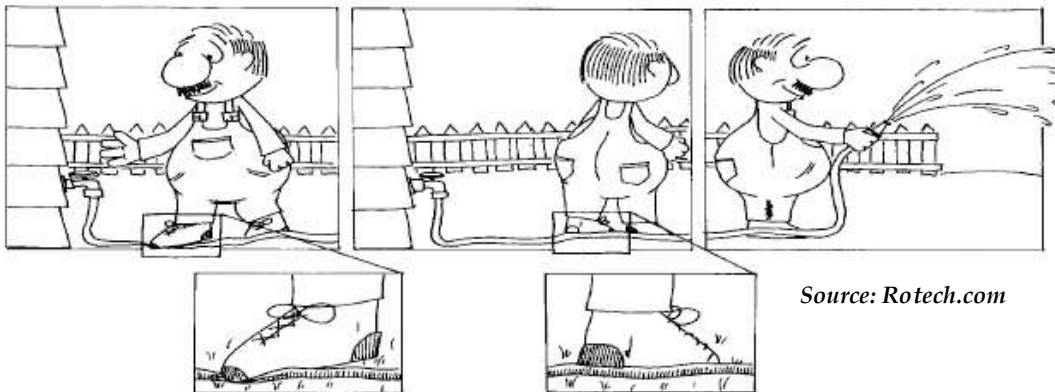
### Pursed lip breathing technique

1. Relax your neck and shoulder muscles.
2. Breathe in (inhale) slowly through your nose for two counts, keeping your mouth closed. Don't take a deep breath; a normal breath will do. It may help to count to yourself: inhale, one, two.
3. Pucker or "purse" your lips as if you were going to whistle or gently flicker the flame of a candle.
4. Breathe out (exhale) slowly and gently through your pursed lips while counting to four. It may help to count to yourself: exhale, one, two, three, four.

With regular practice, this technique will seem natural to you.



Source: [ClevelandClinic.org](http://ClevelandClinic.org)



Your airways respond the same way a garden hose does to pressure. When there is no water pressure in the system, the hose collapses when the gardener steps on it (which corresponds to the force exerted during exhalation). When the hose is full of water, and the nozzle at the end of the hose is closed tightly to form a stream of water (which corresponds to pursed lips), then the water pressure

does not allow the hose to collapse when the gardener steps on it again. When you use pursed lip breathing properly, you should be able to keep your airways open with this same idea of system pressure. It might take a while to perfect the technique, but it will help a lot once you learn how to do it. So practice at least three times a day, and use it every time you start to do something that causes shortness of breath.

## SCLERODERMA & PULMONARY HYPERTENSION

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*Roughly a third of systemic scleroderma patients develop at least mild pulmonary hypertension.*

Scleroderma means “hard skin,” but this same hardening can happen to an organ or tissue because of the growth of too much collagen, the strong fibrous stuff found in connective tissue that connects and supports parts of the body. Scleroderma affects mainly the small blood vessels and the collagen-producing cells throughout the body. It sometimes causes only very mild symptoms, but it can kill as well. When it does, it is most often due to pulmonary disease. Because collagen is affected, patients can develop taut, shiny skin and mask-like expressions. When the small vessels in the fingers narrow, shutting off the supply of blood, patients are very apt to get chilly, bluish fingers when they are exposed to cold, called Raynaud’s phenomenon. The cause of scleroderma is unknown, and there is not presently a cure. About 150,000 to 300,000 persons in the U.S. have the disease, and it strikes around four times as many women as men.

Scleroderma can lead to PH because it can cause scar tissue to build up in the lungs or heart, but it overlaps with PAH because this fibrosis can be missing or mild in the lungs, but severe in the pulmonary vessels (as in PH, cells proliferate in the inside layer of vessels making the muscle layer thicker).

Among the connective tissue diseases, PH is most frequently associated with chronic sclerosis, which affects the entire body (systemic sclerosis), sometimes including the heart and lungs. There is also what’s called localized scleroderma, which affects just some skins areas and usually not internal organs or blood vessels, and is not associated with PH. By looking at the antibodies in your blood, a doctor can tell a lot about the type of scleroderma you have.

Roughly a third of systemic scleroderma patients develop at least mild PH. It isn’t known how often the

mild PH detected in many scleroderma patients grows into serious PH. A yearly echocardiogram is recommended to screen for PH.

Many specialists think yearly diffusing capacity tests should be done on scleroderma patients. If the patients have a diffusing capacity that is less than 55 percent of predicted, they probably have PAH. It is also thought appropriate to get a baseline echocardiogram on all scleroderma patients, and repeat this test periodically. If mild PH is found, it can be wise to undergo a catheterization to rule out false positives that generate a lot of needless worry. It’s unlikely that a cath will find that a scleroderma patient is responsive to vasodilators, but it might reveal blood shunting to where it shouldn’t, or left ventricle problems, or valve problems that are contributing to the PH.

Systemic scleroderma is further divided into *limited* and *diffuse* scleroderma. The distinction depends on the degree of skin involvement and specific antibodies. Diffuse scleroderma affects 50 to 60 percent of scleroderma patients and tends to spread beyond the entire skin. Symptoms include a sudden, severe onset, thickening skin, bad joint pains, and more frequent and severe interstitial lung disease (inflammation and disruption of the walls of air sacs in the lungs, making it harder for them to transfer oxygen).

For more technical information on Scleroderma and PH, go to [http://www.phassociation.org/Medical/Advances%5Fin%5FPH/article\\_list.asp](http://www.phassociation.org/Medical/Advances%5Fin%5FPH/article_list.asp) and use your browser “Find on this Page” feature to search for the articles.

Source: *Pulmonary Hypertension: A Patient’s Survival Guide*. Book available for purchase: <http://www.phassociation.org/Learn/Survival-Guide/index.asp>

**WYOMING  
PULMONARY  
HYPERTENSION  
SUPPORT GROUP**

1206 Timber Lane  
Riverton, WY 82501

PHONE:

307-856-6976

OR

307-856-7783

E-MAIL:

[pinnut3200@yahoo.com](mailto:pinnut3200@yahoo.com)

WEBSITE:

Newsletter Archives &  
Group News

<http://tinyurl.com/6x673h>

<http://tinyurl.com/ywb6e3>

PHA's National  
Patient-to-Patient Helpline  
800 - 748 - 7274

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**

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)

- April 4<sup>th</sup>** .....Remodulin Therapy – Elisha McKim  
United Therapeutics
- June 13<sup>th</sup>** .....PH and its therapies – Elisabeth Ravazzolo, RN  
Accredo Pharmaceuticals
- August 8<sup>th</sup>** ..... Clinical PH Research – David Badesch, M.D.  
University of Colorado Hospital
- October 10<sup>th</sup>** .....Not yet determined
- December 12<sup>th</sup>** ..... Not yet determined

**Write the dates on your calendar  
or clip out this section for future reference**

**Sudoku Puzzle** – fill in the grid with digits in such a manner that every row, every column and every 3x3 box accommodates the digits 1- 9, without repeating any.

8				3	5		
9			2	1		8	
4					7		
7		5	3	2		1	
3	8					6	4
				5			
	3		9				6
	9	8			7		
			1			9	7