Spring/Summer 2007 Volume 2 No. 1

Addressing the needs of the Canadian COPD patient

Living with COPD

Managing my life with COPD

by Bill Beeton

I entered my 10th year on supplemental oxygen last New Year's Eve. I had a terrible time embracing my new facial hardware—a two-way tube of clear, hollow plastic, with a two-pronged nasal canula inserted in my nostrils, stabilized by looping the tube over my ears then under my chin, and then merged into a single 15 metre tube. The tube is attached to an air pump machine that distills oxygen from the available room air. It functions 24 hours a day for as long as you are attached and still breathing.

A government appointed respiratory therapist is assigned the yearly task of evaluating my need for additional oxygen. I came to dread the annual visit of the RT. who had the power to take me off supplemental oxygen, thus saving the government some spare change while destroying my life. In my mind, respiratory therapists were the language police in Quebec, or the fierce, armed, library police in Toronto. I heard tales of people who, without the extra

please turn to next page

Pulmonary rehabilitation

Outpatient care for people with lung disease

Pulmonary rehabilitation is a program that helps people with chronic lung disease learn to live more comfortably and independently in their community. It offers a supervised exercise program stressing cardiovascular fitness, upper and lower limb strength, endurance training, energy conservation and breathing techniques.

The rehab team performs a comprehensive assessment of your needs and develops an individual treatment plan. The goals of pulmonary rehabilitation are to alleviate symptoms, restore functional capabilities as much as possible and to reduce one's handicap thus enhancing overall quality of life.

"We're trying to give individuals control over their disease." With that statement Meeran Manji encapsulated the primary goal of pulmonary rehabilitation. Meeran Manji, RN is a COPD educator at the Pulmonary Rehabilitation Clinic at the Asthma & Airway Centre of Toronto Western Hospital. They have a team consisting of respiratory therapists, a registered nurse, dietitian, doctor, and social worker. Equipment at the centre includes treadmills, ergometers, recumbent steppers, recumbent bicycles, stationary bicycles, free weights and Nautilus-type strength training machines. To attend rehab the general rule of thumb is that your medical condition must be stable and you must be physically and emotionally able to attend the program. To obtain maximum benefit, individuals are encouraged to attend the program three days per week for twelve weeks.

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

What is spirometry? *(asks R.B.B., of Alliston, Ont.)*

Spirometry is a simple breathing measurement that should be available in or near your physician's office. The test is most often conducted by a nurse or respiratory therapist (RT) depending upon whether the test is being done in a physician's office or in a laboratory setting. The nurse or respiratory therapist

please turn to page 5

Pulmonary rehabilitation

continued from page 1

Meeran Manji

However, there are individually devised programs for those who cannot attend the twelve week program.

We met with Ms. Manji recently to talk about the state of the art of pulmonary rehab at one of the countries most advanced clinics. "We try to keep people out of the emergency room," said Ms. Manji, "One of our goals is to minimize chances of hospitalization and to help individuals cope better when they have signs of worsening condition or infection." To attend the clinic all patients must be motivated to improve and must stop smoking or enter the smoking cessation program they offer. "Quitting smoking is the only way to slow the progression of COPD," Ms. Manji added. "Sometimes part of the motivation to quit smoking is the desire and need to be in pulmonary rehab."

For new patients a needs assessment is developed and then patients are introduced to breathing and relaxation techniques. The patient soon learns how to control their breathing and how to relax. Ms. Manji also teaches newcomers how to conserve energy and utilize relaxation techniques to control general anxiety and stress. Individuals learn about their medications and proper inhaler technique. Educational sessions on the value of action plans and the value of their use are also discussed.

During orientation, the patient is shown the facilities and gradually introduced to the equipment. Prior to using the equipment patients are taught how to properly warm up before they start their exercises. The clinic also gives instruction on diet, as well as teaching the value of moderation in both life and alcohol use.

Ms. Manji encourages patient-to-patient interaction within the rehab population. "We find this to be powerful as patients are able to offer valuable advise through their personal experience and knowledge," she said. Support from other patients and the friendships that develop are very important to members of the group. Mentoring and interaction, however, is not for everyone. Over time you learn that there are some in the group who prefer to get involved and share. However, the group respects those who would prefer to be private and less engaged with others. The clinic does not force interaction.

