

Inspiration

Fall 2005

A newsletter for people with COPD and those who love them

When It's Cold Outside

If you could take a pill that gave you more energy, increased oxygen intake, maintained your weight, improved your mood and helped you sleep, would you take it? Most of us would.

Believe it or not, that near cure-all exists. It's exercise! Best of all, you don't need a prescription (although you should talk to your doctor first), and it doesn't have to cost a penny.

Research shows that regular physical activity provides a wide range of physical and emotional benefits and is a necessary part of a COPD patient's treatment. Living in Chicago can make it difficult to get out and get moving in the wintertime, but sometimes all we need is just a few good ideas:

- **Walking.** With the right walking shoes, a warm, lightweight coat and a hat, walking can be a pleasure on all but the coldest days. Ask a friend to walk with you to make it easier.
- **Gym or rehab center.** At a health club, you can walk on a treadmill, use weight machines and much more. Many hospitals offer the same options. (See last page for more information on Pulmonary Rehabilitation Centers and Support Groups)
- **Dancing.** At home or out with a partner, dancing is a fun way to get physical. Cue up your favorite singer and swing.
- **Stretching at home.** See recommendations below. The only props you need are a sturdy chair and a wall.
- **Videotapes.** Look for fitness videotapes for older adults. You'll find everything from yoga and t'ai chi to seated stretches. Buy your own or borrow them from the library.

Think about what you enjoy doing, and use that as a basis for choosing activities. Try to find a few different types of activities to help you through the long Chicago winter.

Take Time to Relax

Use these exercises to unwind throughout the day.

Relaxed Breathing

1. Inhale slowly through your nose for six seconds and hold it in for four seconds.
2. Exhale slowly through your mouth for six seconds.
3. Repeat three to five times.

Progressive Muscle Relaxation

Hold each exercise for five seconds then relax for 30 seconds before moving on. Your whole body should take about ten minutes.

1. Start by scrunching your face, neck, then shoulders. Shrug your shoulders up around your ears.
2. Tighten your upper arms, then lower arms and hands. Make tight fists.
3. Tense your chest, shoulders and upper back. Try to make your shoulder blades touch.
4. Pull your stomach toward your spine.
5. Squeeze your upper legs, knees together. Now lower legs.
6. Turn your feet inward and curl your toes up and out.
7. Relax everything.

 **AMERICAN LUNG ASSOCIATION®**
of Metropolitan Chicago



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Inspirations

FROM THE EDITOR

Let's Make It "Flu-Free Season"



It's that time of year again—time to get your flu shot. Unlike last year, there should be enough vaccine to go around. Of course, if you're over 65 or have COPD, even an extreme shortage shouldn't keep you from getting immunized. People in those groups are considered "high risk" and have

priority over younger, healthy adults.

Getting your flu shot each year is one of the fastest, easiest things you can do to cut down on COPD exacerbations. After all, studies show that about one-third of acute exacerbations are related to viral infections such as influenza.

Yet, even though we try to get the word out about flu shots each fall, one in three people for whom the shot is strongly recommended won't get one. Does that include you?

Many people believe that catching the flu is just like having a bad cold—if they wait a few days, it'll go away. But the reality is much more serious. For people with COPD, the flu can lead to:

- Severe respiratory exacerbations
- Pneumonia
- Worsening of other existing conditions, such as heart disease or diabetes
- Hospitalization

You might be surprised to find out that, according to the Centers for Disease Control, approximately 36,000 people die each year from complications of the flu.

Whether you have mild, moderate or severe COPD, a flu shot can cut your risk of serious respiratory complications and hospitalization by up to 80%. If you could save 80% at the grocery store, you'd be there—so

why not take the same approach to your health? Talk to your doctor about a flu shot, go to www.lungchicago.org for more information, or visit one of the locations listed below.

