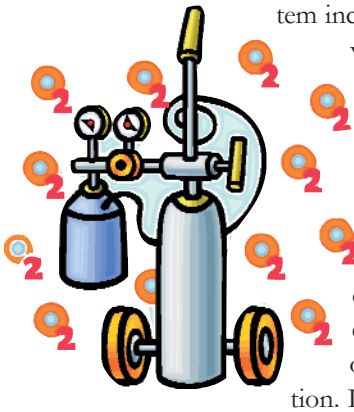
Fall/Winter 2007-8 Volume 2 No. 2

Addressing the needs of the Canadian COPD patient

Living with COPD

The oxygen transport system

The oxygen transport system generally refers to the process of getting oxygenated blood to the muscles and tissues and then returning the partially de-saturated blood to the lungs. This system includes the airways, lungs, pulmonary circulation, heart, blood and peripheral circulation. It involves diffusion, gas exchange, and oxygen extraction. If any portion of this process fails or is limited in its efficiency the system will try to compensate for the impairment.



The body is very responsive to changes in oxygen consumption and as such it maintains a considerable reserve of oxygen. This reserve can be severely compromised by disease. Oxygen consumption is normally 23% of oxygen delivery—to meet resting metabolic demands. The rate of oxygen consumption and carbon dioxide production varies with one's level of activity. Vigorous exercise can increase the demand of the muscles and tissues for oxygen by 20 to 25 times. This increased demand is met by increasing the rate and depth of breathing.

The major role in regulating breathing is a rising concentration of carbon dioxide, not a declining concentration of oxygen. The concentration

please turn to next page

Sex and COPD

COPD isn't the end of an active, enjoyable sex life

Sex is a big part of a person's life, and keeping it alive after a COPD diagnosis can be difficult. COPD patients must deal with many symptoms that can affect their sex life such as shortness of breath and fatigue. As if the disease isn't enough, many medications can also cause sexual dysfunction. As well, the healthy partner may be concerned about hurting their loved one during sex. Patients who use oxygen may be concerned about having to wear a nasal cannula for oxygen support during sex. Others may feel undesirable to their partner.

If you have found that your sex life has decreased since your COPD diagnosis but want to keep it alive you should talk to your partner openly about your feelings and concerns. Also, don't be shy about seeing a sex therapist or seeking out a support group for advice to improve your sexual relationship.

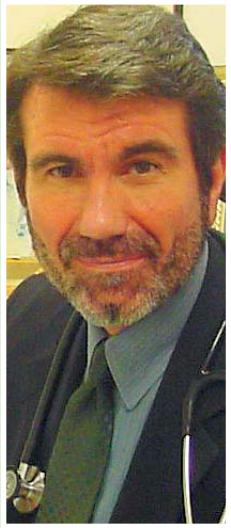
There are many options available to you to try to spice up your sex life. Try having sex in the morning when fatigue is at its lowest level. If you are oxygen-dependent, get longer tubing to allow for placing the oxygen tank away from the bed or even out of the room. Avoid consuming alcohol before making love and do not eat a large meal prior to sex. Check with your doctor about using a bronchodilator before sex so your airways are clear. And, make sure you keep it within arms reach while making love.

Try to relax and free your mind of day-to-day worries. If your body is

turn to next page

Ask Dr. Chapman

by Kenneth R. Chapman, MD, MSc, FRCPC, FACP
Director of the Asthma and Airway Centre of the University Health Network, Toronto



How many stages are there of COPD? How do I know what stage I'm in?

(asks R.L., of Niagara Falls, Ont.)

Doctors have subdivided COPD into severity stages based upon breathing measurements done with a spirometer. The forced expiratory volume in the first second or FEV_1 is the amount of air that can be expelled forcefully in the first second of

please turn to page 5

Sex and COPD

continued from page 1 less responsive than it once was let your partner know what feels good and where it feels pleasurable. Be aware of which body parts are involved and to what degree. Emphasize stimulation of your most responsive body parts. Don't be afraid to explore a bit. Perhaps cuddling and intimacy may suffice for sexual gratification.