A typical rehab session here begins at 9:15 am and finishes at 11:00 am. Although there are many similarities between rehab centers across the province, the framework of the programs will vary. To enroll in a program at a pulmonary rehabilitation clinic you typically need to be referred to the clinic by your family doctor or a respirologist.

With the rise in incidence in COPD across the province, and country, we have insufficient facilities to service those with COPD. The "National Report Card on COPD" produced by The Lung Association recommended an increase in pulmonary rehab capacity stating that currently we are only able to provide rehab services for 1.2% of the COPD population. Governments must make COPD a priority and do more. In the case of pulmonary rehabilitation, the outcomes are measurable—not only in reduced exacerbations and hence hospital visits—but in a general improvement in quality of life for attendees.

Gasp

continued from previous page oxygen, were trapped in their apartments; unable to go shopping or function in any but the most desperate of conditions.

I was aware that when I was interviewed by the RT while seated at the table I showed no symptoms of the need for oxygen, as indicated by the Oximeter attached to my finger. Only when I rose from the table and tried to walk any distance without oxygen, did the Oximeter numbers crash. My appendages would start to take on a quite unbecoming ash blue shade. The result? I was ensured access to the life-giving oxygen for another year.

If you are new to the oxygen experience, you will need to familiarize yourself with using the small portable tanks, including: How to fill them without freezing your air supply (don't overfill), and setting the usage knob to select the rate of airflow. The rate of airflow is determined by the level of effort a planned activity requires and the level your Respiratory Therapist has established with you. For example: If you are able to make your nose whistle an assortment of show tunes by twitching and wiggling it—your oxygen is set too high. If you keep coming to a full stop, aren't certain why you're there, or what your name is, or if your finger tips have acquired an unusual cyanotic hue, then your oxygen might be set too low. First-hand experience is a good teacher and if you survive, learn from it.

If you have several portable tanks—sufficient to allow you to visit friends or at least stay away from your home base for most of the day—you will need to keep detailed records of the duration and litres of use for each tank. The tanks can have more variation than your supplier may indicate, and you need to know exactly what to expect from the tanks you are using. To ensure that you don't run out of air, always allow for a

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 unrestricted educational grant from GlaxoSmithKline Inc.

Pulse: News about COPD

Morphine provides chronic cough relief

Hull, England/ The severity and frequency of chronic intractable cough was reduced by 40% using low-dose slow-release morphine researchers say. Their study provides evidence for another option when a persistent cough does not respond to cough suppressants, reported Alyn H. Morice, MD and colleagues, of the University of Hull and Castle Hill Hospital. The study appeared in the Feb. 15 issue of the American Journal of Respiratory and Critical Care Medicine. The study included 27 patients recruited from a cough clinic. It was a double-blind crossover study and randomized to four weeks of 5 mg extended-release morphine sulfate twice daily and four weeks of matched placebo. The patients all had chronic, persistent cough for greater than three months and had failed to respond to trials of specific cough suppressants. None had significant lung disease or used any other cough remedies during the study. The average age of the patients, 18 of whom were women, was 55.

☞ http://tinyurl.com/2t2k2y

Cough and phlegm doubles COPD risk

Pavia, Italy/ Young adults with chronic cough and phlegm are at nearly double the risk of developing chronic obstructive pulmonary disease (COPD), stated researchers here. They also found that chronic wheezing and shortness of breath do not appear to be linked to an increased risk of COPD. These findings were reported by Isa Cerveri, MD, of San Matteo Hospital and the University of Pavia. The findings are derived from a study of 5,002 volunteers. They were monitored for a median of 8.9 years and their ages ranged from 20 to 44. Dr. Cerveri and colleagues reported their findings in the January issue of the *American Journal of Respiratory and Critical Care Medicine*. ☞ http://tinyurl.com/2tog7a

