

Living with COPD



CLINICAL NEWS: NOVEL TREATMENT SHOWN TO BOOST OXYGEN TO LUNGS3



COMMENTARY: OBSERVATIONS, IN RHYME, ABOUT LIVING WITH COPD BY BILL BEETON6



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Up, up and away: COPD and air travel

Whether you plan to be gone for a day, several days or weeks, planning ahead and preparing well will ease the stress of travel. Before you begin making your travel preparations, it's wise to get your doctor's permission for the trip. Take an up-to-date list of all of your medications and if possible, try to get the names of doctors, clinics and hospitals along your travel route.

Air travel

The air pressure in aircraft cabins can be especially dangerous for people with lung disease and in particular to travelers with emphysema.

Most commercial airplanes fly around 35,000 feet above sea level, where the air is too thin for anyone to survive. As a result, cabins are pressurized to the equivalent of about 6,000 to 8,000 feet above sea level. At that pressure, however, a given volume of air contains only 75% of the oxygen that it does at sea level. While this level of oxygen saturation is harmless for most people it can have a significant impact on people with lung disease who may already have a relatively low level of oxygen in their blood—even at sea level.

You may need supplemental oxygen during airplane flights even if you don't normally use supplemental oxygen. COPD patients need to check with their doctors about their need for oxygen during air travel, and to check with their airline to make the appropriate arrangements. A simple test at your doctor's office can help you decide if you need oxygen on the plane.

Most airlines require certification from your doctor that you need oxygen for your flight. That can range from a signed certificate obtained from the airline to a phone call from the airline to your

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COPD patients get all wet

Dipping a toe into one hospital's successful pulmonary rehab program

COPD Canada recently had occasion to visit the Credit Valley Hospital in Mississauga, Ont., to discuss their use of a swimming pool as part of an innovative new rehab program they have instituted for COPD patients and others with serious lung disease. The coordinator of the rehab program, Debbie Coutts (top right), was joined in our discussion by Heather Craig (bottom right), a physiotherapist with the hospital.



Tell us a bit about your program.

Each individual referred to our facility has a full medical assessment by one of our lung specialists. We do assessments on lung function, exercise capacity, strength and nutrition. During the program we work with the patient to determine exactly what they want to accomplish and together we try to meet those goals.

Why swimming?

We develop individualized exercise programs both in the gym and the pool.

How do you sign up for the pool program?

Everyone in our general rehab program is invited to participate in the pool activities. We also provide

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Ask Dr. Chapman

by **Kenneth R. Chapman, MD, MSc, FRCPC, FACP**

Director of the Asthma and Airway Centre of the University Health Network, Toronto



Do all smokers eventually develop emphysema?

(asks CBP, of Smiths Falls, Ont.)

Tobacco smoking is the most obvious cause of emphysema but other factors contribute as well. Being born with the wrong set of genes will make a person susceptible to the destruction of

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Rehabilitation Program

continued from page 1 these rehab services to other people with lung disease—it's not just limited to COPD patients. We have people with pulmonary fibrosis and other conditions.

Who wrote the curriculum?

We looked at some of the studies that have been done on effective exercise programs for COPD patients and selected those programs. We pretty much adapted those programs that worked well on the ground and adapted them for the water. We concentrate on building flexibility, strength and improving cardio function.

People are lighter in the water—does that have an impact on the exercises?

Our patients get the benefits of using the resistance of the water without having to deal with the heaviness and weight of some of the movements. For some it's wonderful not having to deal with one's body mass in quite the same way.

Can patients on oxygen participate?

Yes. We have to be careful where we position the patients in the pool because the oxygen is located outside the immediate perimeter of the pool. We have one patient who loves the water and will actually go under the water while wearing his cannula.

Older people are often cold all the time. How do you get them to go into the water?

The pool is very warm—around 35 to 36 degrees Celsius, which is very comfortable for our patients.

Are there criteria for limiting access to the pool?