Yours in lung health,

Peter H.S. Sporn, MD

*Associate Professor of Medicine
Director, Pulmonary and Critical Care Medicine Fellowship Program
Feinberg School of Medicine, Northwestern University*



Flu Vaccine Sites

10/30/2005	8:30am-3pm	St. Procopius	1625 S. Allport	Chicago
11/4/2005	10am-2pm	Marquette Park	6734 S. Kedzie	Chicago
11/6/2005	12-4pm	Cristo Rey High School	1852 W. 22nd Ave.	Chicago
11/12/2005	8am-12pm	Park Federal	5400 S. Pulaski	Chicago
11/13/2005	10:30-11:30am	St. James Social Care	2942 S. Wabash	Chicago
11/18/2005	9-10am	American Diabetes Assn.	30 N. Michigan Ave.	Chicago

For more flu shot locations, visit the public health department link at www.egov.cityofchicago.org or call 312-747-9884.

Living with Oxygen Therapy

Long-term oxygen therapy can make it easier to live with COPD, as long as you know a few tricks to help you through day-to-day activities.

Eating. Digesting food requires a lot of energy—that's why it's a good idea to rest before eating. Don't remove your nasal oxygen—if you can use it in the dentist's chair, you can use it while you eat.

Sleeping. Some people find that holding their tubing to their cheekbones with small pieces of hospital tape or Band-Aids keeps them from pulling out the cannula at night.

Bathing. This can be difficult with COPD, and a continuous flow of oxygen can help. Keep the water warm, not hot, and invest in a shower stool. That way you can sit down and it will be easier to get in and out of the tub.

Running Low. Remember to keep your tanks filled and extra supplies handy. Should you ever find yourself without oxygen, keep your cool. Breathe in slowly through your nose and out through pursed lips.

Being Equipped. In addition to basic equipment recommended by your doctor, look into retractable tubing, swiveling connectors, humidifying "bubblers," backpacks or carts, and other options that can make you more comfortable.

Become an E-Advocate

The Smoke-Free Chicago ordinance introduced in June 2005 is a comprehensive ordinance that intends to make all public and work places, including

restaurants and bars, smoke-free. If you would like periodic updates concerning Smoke-Free Chicago and other lung-related legislation, sign up for the American Lung Association of Metropolitan Chicago's E-Advocacy: <http://lungaction.org/alaservingillinois/join.html>



Flying with Oxygen: Ready for Takeoff

The Federal Aviation Administration (FAA) has finally given its approval for people who require supplementary oxygen to use portable oxygen concentrators (POCs) during flights. But there are still a few wrinkles that need to be ironed out:

- Only the Inogen One and AirSep LifeStyle concentrators have been approved so far.
- Airlines may still deny passengers the right to bring the devices on board.

For a long trip, patients may need to carry several batteries with them. Availability of electric outlets on the plane cannot be guaranteed.

In addition, it's important to know that:

- You must notify the airline in advance.
- You must carry a physician's statement of medical necessity.

We hope that the FAA will soon require airlines to accept all POCs and revise the ruling to truly benefit those who need oxygen to travel. For more information about the ruling go to www.faa.gov/apa/pr/pr.cfm?id=1963

We'll keep you advised of any new developments!



Patient's Perspective

Making Life Easier for Patients and Caregivers



At 67, Marlene Romozzi sounds like she has the energy of a person half her age. She certainly has the positive outlook.

Just last April, however, it was a different story. Over the years, Marlene hadn't really noticed how out of breath she'd gotten. "It happens gradually," she explains. "So you don't even realize it. You go into denial. I'd had trouble breathing for years."

Things changed at a routine visit to a cardiologist last spring. After a few tests, Marlene was admitted to the hospital for a two-month stay. She couldn't help thinking about all the things she had to do at home, but her daughter supported the decision. "In a couple more days, I wouldn't have been able to take another breath."

From the hospital, Marlene was taken to Manor Care of Northbrook for the pulmonary rehab program. When she arrived, she was on oxygen full time. "It's a lovely facility, and the people at

Manor Care were great. I started learning about COPD, getting therapy and exercise, and people were always available to answer my questions," offers Marlene. "But my goal was to be off the oxygen when I went home."

