

# Breezeway

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### Did you know?

- Healthy individuals only use about 1/3 of the capacity of their lungs.
- It is not possible to breathe and swallow at the same time. The two actions have to be coordinated and well timed.

## PRACTICAL TIPS – BREATHING, EATING, TALKING

by Dr. Lynette Hodgson – Speech Pathologist

In chronic lung disease the actions of breathing, speaking, and swallowing can sometimes get mixed up. Try the following practical tips to overcome any problems you may be having.

**Breathing:** When feeling tight in the throat, and breathless always *push* air out (on a long whhhh. . .through pursed lips). This causes air pressure to fall in the larynx, so that the vocal folds open, the lungs and surrounding muscles automatically work like bellows, and air is sucked back in. Struggling to take “a big breath in” can work against you, by tightening the throat and upper chest so that breathing is tense and shallow. Remember: PUSH AIR OUT TO ESTABLISH BREATH CONTROL.

**Talking:** The biggest strains on the voice are talking loudly, talking for a long time, and using extremes of pitch. Minimize strain by avoiding these behaviors. You can use gentle voice sounds like “mmm” to listen to your own voice and think to yourself, “I need to keep my voice relaxed and calm like this” and “I should talk on a nice relaxed low tone like this.” Another trick is to imagine you are having a relaxed quiet laugh, or to talk to people with “a smile in the voice” – this tends to relax the laryngeal muscles. Establish good breath support for speech by focusing on pushing the lower chest (or tummy) area in as you say: “Hi or Hey!” Make sure there is no tightening occurring in the throat. It must stay relaxed.

Swallowing problems are frequently reported to me. People may have the sensation of having a “lump in the throat” when they swallow, with the commonest causes of this being reflux or chronic extra tightness or constriction in the larynx. The other

difficulty may be coordinating eating with breathing. Studies done by speech pathologists of people with chronic respiratory conditions show that compared with the general population, they are more likely to have difficulties chewing and swallowing food, or clearing food and fluid from the throat.

**Eating and Swallowing:** Make time for stopping and taking a few breaths in and out during meals. Sometimes, you might have to stop during chewing. Just hold the food in the mouth, and take a few breaths in and out through the nose. During the actual act of swallowing, the breath actually has to be held. To make the swallow easier and more effective, tuck your chin down slightly (this puts the base of the tongue in the swallow “starting position”), hold the breath and squeeze hard as you swallow.

If chewing your way through a big meal takes a lot of energy, it is helpful to convert some of the foods to smooth, soft foods, thick liquids, or moist, well-cooked foods that have been well cut up or minced. Some people cough or sputter when drinking fluids. There are several types of fluid thickeners available to help with this, Resource Thicken-up, for example. Remember water can always be converted into soft gels or icy poles. Keeping hydrated is really important.

Take time to coordinate swallowing, breathing, and eating. Try to eat meals where it is quiet, free of distractions, and pressure. Remember to take your time and treat yourself to some relaxation after each meal.

Source: *LungNet*, the Australian Lung Foundation.

## PRIVACY & YOUR HEALTH INFORMATION

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*The Health Insurance Portability and Accountability Act (HIPAA) is a federal law that sets rules and limits on who can look at, receive, and even talk about your health information.*



### What is my health information?

It includes all of the information your healthcare providers put in your medical records, plus conversations your healthcare providers have about your care or treatments with nurses and other healthcare professionals, information about you in your health insurance company's records, and billing information about you and your healthcare provider's office, clinic, or hospital. A federal law exists to help you keep this information private and to make sure you have control over who is and isn't allowed to see it. The law says that only healthcare providers with a "need to know" can have access to your health information.

### How is my health information protected?

The Health Insurance Portability and Accountability Act of 1996 (also called HIPAA) is the federal law that sets rules and limits on who can look at, receive, and even talk about your health information. Healthcare providers, nurses, pharmacies, hospitals, clinics, nursing homes, health insurance companies, Medicare, and Medicaid must follow this law.