Yes, our patients cannot be incontinent. They can't have open wounds—their general hygiene has to be good. We use salt water in the pool rather than having it highly chlorinated which could bother our patients.

What does your patient population look like demographically?

Most of our patients are over 60 years of age and they're about 50:50 male to female. About one-third of them are on oxygen and about the same number use walkers to get around.

And what component of the patient group has COPD?

Most of them have COPD, a few have pulmonary fibrosis. A couple have occupational lung disease—most of our COPD patients are ex-smokers.

Anything you'd like to add about your program?

I'd like to emphasize that the pool program is just a different way of exercising to improve lung function. The variety of exercises is often what keeps you exercising. For our patients, one time they're going for a walk, the next time they're on a piece of equipment and then they may be in the pool. It's the variety of choices that we've found to be important for our patients. We've even taken our patients bowling, which was a blast and another form of exercise.

What kind of outcomes are you looking for?

We want to improve their quality of life. If we don't improve their quality of life they won't continue. We teach them to use what they've got more effectively. We teach them how to breathe more effectively.

COPD Canada is an independently registered non-profit organization whose primary mandate is to assist Canadians who suffer from chronic obstructive pulmonary disease.

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Up, up and away

continued from previous page physician. Check with the airline to determine what is required. Also, carry a valid current prescription from your doctor for your oxygen requirements.

You must make arrangements—in advance—with the airline's special needs department to arrange for oxygen on the plane. The oxygen is set up for you at your seat, with tubing and a canula, and is waiting for you when you board the plane. Please be aware that some airlines will not accept travelers who require oxygen. And, no airline will allow you to fly using your own oxygen. Because of this you will need someone to be with you at the airport to take your personal oxygen from you as you board the plane and you'll need someone to meet you at your destination, with oxygen, when you arrive. Some oxygen suppliers will provide this service for you for a fee.

Airlines charge you for oxygen per leg of each trip, so if possible try to schedule non-stop trips to keep costs down. Also, most major airlines offer a number of services for customers with disabilities. You should identify your special needs at the time of your booking to allow the airline time to meet your requirements. The airlines typically ask for at least 48 hours notice to make special arrangements for travelers.

Additional special needs services from the airlines can include assistance with the following:

- Registering at the check-in counter;
- Proceeding to the boarding area;
- Proceeding to the general public area on arrival, or if in the same terminal, to a representative of another carrier;
- Boarding and deplaning; and
- Stowing and retrieving luggage and mobility aids.

At your request, most airlines will also:

- Arrange for the use of your own wheelchair until boarding the aircraft and for the delivery of your wheelchair at the gate upon arrival;
- Disassemble and package batteries on your motorized wheel-

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Pulse: News about COPD

Novel treatment shown to boost oxygen to lungs

■ **Frankfurt, Germany/** An innovative, minimally invasive treatment on leg vessels may greatly improve quality of life for COPD patients. The approach is to implant a shunt-like device between two major blood vessels in the leg, utilizing cardiovascular reserve to improve breathing by boosting oxygenation to the lungs. "The objective of this new procedure is to improve quality of life in patients suffering severe COPD by increasing oxygen delivery," said Dr. Horst Sievert. Dr. Sievert described a case study in which a 57-year-old truck driver, a five-pack-a-day smoker, was severely disabled by COPD. He could not leave his home without a supplemental oxygen supply, and he required oxygen for several hours per day even when at rest. Walking tests of six minute duration showed that without oxygen the man was only able to walk 420 meters and with oxygen he could walk 510 meters. In this experimental procedure, clinicians perform simultaneous arterial and venous angiograms to locate the region where the femoral artery and the iliac lie near each other in the leg. The vein is punctured and then the artery is punctured. A 5-mm-wide stent-like shunt connects the blood vessels, creating the passageway. Implantation of the shunt can increase cardiac output by about one liter of blood per minute, without impacting heart rate or oxygen consumption. The treatment increases venous oxygen content and arterial oxygen content.  <http://tinyurl.com/6bbatt>