Avoiding extremes

If erectile dysfunction is a persistent problem your doctor may recommend ED medication. If you suspect your erectile dysfunction is being caused by medication, explore other alternatives with your doctor.

Avoid sexual activity when anxious or in an extremely hot, cold or humid environment. Use a well ventilated or air-conditioned room.

Many COPD patients also have joint, back or neck pain. If you have these conditions try finding positions that do not put pressure on joints. Maintain pelvic tilt during intercourse when on your back. Keep your knees above your hips. Avoid bulky pillows under your head and try to keep your back and neck aligned. Keep your back supported with a firm mattress and avoid pelvic thrusting if you have lower back pain.

Don't be frantic—go Tantric

The traditional view of sex is that it focuses on orgasm and the release of pent up sexual tension. The climax is achieved only after escalating stimulation and excitement. Tantric sex, based on various eastern philosophies, offers an alternative to the traditional view of sex. Tantric sexual practices teach one to prolong the act of making love and to utilize potent orgasmic energies more effectively.

Instead of moving quickly towards a climax, Tantric philosophy teaches the participant to slow down, remain in the moment and relax. In the traditional view, sexual energy builds up to climax then is quickly lost. In the Tantric view, energy is not lost, but gained. Instead of using a partner for one's own gratification, Tantric partners focus on providing energy and pleasure to each other. The philosophy teaches to concentrate on sensations not performance. The emphasis is on the pleasure at that moment and one of the objectives is to expand the sexual experience over longer periods of time.

There is no doubt that dealing with physical disability can negatively affect sexual desire and response, which is not great for one's self-esteem. Try not to feel uncomfortable with your body. Focus on the good things about yourself. Regardless of your disabilities, sexual relationships are still possible and so is intimate pleasure. Most relationships are based on friendship, trust and respect. Creativity, flexibility and open and frank discussion is needed to solve the unique considerations your disability may present. If you deal honestly with the frustrations and limitations that are associated with COPD there's no reason you can't have an active and enjoyable sex life.

Oxygen transport

continued from previous page of CO_2 is monitored by a part of the brain stem called the medulla oblongata. The medulla oblongata is responsible for controlling several major autonomic functions of the body. If the CO_2 level rises, the medulla responds by increasing one's breathing rate.

The smooth muscle in the walls of the bronchioles is very sensitive to the concentration of carbon dioxide. A rising level of CO_2 causes the bronchioles to dilate. This lowers the resistance in the airways and assists in increasing the flow of air in and out.

Under normal conditions, when red blood cells pass through the lungs, 95 to 100% of them are loaded, or "saturated," with oxygen. Oxygen then passes readily from the lungs into the bloodstream and is pumped by the heart to all parts of the body. If you have lung disease or other types of medical conditions, fewer of your red blood cells will be carrying their usual load of oxygen and your oxygen "saturation" will be lower than 95%. When lung disease occurs, oxygen may not be able to pass as readily into the bloodstream. And, if the heart is diseased, it may not be able to pump as much oxygen-carrying blood to the body.

Supplemental Oxygen

The air around us is made up of 21% oxygen as well as some other gases. Supplemental oxygen that your doctor prescribes is almost 100% medically pure. Because of this, it's considered a drug.

Not all COPD patients require supplement oxygen and your doctor can determine if oxygen will help.

Some patients may only need to use extra oxygen during a disease flare-up or infection, and may be able to reduce or stop its use if their condition improves. However, most patients who require extra oxygen to treat their chronic illness will need to continue their oxygen therapy for life. **please turn to page 5**

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

Living with COPD is published for COPD Canada by Chronicle Information Resources Ltd., from offices at 555 Burnhamthorpe Road, Suite 602, Toronto, Ont. M9C 2Y3.