ASA may have role in preventing asthma

Bethesda, Md./ The risk of new-onset asthma in adult males may be reduced by daily use of ASA. A retrospective analysis of thousands of physicians investigated the role of ASA in preventing first heart attacks. The study randomized 22,071 healthy male physicians, ages 40 to 84 to ASA or placebo. A post hoc analysis of data from the Physicians' Health Study revealed that men who took 325 mg of ASA every other day had a 22% reduction in risk of new onset asthma. The possible protective effect of ASA was not modified by baseline risk factors including smoking, body mass index, or age, but the benefit appeared to be greater among younger men., The study was reported in the January issue of the American Journal of Respiratory and Critical Care Medicine. ☞ http://tinyurl.com/2tpsbp

Pulse: News about COPD

Treating COPD: The TORCH trial

Toronto/ An international study published recently in the *New England Journal of Medicine* showed that patients with chronic obstructive pulmonary disease (COPD) who took 50/500 mcg salmeterol and fluticasone propionate dry powder for inhalation (Advair Diskus) reduced their risk of dying from any cause by 17.5 per cent over three years compared to patients on placebo (p=0.052). "These results are important because the findings in the study point to better outcomes for patients with COPD, adding to our understanding of how to best manage this life-threatening disease," said Dr. Meyer Balter, Associate Professor of Medicine, University of Toronto; Director, Asthma and COPD Education Clinic, Mount Sinai Hospital. ☞ http://tinyurl.com/3dyfae

COPD crucial women's health issue: Lung Ass'n

Toronto/ Almost half a million Canadian women struggle with COPD, yet screening for early detection of this often deadly condition is unacceptably low, says a report by the Canadian Lung Association. Calling COPD a "crucial women's health issue," the report shows that more than 425,000 Canadian women aged 35 and older were diagnosed last year with the breathing disease, which kills more than 4,300 each year. "Canadians need to recognize that the face of COPD has truly changed and we will be seeing more and more women living with and dying from this disease," Dr. Anna Day, head of the Gender Asthma and COPD Program at Women's College Hospital in Toronto. ☞ http://www.lung.ca

Asthma rates decline in 2006

Philadelphia, Pa./ Largely due to increased use of inhaled corticosteroids to manage the disease asthma mortality rates have been declining worldwide. An international group of researchers reported that conclusion while presenting data on world health trends. The decline in mortality was reported at the 2006 annual meeting of American College of Asthma, Allergy & Immunology. Despite the decline asthma still accounts for one of every 250 deaths worldwide ☞ http://tinyurl.com/2wjshm

Cost will burn a hole in healthcare budgets

London, England/ To prepare the UK public and businesses for the new anti-smoking laws, the cost of anti-smoking advertising will top £12 million, making the public health campaign one of the most expensive campaigns ever. Beginning July 1, 2007 the ban on smoking in public places comes into force, and plans call for a Hollywood-style TV campaign. At a time when many hospital trusts need to make difficult spending decisions the cost of the campaign is being questioned. ☞ http://tinyurl.com/2lptay

Ask Dr. Chapman

continued from page 1 will coach the patient to take in as deep a breath as possible and then to blow it out as forcefully and as completely as possible into a measuring device.

The maneuver is repeated several times to ensure that the maximum result has been measured. The test is sometimes repeated 15 or 20 minutes later after the patient has been given an inhaler to use. A report is then sent to the physician describing in precise terms how much air the patient can squeeze out and how quickly that air is moving.

These measurements can be compared to the measurements predicted for normal individuals of the same size and age. In patients who have COPD, the speed or flow of the air is reduced and there is usually little change seen just 15 or 20 minutes after an inhaler has been given.

What are the symptoms of COPD?

By the time patients have a diagnosis, they are likely to have several common symptoms. One of the most troublesome symptoms is breathlessness or "chest tightness." This tends to be most obvious when people are exerting themselves but when COPD is advanced, the breathlessness may be present when people are sitting quietly at rest.

Cough is another common symptom of COPD although not all patients will suffer from cough and many will have cough only intermittently. When COPD is stable, patients who cough may produce little or no sputum and the sputum they produce may be white or clear. At times of infection or "exacerbation" the sputum may be colored yellow or green, may increase in volume and may become stickier.