SFC therapy reduces mortality from severe COPD

■ **London/** Patients with severe COPD may benefit more from therapy that combines salmeterol and fluticasone [SFC] than treatment with tiotropium. "Although we found no difference in the overall rate of exacerbations between treatment groups, SFC treatment was associated with better health status, fewer patient withdrawals, and a lower mortality rate than occurred during tiotropium therapy," said the lead author of the study, Dr. Jadwiga Wedzicha, of the Royal Free & University College Medical School in London. The multi-center study, Investigating New Standards for Prophylaxis in Reducing Exacerbations (INSPIRE), was the first large-scale trial to directly compare the two different treatment approaches. The researchers recruited 1,323 patients with severe COPD and randomized them to receive one of two treatments, either SFC or tiotropium, for two years. While exacerbation rates between the two treatment groups were statistically indistinguishable, there were differences in the ways the exacerbations were treated. Oral corticosteroids were used more often to treat the tiotropium group, whereas patients on SFC required antibiotics more frequently. Despite no difference in the overall rate of exacerbations between treatment groups, SFC treatment was associated with better health status, fewer patient withdrawals, and a lower mortality rate than occurred during tiotropium therapy.  <http://tinyurl.com/36qoq8>

Pulse: News about COPD

Deficiency attacks lungs more often than suspected

■ **Werne, Germany/** Hereditary defects are a more significant contributing factor to COPD than previously suspected, according to the German Society for Pneumology and Respiratory Medicine (DGP). It had been widely assumed in Germany that an estimated 8,000 people suffered from an inherited deficiency of Alpha 1 Anti-trypsin (AAT). "We now have indications that the numbers are significantly higher," said DGP president Helmut Teschler.

 <http://tinyurl.com/57jk76>

Breathing problems during sleep increase with age

■ **Boston/** Researchers here reported that the frequency of breathing irregularities during sleep started to increase after age 50 in completely healthy individuals and rose dramatically after age 65. However, such disturbances may be part of normal aging leaving open the question, which patients should be treated for obstructive sleep apnea. Polysomnographic respiratory abnormalities have been extensively studied in the general population, but studies have not targeted completely healthy individuals, the researchers said. Eligibility for inclusion in the study was determined by extensive questionnaires, physical examination, electrocardiography, and sleep lab analysis. After selection, the volunteers underwent full nocturnal polysomnography in an accredited sleep laboratory using current standard recording and scoring techniques. Data collected included sleep stages, arterial oxyhemoglobin saturation, airflow, abdominal and thoracic breathing-movement gauges, electrocardiography, and detection of periodic limb movements in both legs.

 <http://tinyurl.com/6gxe3p>

Work-related tobacco smoke causes death

■ **East Lansing, Mich./** Three public health surveillance systems were used to identify and conduct a follow-up investigation of a reported acute asthma death of a young waitress in a bar. The waitress collapsed at the bar where she worked and was declared dead shortly after. Evaluation of the circumstances of her death and her medical history concluded that her death was caused by acute asthma due to environmental tobacco smoke at work. This is the first reported acute asthma death associated with work-related environmental tobacco smoke. Recent studies of asthma among bar and restaurant workers before and after smoking bans support this association. This death dramatizes the need to enact legal protections for workers in the hospitality industry from secondhand smoke. The results of this study were published in the *American Journal of Industrial Medicine*.

 <http://tinyurl.com/5pbu2n>

Ask Dr. Chapman

continued from page 1 the air sacs in the lung, the tobacco-related injury doctors call emphysema. The genetic story behind common types of COPD is still being unraveled but one rare genetic form of emphysema has been well understood for more than 40 years. It is estimated that 50,000 to 100,000 North Americans living today were born deficient in a blood protein known as alpha1 antitrypsin (AAT). This protein is normally present to protect the lungs from injury. Without sufficient protein in circulation, the lungs are easily damaged leading to the form of emphysema called alpha1 antitrypsin (AAT) deficiency-related emphysema. This kind of emphysema can develop after only a few years of tobacco smoking and, in some instances, without any tobacco exposure at all. AAT deficiency is thought to account for about 1 to 2% of COPD diagnosed in North America.