Facilities such as Manor Care of Northbrook are an excellent resource for COPD patients and their families. Through an expert team and intensive therapy, they teach patients how to manage their condition better, use medications and diet to feel better, save energy performing daily tasks and regain as much of their previous quality of life as possible. Many patients are eligible for Medicare coverage.

After two months at Manor Care of Northbrook, Marlene is at home and using oxygen only at night. "I didn't notice the difference until one night I forgot to use the oxygen and I couldn't sleep. Another night, I pulled the tube out and I later figured out why I was having a rough morning."

A car accident in August put Marlene's outpatient therapy plans on hold, and showed her how hot weather and stress can make breathing harder. Now she's committed to strengthening her lungs and walking every day,

even if she has to stop and rest from time to time.

Today Marlene's friends and family are impressed at how she can carry on a conversation without running out of breath. They are so glad to see her regain



her vitality. "Therapy helped me get back on track."

To find out more about Manor Care programs, facility locations, and how you can receive help, go to www.hcr-manorcare.com or call 800-736-4427.

There are more than 20 locations in Illinois alone.



Ask the Doctor

What You Can Do to Prevent Exacerbations

Dr. Lewis J. Smith, M.D. is a professor at the Feinberg School of Medicine at Northwestern University, a board member of the American Lung Association of Metropolitan Chicago, and a member of the American Lung Association Scientific Advisory Committee. Today, he spoke with us about how to identify, treat and prevent exacerbations.



What causes COPD exacerbations?

Most exacerbations are the result of an infection like the flu or a cold. When a person with COPD gets a viral or bacterial infection, it worsens the underlying COPD symptoms such as cough, sputum production and shortness of breath. There are other causes, such as smoking, air pollution or seasonal allergies, but infections are the most likely culprit.

What should a person do when an exacerbation occurs?

Every COPD patient should have a plan worked out with his or her doctor in advance. Generally, if you have an exacerbation, you should call your doctor. They may prescribe an antibiotic, recommend increasing the use of an inhaler or suggest a cough suppressant. If it appears likely that you've caught a virus through exposure to someone else who's been sick, the doctor may suggest trying to ride it out for a few days. For people who have had COPD for a long time, they may already know what steps their doctor wants them to take.

Can exacerbations be treated without hospitalization?

Absolutely. The majority of patients are treated as outpatients. Hospitalization may be needed when a person's COPD is severe, when an exacerbation leads to pneumonia or when special oxygen therapy is necessary.

Is there any long-term effect of exacerbations?

Most people will have some degree of reduced lung function, even after recovering from an exacerbation. Of course, you have to remember that after age 30, lung function declines for everyone. COPD and exacerbations accelerate that decline.

So how can someone with COPD prevent exacerbations?

The simplest thing you can do is to get a flu shot every year. Your doctor might recommend a pneumonia vaccine as well. Anything you can do to ward off infection—especially when

“bugs” are going around—will help.

What else can people do to avoid illness?

People with COPD are more prone to viruses and bacterial infections than healthy adults. After all, it's harder to keep the bronchial tubes clear, and harder to rid the body of infectious agents. Good hygiene, avoiding contact with people who are ill, and good nutrition will help you stay healthier.

New Test Measures COPD Risk

March 15: *American Journal of Respiratory and Critical Care Medicine* reported on a new formula designed to measure the risk of death for people with COPD, by comparing their capacity while inhaling to their total lung capacity (IC/TLC). The study, conducted by the Respiratory Research Institute in Spain, evaluated this new formula relative to the BODE index currently in use. They found that the IC/TLC ratio can serve as an independent measure of risk and recommend using it to assess the health of COPD patients.