However, COPD develops after decades of exposure to tobacco smoke. This gradual development means that many people adapt to the disease over time and don't recognize their symptoms until it is far too late.

The middle-aged man who notices breathlessness when climbing the subway stairs may chalk it up to a lack of exercise or "middle-aged spread." It's also surprising to new physicians how often patients ignore a persistent cough attributable to COPD. It's common to hear a patient deny suffering from a cough only to agree that "yes" they may have a "normal smokers cough."

At this earlier stage of the disease when it may be mild and much more easily treated, few patients think to mention such symptoms to their doctor. Regrettably, few doctors are screening their smokers with breathing measurements (spirometry) to detect those who may be developing COPD. Making both the public and their physicians aware of the significance of the symptoms will help to make the diagnosis earlier when our interventions are more effective.

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

Gasp

continued from page 2 grace period to get you home safely. If it looks like you are in danger of running short, turn the knob down so you consume less air, but over a greater period of time. And, get to an oxygen refill source as soon as possible, minimizing speech and unnecessary physical activity. Just *don't panic!*

As a security measure, I carry a cellular phone. This allows me to call for a cab wherever I might be if I need help. Beyond the initial purchase price, it costs ten dollars plus tax for every 30-day period. I only power the cell phone for a specific need. The money, I feel, is well spent.

The only way I can get about without requiring the aid and assistance of others, is to use a walker. Initially I was a bit embarrassed about using a walker. I've been forced, however, to accept that I can no longer afford the luxury of being concerned about what other people think of me. I did make one concession though and stuck a Harley-Davidson logo to the seat of my walker substituting the word 'motorcycle' with 'cripple cart.'

One day, while in the eight items or less cashier's lane at the local Dominion, the lady in front of me noticed the logo and said, "Oh my gawd, are they into those things now?" I told her that they were all the rage with the younger geriatric set in LA.

I truly believe that exercise is the one activity that can make a real difference to people with COPD symptoms. The inhalers and pills are for maintenance only, they allow you to function but have no curative aspect. Exercise, however, while not a cure, will build up muscle and muscle uses oxygen more efficiently than flab.

As long as you're able to walk you can maintain your independence. This is why I have not gone the way of the scooter or other motorized conveyance. Optimal survival skills were summed up best by the late Johnny Lombardi. When asked what he attributed his long life to he responded, "Just keep breathing."

I'm trying to take his advice.

Bill Beeton, a regular contributor to this newsletter, spent his career as an art director in television, feature films and TV commercials. He was diagnosed as having emphysema more than 10 years ago.

The ABCs of oxygen and the respiratory system

The system in the body that deals with this exchange of gases is the respiratory system. The main components of managing this system include the heart and lungs and these components are interconnected through a variety of pipes, veins and arteries. The lungs are contained within the chest, one on either side, with the heart in the middle. These are protected by the rib cage and chest wall. The purpose of the lungs is to bring oxygen into the body while removing carbon dioxide.

Oxygen is brought into the body through either the nose or mouth, travelling through the windpipe (trachea) to the lungs. The air is warmed, moistened and filtered as it moves through the system. As it travels through the larynx and trachea it is divided into two branches to supply the left and right lung. They are called the left and right bronchus. The bronchus further subdivide and branch out into smaller and smaller tubes called bronchioles. These tiny passages end in tiny air sacs called alveoli. Alveoli translates into "bunch of grapes" in Italian, which is similar to what they look like. There are over 300 million alveoli in a normal lung. Very small blood vessels or capillaries surround the alveoli and a special thin membrane between the blood vessels and air sacs allows oxygen to pass into the blood stream when you breathe in. Carbon dioxide passes from the blood into the air sacs and is eliminated when you breathe out.

Oxygen restriction

If, for any reason, there is a blockage in the air passages, the alveoli may not be given enough air to provide oxygen to the body or be able to efficiently get rid of the carbon dioxide. In some types of lung disease the air sacs may have been destroyed or damaged. In these instances although enough oxygen is present it is very difficult for the gases to pass into and out of the lungs. This can result in low oxygen levels which in turn acts as a trigger to tell the body to make more effort to breathe to obtain the necessary oxygen.