Is there a cure for Alpha1 Antitrypsin (AAT) deficiency?

AAT deficiency can be treated but not cured. In addition to the standard treatments for COPD, specific treatment involves adding to or replacing the missing protein with intravenous infusions every week. A lung transplant may be an option for patients who are seriously ill. Staying away from cigarette smoke is crucial.

How can you tell if you have AAT deficiency?

A simple and inexpensive blood test can tell if your alpha1 antitrypsin levels are low. If they are, a second and more complex test is needed to confirm the diagnosis. If the diagnosis is confirmed, family members should also take the blood test.

My wife was diagnosed with cryptogenic organizing pneumonia. What are the symptoms of this disorder and what causes it?

A simple Cryptogenic organizing pneumonia causes a flu like illness with a dry cough and breathlessness. "Pneumonia" means lung inflammation. "Organizing" indicates that strands of scar-like tissue have developed in the inflamed tissues. The cause of this illness remains hidden ("cryptogenic"). The majority of patients completely recover with the use of steroids—usually prednisone, one of the cortisone drugs and one of the best inflammation suppressants available. The disease is also known by another name, bronchiolitis obliterans with organizing pneumonia, commonly shortened to its acronym BOOP.

Dr. Chapman is Director of the Asthma and Airway Centre of the University Health Network, President of the Canadian Network for Asthma Care and Director of the Canadian Registry for Alpha1 Antitrypsin Deficiency. A graduate of the University of Toronto and a former member of the faculty Case Western Reserve University, he is now a Professor of Medicine at the University of Toronto

We invite your questions. Please mail questions to: Ask Dr. Chapman c/o COPD Canada; 555 Burnhamthorpe Road, Suite 602; Toronto, Ont. M9C 2Y3. Or you can e-mail questions to: copd.canada@gmail.com

Before making medical decisions

Your physician should be consulted on all medical decisions. New procedures or drugs should not be started or stopped without such consultation.

While the contributors to this newsletter believe that our accumulated experience has value and a unique perspective, you must accept it for what it is... the work of COPD patients. We vigorously encourage individuals with COPD to take an active part in the management of their disease. You can do this through education and by sharing information and thoughts with your primary physician and respirologist.

However, medical decisions are based on complex medical principles and should be left to your medical practitioner who has been trained to diagnose and advise.

Up, up and away

continued from page 2 chairs, unpack the batteries and reassemble the wheelchair on arrival;

- Stow your small mobility or other aid in the cabin;
- Provide refrigeration free of charge for baby's milk, insulin, or other temperature-sensitive medications. Please request this service at time of boarding;
- Assist you in transferring between mobility aids or onto and from the aircraft seat;
- Assist you in moving to and from the aircraft washroom (except by carrying) with the use of the on-board wheelchair; and
- Arrange for alternate transportation for your large mobility aid when traveling on an aircraft with less than 60 seats that cannot accommodate the aid.

It is important that you pre-arrange these services with the airline well in advance of your travel dates.

Travel check list:

- Check with your doctor for final clearance before traveling.
- Did you obtain the necessary paperwork to travel? You may need a letter from your doctor that verifies all of your medications.
- Do you have the name and phone number of your doctor, your respiratory therapist, your oxygen supplier and travel insurance company?
- Do you have enough medication with you? Remember to pack all medication and supplies in your carry-on luggage.
- Are you wearing your emergency medical identification?

Oxygen check list:

- Did you contact the travel carrier (airline) to pre-arrange special needs?
- Do you have a copy of your oxygen prescription? Carry the prescription with you. You may need to show the prescription to travel personnel.
- Do you know how to use your portable oxygen system (if one has been ordered)?
- Do you know how long your oxygen will last?
- Did you check to see if you will need oxygen refills to complete your trip and if so, have you made the necessary arrangements?
Have a safe trip!