By law, you have the right to:

- *ask to see and get copies of your health records.* You may have to pay for the cost of copying and postage if you request they be mailed to you. In most cases, your copies must be given to you within 30 days after you ask for them.
- *have mistakes in your health information corrected.* If you see any information that's wrong in your files, such as wrong test results, you can ask to have it corrected. In most cases, the file should be changed within 60 days after you inform your healthcare provider or insurance company of the mistake.
- *receive a notice that tells you how your health information is shared.* Your healthcare provider or insurance company must give you a notice that tells you how they may use and share your information. In most cases, you should get this notice on your first visit to a healthcare provider or in the mail from your insurance company. Read the notice carefully before

you agree to it; if you have any questions, ask the nurse or insurance agent. You can request this information at any time.

- *decide if you want to give your permission before your health information can be used or shared.* Healthcare providers and insurance companies can't give your health information to your employer, or a family member, use it for marketing or advertising purposes, or share private notes about mental health counseling sessions unless you give your permission. To allow access to your records, you'll sign a form that says who will get your information and how they'll use it.

- *get a report on when and why your health information was shared.* Your health information can be shared with other healthcare providers for your treatment and care, to pay healthcare providers and hospitals, for making sure healthcare providers give good care and nursing homes are clean and safe, to protect the public's health (for example, reporting when the flu is in your area), or making required reports to the police, such as reporting a gunshot wound. You can get a free report of who your healthcare information has been shared with once a year. Visit [www.hhs.gov/ocr/privacy/hipaa/understanding](http://www.hhs.gov/ocr/privacy/hipaa/understanding) for more information.

### What do I do if I think my health information was used without my permission?

If you think your privacy has been violated, you can file a complaint with your healthcare provider or insurance company, or with the U.S. Government. Ask your healthcare provider or insurance company for a complaint form.

For more information on health information privacy, visit [www.hhs.gov/ocr/privacy](http://www.hhs.gov/ocr/privacy)

Source: *Nursing2009*, December, pg 33.

## HARNESS THE POWER OF THE INTERNET – WEB OF FRIENDS

How often have your friends or family members asked: “How can I help?” when they learned that you were living with pulmonary hypertension?

The Pulmonary Hypertension Association (PHA) knows that answering that question can be difficult. PHA’s Web of Friends offers an easy solution. By inviting your friends and family to support you through this exciting program – you’ll be raising awareness about PH and funds for PHA-provided services.

PHA has teamed with FirstGiving.com, an online fundraising service, which allows you to take your story across the country – or around the world – in just minutes.

Every person whose life has been touched by PH has the right to fight back as much or as little as health and interest allow. PHA has the obligation to build programs to make that possible.

In PHA’s first year using FirstGiving more than \$60,000 was raised online (and much more offline!) on more than 80 fundraising pages, giving a big boost to PHA programs and services. Not only that, countless people learned about PH and were given an opportunity to make a difference.

If you decide to do a Web of Friends campaign or are ready to get started, PHA can help assist you at every point in this process (see steps at right), and they have a few tricks up their sleeve that they’d like to share with you. Contact: [giving@PHAssociation.org](mailto:giving@PHAssociation.org) or call 301-565-3004, ext 767.

### Creating a Personal Fundraising Page is Free and Easy!

1. **Write a letter.** The most important elements of your letter are the portions that tell the story of how PH has affected you and why you want to support PHA.
2. **Set a goal and clearly state it.** Your financial goal should be large enough that friends and family realize that supporting PHA is important to you. Don’t be shy – one page host had to increase his goal from \$1,500 to \$27,500 just to keep up with donations.
3. **Make a list.** Include friends, family, neighbors, co-workers, and others. The list should be long enough to give you a good chance of meeting your goal.
4. [www.firstgiving.com/PHAssociation](http://www.firstgiving.com/PHAssociation) -- visit and click “**Get Started**” at the bottom of the page.
5. **Link your personal fundraising page** to an upcoming PHA event, or scroll down to “**What kind of page would you like to create?**” Select from the drop-down list, and click “**Continue.**”
6. **Follow the prompts** to register for FirstGiving and customize your page.
7. Once your page is complete, **email the link to your page** to everyone on your list and encourage them to support patients and help find a cure for PH by making a donation. Don’t worry about asking family and friends for money. You are helping all patients with PH, not just yourself. You are doing this for the greater good. *Make sure to remind people that their donations are tax-deductible.*
8. **Sit back and relax** while friends and family donate to your campaign, leave messages and words of encouragement, and email a link to your FirstGiving page to their acquaintances.
9. **Send a follow-up “Thank You” note** to those who gave to your campaign. Let them know whether you reached your goal and give them an update on your health. They want to know how you are doing.