The effort involved in trying to obtain the extra oxygen needed can result in tiredness and breathlessness, particularly after coughing or activities such as walking. As well as breathlessness, too little oxygen can interfere with other parts of the body such as the heart, causing ankle swelling and fluid retention.

The case for supplemental oxygen

For some people with lung problems, breathing air with a higher concentration of oxygen can help reduce some of the symptoms caused by a lack of oxygen. These patients may need only a small additional amount of oxygen. Oxygen is not for everyone and some patients could be harmed by getting too much oxygen. This is why every patient should be individually assessed to find out if they will benefit from oxygen therapy and how much they will require. In many cases people may only need oxygen therapy for short spells when their oxygen levels are low. When oxygen therapy is needed 24 hours per day, this is known as continuous oxygen therapy.

Severity of breathlessness is not a reliable way of deciding if oxygen therapy will be helpful. The need for oxygen therapy should be assessed by a hospital specialist in respiratory medicine, who will look at recent pulmonary function tests (breathing tests) and at the levels of oxygen in your blood. If it has been decided that you may benefit from oxygen, you should have regular reviews to ensure that your oxygen levels are correct and that you using the oxygen correctly and often enough.

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. They do this through education and by sharing information and thoughts with their 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

Mary Layton

co-founder, COPD Canada

An avid athlete, Mary Layton taught skiing, curled, sky-dived, golfed, and enjoyed swimming, going to the theatre, and jogging.
She loved her active lifestyle but she smoked two and a half packs of cigarettes a day for 25 years. Mary is an emphysema patient who was forced to take early retirement in 2001. After living such an active life, she has found it difficult to slow her pace down.
Through speaking to other people with COPD, she recognized the need for an organizing body that could provide information to patients and increase awareness of COPD amongst Canadians. Mary's role within the organization is multi-functional: She is a co-founder of COPD Canada, an educator and a spokesperson.

Where were you born?

Sherbrooke, Que. We moved to Montreal when I was two.

Do you still visit Montreal?

As often as I can, I have friends and family there.

Were you an outdoor enthusiast?

I taught skiing in St. Sauveur, Que. and Banff, Alta., as I lived and worked in Calgary for six years.

Competitive skiing—like racing?

No, downhill—pleasure skiing.

Why did you feel you were qualified to instruct?

I got my skiing teaching certificate at Mount Tremblant, north of Montreal.

How did you end up in Toronto?

I was a media director for an advertising agency in Montreal, and was transferred at the request of our largest client.

What kind of accounts did you handle?

Mostly pharmaceutical accounts, although I started my career looking after the Olympic Coin Program for the '76 Olympics. My first television buy was for six million dollars—for the Olympic coin program. That was exciting, plus I spent a lot of time at the Olympic Village where I got to meet all the athletes

When did you discover you had a problem with your lungs?

I was living with a chiropractor who didn't smoke, who kept telling me that there's something wrong with my breathing. That I was wheezing all the time.

Were you still smoking at the time?

Yes, I actually had two packs of smokes in my purse when I was told of my condition by the respirologist.

What was the diagnosis?

I was told that I have emphysema.

Did that surprise you?

My first reaction was: *no, I don't!* I was devastated! But, my mother had emphysema. It runs in the family—so I accepted the reality pretty quickly.

What did you do with the cigarettes?

I went outside; there were some street people hanging around who I gave the cigarettes to.

You were pretty active before. What do you miss most?

I miss the winter, but because of my lung condition I can't get out and enjoy it anymore. I curled and loved skating. I was with the Montreal Figure Skating Club for a number of years. Skating was very important in my family. My dad was a professional hockey player. I inherited his "hockey legs" and I inherited my mother's emphysema. Hey… you can't win them all!

Have you learned to love the Toronto Maple Leafs yet?

No comment.

This regular feature of *Living With COPD* is intended to allow Canadians to put a face on COPD, through engaging in dialogue with patients from diverse backgrounds and communities. We invite your comments and suggestions.

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