Reflections: Life in a Can

Ozone and smoke fumes
and grey tasting ash
carcinogenic nitrites
with monoxid gas
these are a few of my least
favourite things.

It's very unfair,
when they ration the air
and you can't get enough
for your breathable share.

In my wildest of dreams
I could never suppose
that the air in my chest,
pure and sweet as a rose,
would arrive there
by means of a hose up my nose.

Time soon will be over
when clean waters did pour,
replaced now, by apollonaris,
by evian and more.

All bottled and marketed
for the retail trade
be it boutique or store,
as seen on tee vee,
soon sold door to door.

The future will say
the next thing to sell
is the air that we breathe
as we shuffle through hell.

Must cut this note short,
as it's oxygen day
and the medigas man
has pulled up in front
with his oxygen van.

He'll fill up my tank
for its next seven day span,
so I can continue
my life in a can.



Poem and illustration by Bill Beeton,
a retired TV art director and a member of
COPD Canada's Advisory Board



COPD people

Joyce Stewart

After a 46-year habit, helping others to 'smoke no more'

Joyce Stewart was born in Montreal but has spent most of her life in Toronto. She is the mother of two sons—her eldest was killed in a car accident when he was 24. Over the span of her 30-year work career, she was the supervisor of the Data Entry Department for Sterling Drug and held the same position at Canadian Tire. Joyce has led an active life and she's enjoyed skiing, bicycling, going to the theatre, attending music venues and reading. She is currently retired and lives in downtown Toronto with her son. Joyce was diagnosed with emphysema in 2002. In spite of her illness, she continues to be active in the community and is involved with a smoking cessation support group called "Smoke No More."

What made you suspect that you had a health problem?

Breathing was becoming more and more difficult for me. I assumed it was because I was a smoker. I began to wake up in the middle of the night with breathing difficulties.

How long did you smoke?

I smoked for 46 years.

How many cigarettes did you smoke per day?

I smoked a large pack per day—on the weekends a bit more. On weekends I would get together with friends at a local jazz bar.

Was there a specific event that made you quit smoking?

I woke up one night and could hardly breathe at all. I was gasping and kind of croaking for air. The noise I was making woke my son, who called an ambulance. The EMT immediately gave me oxygen. At the hospital I was told that I had COPD-emphysema.

I quit smoking that day. I was very upset, upset with myself.

Were you able to get help in dealing with the disease and your emotions?

I went on-line and found this COPD chat group. I cried so hard. I felt so sorry for myself. I couldn't even see what I was typing through the tears. They really, really helped me. They told me that COPD was not a death sentence—that there was a lot you can do to stop or slow it down. There are rehab programs you can join and exercises you can do to help with your condition. The first thing you need to do is go

see a respirologist.

Is that what you did?

I met with my family doctor who then referred me to a pulmonary specialist.

Are you in physical rehab?

I attend a weekly maintenance rehab program every Wednesday. As well, I belong to an online exercise program called "Let's Get Fit."

You're also involved in a smoking cessation program?

It's called Smoke No More—we refer to it as S-'n'-M. It gets quite a few laughs when you say you're involved in S-'n'-M. We have members from all over the world. It's a quit smoking support program. We talk people through the difficult periods of withdrawal and have daily on-line sessions. I'm one of the team leaders.

Are most of the members female?

Yes. Men don't seek help as readily as women.

As a former member of a ski club, you must have been athletic in your youth?

Yes. I loved to ski. In the summer we would bicycle and had a weekly exercise program. The club ran throughout the year.

Did you ski competitively?

No, no. I considered myself to be an Apprehensive Intermediate.

Do you have any hobbies?

I read a lot. I found a second hand book store near here that has everything you could possibly want to read—at very good prices too. I also enjoy gardening.