Supported by an educational grant from GlaxoSmithKline Inc.

Pulse: News about COPD

Effectiveness of home oxygen studied

Toronto/ Home oxygen may not be all it's cracked up to be for COPD if patients show no signs of low blood oxygen levels while at rest. So found Dr. Roger S. Goldstein of the University of Toronto, and colleagues. The series of randomized trials involved 27 COPD patients—all of whom acted as their own control. Although oxygen use improved endurance and the number of steps taken it was shown that few patients, with normal blood oxygen levels at rest, recorded improved breathing and quality of life scores by using oxygen. The study questions the use of home oxygen therapy for COPD patients who do not meet criteria for mortality reduction with long-term oxygen. In the trial the patients underwent three pairs of two-week tests using either oxygen or a placebo mixture (compressed air.) At the end of each trial, patients were given a five-minute walk test to assess exercise performance. Few patients with normal resting blood oxygen levels showed any statistical or clinical difference between oxygen and placebo. Implicit in the study authors' conclusion is the assumption that patients were in fact mobile and active during the study period. It was noted that oxygen use is designed to improve shortness-of-breath and will likely have no measurable effect if the patient is not involved in activities that induce shortness-of-breath. The total time per day participants used portable oxygen was approximately 40 minutes. The study was published in the *American Journal of Respiratory and Critical Care Medicine*. ☞ http://tinyurl.com/2h3eun

Interferon lozenge relieves chronic cough

Lubbock, Texas/ Low-dose oral interferon may relieve chronic coughing in idiopathic pulmonary fibrosis (IPF) patients, it was observed in a study of 18 patients enrolled in a trial at Texas Tech University. More than half of the patients treated with interferon lozenges for at least one year showed no signs of disease progression. IPF is normally rapidly progressive. ☞ http://tinyurl.com/2a4eo3

Cholesterol lowering drugs shown to benefit lungs

Boston/ A new report hints at another possible therapeutic use for the cholesterol lowering drugs known as statins. Statins are known to have antioxidant and anti-inflammatory properties, and because inflammation and oxidative stress are associated with decreased lung function, the group sought to determine whether statins could moderate the decline in lung function in COPD patients. "To our knowledge, this is the first study to report a beneficial effect of statins on the rate of lung-function decline," write lead investigator Dr Stacey Alexeef (Harvard School of Public Health, Boston, MA) and colleagues in the October 15, 2007 issue of the *American Journal of Respiratory and Critical Care Medicine*.

☞ http://tinyurl.com/22tz5y

Pulse: News about COPD

COPD under-reported as major disease

Portland, Ore./ The prevalence of COPD is higher than previously thought, and cigarette smoking is not the only factor contributing to to the disease, investigators led by Dr. A. Sonia Buistreport of the at Oregon Health Sciences Centre report in *The Lancet*. ☞ http://tinyurl.com/2xkpph

Stent shown to relieve emphysema symptoms

New York/ Treatment with a drug coated stent to reduce hyper-inflation of the lungs appears to be a feasible treatment for patients with severe emphysema. According to researchers involved in a small study, the treatment can improve lung function and reduce shortness of breath. "These results indicate that airway bypass is a potentially viable therapeutic option for patients with marked severe pulmonary destruction," stated lead author Dr. Paulo F. G. Cardoso, from Santa Casa de Porto Alegre-Pavilhao Pereira Filho Hospital in Brazil. Cardoso added that airway bypass is a particularly important advance for patients with "more uniform destruction of the lung" because usually their only option is a lung transplant. Stents are tiny wire mesh tubes typically used to prop open diseased heart arteries. A drug eluting stent releases a drug to keep the artery open in heart patients and to keep the vessels open after they are cleared of the clog-forming plaque that can cause heart attacks. In this study, the stents are placed through the airway walls to release the air trapped in diseased segments of the lung, allowing it to be expelled normally. Airway bypass was first shown to be feasible in 2003, when researchers tested the procedure on diseased lung removed from emphysema patients. The focus then shifted to maintaining the opening of the segments, which led researchers to consider the use of drug-coated stents. Their report was published in *The Journal of Thoracic and Cardiovascular Surgery*. ☞ http://tinyurl.com/ywvtk8