Community Spirometry Initiative— Get Involved



As mentioned in our summer issue, on June 20, 2005 the Community Spirometry Initiative kicked off a year-long program to conduct spirometry testing at 80 Walgreens Drug Stores throughout the greater Chicagoland region. The project is divided into eight cycles, the last one to take place in March

of 2006. Four cycles have been concluded so far and we are enthusiastic to share with you that we have trained 84 Respiratory Therapists and we have performed over 1,000 spirometries. Participants have also been provided with education on Chronic Obstructive Pulmonary Disease and Smoking Cessation. Nearly 800 participants have been included in a research study to evaluate the impact of the Initiative on individuals' behavioral changes.

Each test is analyzed by a group of pulmonary specialists at Stroger Cook County Hospital headed by Dr. Robert Cohen and the results and interpretations are sent directly to each participant approximately 60 days later.

Thus far, of those screened, between 10% and 20% show signs of obstruction. This high percentage signifies the importance of having spirometry screenings available for the public. The ALAMC is committed to this project for early detection of lung disease and for providing the public with resources to manage their lung health resulting in a higher quality of life.

For information on future events, see the calendar to the right and the insert in this issue of *Inspiration*. If you would like to learn more about this Initiative please visit www.freelungtest.com or call Jeanine Solinski at the American Lung Association of Metropolitan Chicago.



Walgreens Stores' Test Schedule

January 16, 2006
160 Robert Palmer Dr.
Elmhurst
9 am - 1 pm

January 17, 2006
7960 W. 159th St.
Orland Park
9 am - 1 pm

January 18, 2006
2205 W. 22nd St.
Oak Brook
9 am - 1 pm

January 19, 2006
225 E. Roosevelt Rd.
Lombard
2 pm - 6 pm

January 20, 2006
200 E. Roosevelt Rd.
Villa Park
9 am - 1 pm

January 21, 2006
16675 S. Oak Park Ave.
Tinley Park
10 am - 2 pm

January 23, 2006
13501 S. Cicero Ave.
Crestwood
2 pm - 6 pm

January 24, 2006
6430 W. 111th St.
Worth
9 am - 1 pm

January 28, 2006
8701 S. Cicero
Hometown
10 am - 2 pm

January 30, 2006
1801 Ingalls Ave.
Joliet
2 pm - 6 pm

See insert for more details.

Advances & Updates

Can You Inherit Lung Disease?

Morgan Roth, *School of Medicine, UIC*
H. Ari Jaffe, MD, *UIC*

When you have a common illness or are exposed to chemicals, like tobacco smoke, your lungs are protected by a protein released from the liver called Alpha-1 antitrypsin (AAT). It is possible to inherit a disease known as AAT deficiency that causes your body not to produce this protective protein, which can lead to a lung disease known as emphysema.

Unlike the common form of emphysema seen in smokers, AAT deficiency can cause emphysema at an unusually young age and after

minimal exposure to tobacco. For those who have AAT deficiency and are smokers, emphysema may start 10 years earlier than those



without the disease. AAT deficiency occurs in 1 out of 3,000-5,000 people and is one of the most common, deadly hereditary diseases.

The most common symptom of AAT deficiency emphysema is shortness of breath during physical activity and eventually during normal daily activities. Shortness of breath usually starts at ages 30-45, which is 20-30 years earlier than smokers with emphysema without AAT deficiency. Other symptoms include cough, sputum production, intermittent wheezing, and recurring chest colds. Jaundice, abdominal swelling, gastrointestinal bleeding, and unexplained liver problems may also occur. AAT deficiency is often incorrectly diagnosed as asthma, sinusitis, postnasal drip, or acid reflux.

Testing for AAT deficiency is

quick and highly accurate with a simple finger stick or a regular blood draw. If your level of AAT is low, your doctor may follow up with genetic and other diagnostic testing.

Who should be tested for AAT deficiency? Anyone with a family history of emphysema or liver disease at an early age, adult-onset asthma, or recurrent bronchitis. It is also recommended that individuals with COPD, as well as individuals with asthma that is not fully reversible, be tested for AAT deficiency. Testing is not only important for accurate diagnosis and treatment, but should be used to alert other family members about their potential risk of disease.