## 30 WAYS TO CELEBRATE YOUR LIFE



1. Practice random acts of *kindness* – make it a habit to do nice things for people who will never find out.
2. **Relax** with music – find that tune that makes you remember a special time or special person.
3. Tell the people you *love* you love them – randomly hug your child or spouse.
4. Write down three short-term and three long-term *goals* you have for yourself (might be to lose five pounds or to go on a cruise next summer) – revisit them monthly.
5. Call or write a *friend* you have not seen lately.
6. Start with a daily five-minute *walk*.
7. Cancer **Prevention**: Breast – Colon – Prostate: do it yourself – remind others.
8. Try a *new* recipe or learn a different kind of cooking – then invite family or friends to enjoy.
9. **Donate** a bag of clothes, shoes, or food.
10. Forgive yourself – let go of regret – try to *forgive* someone.
11. Take a *day off* from TV.
12. Borrow someone’s crayons and **rediscover** the artist within you.
13. Collect your family medical history and **share** it with your siblings and children.
14. Upon awaking and going to sleep tell yourself *you love you*.
15. Write (not email) a **thank you** note to a person who inspired you – could have been a teacher or a fellow worker.
16. **Sing** or whistle in the shower.
17. Allow 5 minutes a day to sit in silence or *solitude* (turn off the cell phone – post a sign DO NOT DISTURB).
18. **Volunteer**.
19. Ask your parents/grandparents or elderly friend to tell you a *story* from their life experience.
20. **Know** your total cholesterol – HDL – LDL – triglyceride numbers and what they mean.
21. Update the *photos* of friends and family – do not wait for the special occasion – then share copies.
22. Each Sunday, write down 5 things you are *grateful* for and post it on your bedroom or bathroom mirror.
23. **Update** your first aid kit – smoke alarm – emergency kit and then review with your family what to do during a home or local emergency.
24. Take time to *listen* – to others and to yourself.
25. Remind yourself often: **Live in the present – learn from the past – try not to fear the future**.
26. **Allow** laughter – allow tears.
27. Know the signs and *symptoms* of a heart attack and stroke and share them with a friend.
28. **Slow** down – discover meditation – prayer – relaxation.
29. ICE your cell phone: use the entry of **ICE** in your cell’s phone book to record the number of your “In Case of Emergency” contact – EMTs routinely check this listing to call and notify someone of your emergency if you are unable.
30. **Keep** a journal of your thoughts and feelings – reflections of your surroundings and your life.



Saturday, February 13, 2010

Bill Winter, an estate attorney, will explain Advance Health Care Directives & other important legal documents

Riverton Public Library – Children’s Theater  
1330 W. Park Ave., Riverton, WY  
1 – 3 PM

This meeting is sponsored by the Pulmonary Hypertension Association’s Support Group Central Fund. The Central Fund is made possible by a Platinum level sponsorship from Actelion Pharmaceuticals and by a Gold level sponsorship from Gilead Sciences.

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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.

**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.

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

**Support Group Meetings for 2010**  
Held at the Riverton Public Library, 1 – 3 PM

- February 13<sup>th</sup>** ..... Bill Winter, Estate Attorney  
Advance Healthcare Directives
- April 10<sup>th</sup>** ..... Karen Buck, RRT, Cheyenne Regional Medical Cntr  
Breathing Lesson & Harmonica Techniques
- June 12<sup>th</sup>** ..... Mike Fisher, M.D., WY Cardiopulmonary Services  
PH & Sleep Disorders
- August 14<sup>th</sup>** ..... Elisabeth Ravazzolo, Accredo Health Grp  
Coordinating with ERs and EMTs
- October 9<sup>th</sup>** .....(Tentative)  
Traveling w/ Portable Oxygen Concentrators

**NOTICE**