Poor indoor air quality affects COPD patients

Aberdeen, Scotland/ Poor indoor air quality can significantly worsen health problems in people with COPD, according to researchers in Scotland. High concentrations of fine particulate pollution—the type of pollution associated with second-hand smoke and, in developing countries, indoor cooking and heating fires were strongly linked to poorer health status. While the exacerbating effects of outdoor pollutants on COPD patients have been well-documented, few studies have analyzed the impact of indoor air quality on COPD patients. "Although exposure to outdoor pollution is important, most people spend the greater part of their time indoors," wrote Dr. Liesl M. Osman in the article that appeared in *The American Journal of Respiratory and Critical Care Medicine*. The researchers found that indoor concentrations of particulate pollution in the subjects' homes frequently exceeded standards for outdoor air. ☞ http://tinyurl.com/2zhl2t

New treatment guidelines for COPD

The Canadian Thoracic Society (CTS) recently released new guidelines for the treatment of chronic obstructive pulmonary disease.

With a focus on the prevention and management of exacerbations the guidelines were updated to ensure that patients are receiving adequate therapy appropriate to their disease severity. Exacerbations (or the worsening of symptoms) can be triggered by a common cold, change in weather, or allergies. Often they result in visits to the local ER, hospitalization and, in severe cases, can lead to death.

"It's vital that physicians recognize the importance of exacerbations in the life of a patient with COPD" says Dr. Paul Hernandez, a member of the CTS COPD Guidelines Development Committee and an Associate Professor of Medicine at Dalhousie University. It is stressed that COPD is not just a nuisance disease but a serious disease that people die from. Exacerbations in COPD patients should be considered as important as heart attacks in people. "We need to not only prevent the first exacerbation, but work more proactively to prevent all subsequent flare ups of the disease."

With appropriate treatment, COPD patients can experience less shortness of breath, better exercise tolerance, fewer hospitalizations and improved quality of life. The guidelines outline optimal uses of medicines as well as non-pharmaceutical interventions. The importance of spirometry is reviewed as not just a diagnostic tool but to determine which patients will benefit most from specific medications.

"The important take-away message for physicians from the revised guidelines is that this is a treatable disease, and with the right treatment options available, patients can do better," says Dr. Denis O'Donnell, Chair of the CTS COPD Guidelines Development Committee and Professor of Medicine and Physiology, Queen's University. "Through early diagnosis and correct assessment of disease severity through spirometry testing, along with early and aggressive treatment with both lifestyle changes and medications, COPD can be managed and patients can maintain an improved quality of life."

The complete guidelines are available through the CTS's web site:

http://www.copdguidelines.ca

Ask Dr. Chapman

continued from page 1 exhalation. If the FEV_1 is reduced, it's usually an indication that the breathing passages are narrowed, the hallmark of COPD. There are four stages of COPD based on this measurement:

Stage 0 *(At risk):* Normal FEV_1—A smoker without a serious COPD injury.

Stage I *(Mild):* Although the FEV_1 is within the normal range, it's low in proportion to the other spirometer measurements. Mild breathing passage narrowing is now present.

Stage II *(Moderate):* FEV_1 is 50 to 80% of what it should be.

Stage III *(Severe)*: FEV_1 is just 30 to 50% of its predicted value.

Stage IV: FEV_1 less than 30% of predicted. This staging tells doctors something about what symptoms to expect, how much medicine is likely to be needed and how often follow-up visits and certain tests should be done.

What is CO2 retention?