Once diagnosed, there are several steps that can be taken to prevent or slow the progression of the disease. The highest priority for patients with AAT deficiency is to quit smoking to reduce the risk of death and increase quality of life. The second priority is sound treatment including pulmonary rehabilitation and bronchodilators to maximize lung function. Pneumonia and annual influenza vaccination can also help prevent respiratory infections. Additionally, weekly intravenous infusions of Alpha-1-antitrypsin as a replacement therapy for AAT may reduce symptoms, decrease the loss of lung function, and increase the survival of patients. Lung transplantation may also be an option for some patients with severe disease.

If you have any questions or would like more information, please visit www.alphaone.org or ask your doctor about A1A and testing for A1AT deficiency.

Medicare News

New Medicare Benefits are coming in 2006. A new law provides for prescription drug benefits as well as wellness coverage. Wellness benefits cover screenings for early detection of heart diseases, diabetes and more. Open enrollment for prescription plans is November 15, 2005 through May 13, 2006, so visit www.medicarerxeducation.org or call 1-800-MEDICARE to sign up. If you would like to find out if you qualify for extra help and other benefit programs, log on to www.accesstobenefits.org.

HEDIS Addresses COPD in 2006

The National Committee for Quality Assurance recently released new criteria to be included in the 2006 edition of HEDIS®, its tool for measuring health care quality. New indicators measure the overuse of antibiotics, proper follow-up for children taking certain medications and how COPD is diagnosed.

The new standard looks at whether initial diagnosis of COPD involves spirometry, which is widely agreed to be the most accurate means of diagnosing the disease. Another measure assesses whether COPD patients receive prescriptions for corticosteroids, which have been shown to shorten recovery periods, prevent relapses, and reduce COPD-related mortality.

Relevant sections of the HEDIS 2006 draft can be downloaded from NCQA's Web site at www.ncqa.org

Those who wish to comment on the new measures may do so by sending an e-mail to hediscomment@ncqa.org.

Spotlight

In each issue, we spotlight four COPD-Emphysema support groups and/or pulmonary rehabilitation centers that can help you. For a list of programs and detailed descriptions in your area, visit www.lungchicago.org

CHICAGO

Mercy Hospital and
Medical Center
2525 S. Michigan Ave.
Chicago, IL. 60612
(312) 567-2477
Linda M. Thompson, RRT, RCP
Fax: 312-567-8751

SOUTH SUBURBAN

IOMS Therapy Centers
18425 West Creek Drive
Tinley Park, IL. 60477
(708) 532-1337
Jan Nass
Fax: 708-532-1899

WEST SUBURBAN

Core Solutions
9500 W. Bryn Mahr Ave., Suite 500
Rosemont, IL. 60018
(800) 343-6311
Fax: 847-671-6853

NORTHWEST SUBURBAN

Good Shepherd Hospital
Cardiac Pulmonary Rehabilitation
450 W. Hwy 22
Barrington, IL. 60010
(847) 842-4334
Fax: 847-842-4335

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To receive future issues of *Inspiration*, please call us at 312-628-0227.
Please feel free to copy and distribute this newsletter.



Spirometry Study: Initial Results

In 2004, we launched a Community Spirometry Initiative, designed to raise awareness about COPD and spirometry. Spirometry screenings were held at ten locations, each attracting between 20 and 60 participants.

While the reliability of community COPD education and screening needs more study, it appears that this may be a useful way to identify and motivate people who need more comprehensive testing and who need to change certain

behaviors to improve their quality of life. The ability to personalize COPD education based on the participant's risk factors and spirometry results was also a plus. The results of this pilot project are currently being used as the basis for a more comprehensive and ambitious Community Spirometry Initiative as mentioned in the last *Inspiration* issue. For an update on this project, please see page 6.



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