Breathing delivers oxygen to the body and removes carbon dioxide that living tissues produce. If breathing is impaired, oxygen levels can drop and carbon dioxide or CO_2 can build up. This "CO_2 retention" happens either because the lungs are so damaged they cannot breathe out the carbon dioxide the body produces ("can't breathe") or because the brain isn't driving the breathing muscles hard enough ("won't breathe".)

Some patients with COPD have CO_2 retention persistently because of very severe obstruction and some have it temporarily during exacerbations when their obstruction is a little worse than usual. Some COPD patients have breathing drive that is impaired by the use of pain medications, sedatives or by sleep apnea, a disruption of breathing during sleep.

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 Anti-trypsin 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

Oxygen transport

continued from page 2 Although long-term oxygen therapy has myriad benefits, it is expensive and intrusive. Effective therapy requires thorough patient education and a steadfast commitment by the patient and often by their caregiver. Many patients need extensive counseling to overcome their reluctance to wearing a nasal cannula, especially in public.

Only a small percentage of the millions of people with lung or heart problems can benefit from supplemental oxygen. The only way to know for sure if you need supplemental oxygen is to measure the amount of oxygen in your blood with an Arterial Blood Gas test or Oximetry. Your physician will evaluate your test results and symptoms to determine if you might benefit from additional oxygen. If so, a specific flow (litres per minute) of pure oxygen will be prescribed as well as the length of time you should use oxygen. Be aware that if not taken as prescribed oxygen can cause serious medical problems.

Opinion: The **case** for **political activism**

by Henry Roberts

It is estimated that upwards of 750,000 Canadians are suffering with Chronic Obstructive Pulmonary Disease. The nation as a whole also suffers, with the economic burden of related health care costs, lost years of work and premature deaths. This is not only a large and growing medical problem but it is also a social problem. There is very little public awareness of the disease or any significant high-profile political action to combat this public health disaster.

> "Guilt over cigarette smoking and the **feelings of remorse** over the self-induced cause of the disease **must end**"

Do people not seem to care about COPD because of the belief that current therapies have not been able to stop the progression of the disease and that the lungs have been seen as basically unrepairable? Perhaps this national passivity is an off-shoot of smoker's guilt or disdain of smokers. The reality is that COPD can affect never-smokers.

Second-hand smoke is a form of passive smoking and is known to cause the disease. As well, COPD can be caused by factors other than cigarette smoke—through airborne particulates in the work place and general environment. In the face of such public ignorance and apathy we need to radically change the status quo if we are to improve COPD awareness, prevention and treatment in this country.

Recent medical research indicates, that in animals at least, actual lung regeneration can be induced. Stem-cell research also offers hope for lung regeneration and is an area that is virtually unexplored. If significant, life extending medical breakthroughs can be made for AIDS, cancer and other diseases, why not COPD? If patients, their families and friends become highly proactive in the fight to cure COPD it is likely that action alone will increase awareness, which will result in more funds for research and treatment.

For the most part, progress and success in medical research is directly related to the amount of research being done on a given disease. The amount of research is directly proportional to the amount of money and attention the government and private citizens put toward the effort. When compared to other major diseases COPD is nowhere to be found. What's the difference here? The answer must be "political and social activism."

No excuse for lack of effort

The Canadian public is silent when it comes to lobbying for funds for COPD. Has there ever been a demonstration to increase funding to cure the disease? Almost no private money is raised for COPD research in this country and no organization effectively lobbies the government for increased funding for COPD treatments or cures. One could argue that this perceived lack of effort is because the outlook for progress in COPD is abysmal. But this is no longer the case. Based on promising advances in technology there is no excuse, from a scientific standpoint, that more effort is not being made in COPD research.

Guilt over cigarette smoking and the feelings of remorse over the self-induced cause of the disease must end. This "guilt" has not prevented the AIDS community for fighting for funds and government action, and it should not prevent the COPD community for asking for more. Most of today's COPD patients grew up in the middle of the radical '60s. Maybe some of that bra burning activism needs to be re-discovered if we are ever going to move COPD toward the top of the Canadian health agenda.

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.

COPD people

Vivian Rosenberg

A double lung transplant survivor

Vivian Rosenberg started life in Austin, Texas. At a young age she moved to Winnipeg where, as an adult, she worked for the Manitoba government. Her job experience enabled her to move to Jerusalem where she stayed for six and one-half years working for the Israeli government's housing department. She found Jerusalem to be an advanced society and a fabulous place to live and work. She eventually made her way to Toronto, finding employment with the Ontario Ministry of Health, where she specialized in chronic care. Vivian is currently employed by The Hospital for Sick Children in Toronto where she works as the Grants Coordinator for scientific research into fetal alcohol disorder. Over the years, she has dealt with chronic bronchitis, emphysema and has fought a continuous battle with recurring lung infections. The cause of these ailments is unknown. Vivian has never smoked cigarettes. A few years ago she had both of her lungs replaced.

When did you sense that there was something wrong with you?

In the '70s it was discovered that I had chronic bronchitis but I didn't think much of it as I was a pretty healthy person. I was quite a walker. Eventually I needed puffers to help me catch my breath. I never expected this problem would progress. Then I started getting a series of lung infections and eventually had to be hospitalized.

Did anything trigger the infections?

No, they just kind of arrived. Over time my condition worsened and this led to the use of oxygen and a diagnosis of emphysema.

Do you know the cause of your emphysema?

No, they think that I may have been predisposed to this disease.

How did the subject of transplantation come up?

I started getting more infections and ended up in hospital more often. The specialist and I discussed a number of options which could add a few years to my life but the best option turned out to be a double lung transplant.

What criteria do they use to select candidates for lung transplantation?

They have to be convinced that you will follow through with the program and that there is a good chance of success. They want to be sure that you have the strength and determination and will be able to deal with the side effects and not quit. The key organ factors are size and blood type.

Do they tell you anything about the donor?

No, nothing at all. I wanted to know the gender and age range. They don't want families getting in touch with each other. I understand the ethics of that..

Where did you have the surgery?

Toronto General Hospital. They have a transplantation wing. You get excellent one-on-one care in that facility.

Is there a lot of pain?

No. They don't want you suffering at all. They give you enough pain medication. The whole premise today is that people recover better if they're pain free.

Do you have any advice for people who are facing a similar situation?

People can and should hope. There is a solid scientific foundation for hope. Be positive. In my view hope is critical to good maintenance during illness and enormously helpful to better recovery. I truly believe that.

Are you into jazz as much as your husband Sydney is?

I like a melody. I love Louis Armstrong. I don't like that new age stuff—the stuff that's way out there

Have you seen any movies lately?

I love movies. We recently saw Michael Clayton and also saw Eastern Promises, which I really liked. A perfect day for me would be to spend time with family and friends and go to a movie.

How is life now?

Life is sweet.

COPD Canada's web resource

www.copd.ws

Join today: The COPD Canada web site is your portal to our association, new and varied educational materials, medical resources and community interaction.

Membership is free of charge but is restricted to individuals living with COPD or their caregivers. Joining is fast and easy. Just visit our web site www.copd.ws and click on membership and follow the step by step instructions. **Once you've joined** you will begin receiving our quarterly "Living with COPD" newsletter and will have complementary access to all COPD Canada seminars, on-line discussion forums and our member chat section. **Coming soon:** COPD Chat. The people who know COPD best are those coping with COPD. Members can talk with their peers worldwide through our new interactive chat room. Ask questions, supply answers, share tips and frustrations: all within the comfort of a peer setting. • To assist members with complaints about the Canadian healthcare system, your website is introducing a complaints section. This node will allow anonymous communication about problems with a healthcare provider or the system in general.

COPD Canada
555 Burnhamthorpe Road Suite 602
Toronto, Ontario
M9C 2Y3

CANADA POST / POSTES CANADA
Postage paid / Port payé
Addressed Admail / Médiaposte avec adresse
2858886