

# The BreathWorks Program

## The Lung Association Helps Patients Learn to Manage COPD

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Looking hopeful and gazing skyward, Lorraine LeBlanc is pictured on the front cover of *The BreathWorks Plan*, a 41-page educational guide about living with Chronic Obstructive Pulmonary Disease (COPD) written for those, like Ms. LeBlanc, who know they have the disease or those who suspect they might have it. The guide is plainly written and full of practical advice for COPD patients on how to work together with their doctors to manage their disease, and is also intended for use by the family, friends and caregivers of those with COPD.

The *BreathWorks Plan* is distributed free of charge and forms an integral part of The Lung Association's recently announced *BreathWorks Program*.<sup>1</sup> The *BreathWorks Program*, portions of which are still in a pilot phase, will be Canada's premier source of information and support for people with COPD and their caregivers, and will include:

- a national telephone helpline staffed by COPD educators offering information, guidance and tips on how to manage the disease, details concerning links to other support services as well as support and reassurance;
- print materials including *The BreathWorks Plan*, fact sheets about COPD and clinic-specific items including tear sheets and checklists and;
- a website providing the same information as the print materials and electronic copies of the print items available for download.

The *BreathWorks Program* is designed to help sufferers and their families learn to better manage COPD through improved understanding of the disease, its symptoms and its treatments. The goal is straightforward. The *BreathWorks Program*, in conjunction with reinforcement

from other support systems including physicians, may lead to improved health-related quality of life for people with COPD, decreased health care utilization and decreased hospitalizations for acute exacerbations of COPD.

### Education Plays an Important Role in COPD Management

Learning that she could take control and manage her COPD transformed Ms. LeBlanc's life for the better. When Ms. LeBlanc was diagnosed with emphysema more than 20 years ago, she'd never heard of the disease. Offered no guidance by her family physician, she assumed there was nothing she could do to help herself live with the disease. As the years progressed, "I became unable to do the things I wanted to do and I worried all the time," she recalls. Not until she entered a hospital-based pulmonary rehabilitation program did she learn what she was capable of: "I can still do pretty much everything. At rehab, they taught me the details of my illness and how to do things differently. Now, I can climb stairs without becoming breathless. I couldn't do that before learning about my disease."

"Our research showed that there is currently a tremendous need to equip people with COPD with the information, access to programs and products and services that will contribute to their well being," said Alan McFarlane, Chair of The Lung Association's COPD Working Group and National *BreathWorks Program* Manager. Gaps in the services available across the country leave many Canadians ill-equipped to deal with their disease. Hospital-based pulmonary rehabilitation programs, for example, serve only 1% of the COPD population in



Canada, leaving 99% who need to find COPD education elsewhere. Ms. LeBlanc was one of the lucky individuals, living in a large urban centre, who had access to a hospital-based pulmonary rehabilitation program.

Further, the need for COPD information programs, products and services is expected to continue to grow as the baby-boom generation—many of whom were and are smokers—becomes older and reaches the age of a typical COPD patient.

### The Lung Association Plays a Vital Role in COPD Education

Founded in 1900, The Lung Association is one of Canada's most respected voluntary health organizations. The Lung Association's mission is to lead nationwide and international health initiatives in preventing lung disease, helping people manage lung disease and promoting lung health.

To address existing and future needs of the COPD population, The Lung Association created the COPD Working Group in 1998, made up of representation from the provincial Lung Associations and medical societies, for the purpose of national collaboration in regard to COPD issues, programming, resources and expertise.

## The BreathWorks Program

The Lung Association also played a vital role in the formation of the Canadian COPD Alliance (CCA) in 1998, a national forum designed to facilitate discussion, exchange of information, cooperation and collaboration among groups working in the area of COPD.

Disease management is a multidimensional philosophy of managing chronic illness that involves contributions from all health care workers, including physicians, respiratory therapists, physiotherapists and pharmacists. It empowers the patient to take an active role in supported self-management. Disease management has become a primary focus of The Lung Association's efforts regarding COPD, through both the COPD Working Group and the CCA.

"Disease management programming for other chronic diseases, including diabetes, arthritis and asthma, has shown improvement in various quality of life indicators, including health status, number of hospitalizations and number of exacerbations," said Mr. McFarlane. For years, a nihilistic attitude prevailed among health care workers and patients—nothing much could be done to help those afflicted with COPD, in part because no COPD-specific drug therapy existed and COPD was considered self-inflicted through smoking. That attitude has changed. Despite lung damage caused by COPD, a comprehensive disease management approach including patient education can result in significant improvements in the health status and quality of life of those with COPD.

For example, the COPD guidelines promulgated by the Global Initiative for Chronic Obstructive Lung Disease (GOLD), an international team of scientists working in collaboration with the National Heart, Lung and Blood Institute and the World Health Organization, state that "for patients with COPD, health education can play a role in improving skills, ability to cope with illness and health status. It is effective in accomplishing certain goals, including smoking cessation."<sup>2</sup>

### Education Alone is Not Enough

"Education only works if it empowers and stimulates people to take control of their illness and actively work on improving their health through exercising, eating right and learning how to cope with breathlessness and flare-ups, for example," said Dr. Rick Hodder, an Ottawa-based respirologist and chair of the Patient Education Section of the Canadian Thoracic Society COPD Guideline Initiative. Dr. Hodder also provided advice to The Lung Association during its development of the BreathWorks Program.

"Evidence suggests that respiratory teaching of patients can reduce not only the number of hospitalizations, but also the number of days spent in hospital," said Dr. Hodder.<sup>3</sup> "Education is key for people with COPD. Many, for example, are afraid to exercise because they fear dying from breathlessness. Education is a way for them to learn they don't need to be afraid. They simply need to learn how to do things properly.

"Education by itself is not enough, and that's why the BreathWorks Program is so important. By offering information together with support, BreathWorks will help people with COPD translate knowledge into active self-management plans," said Dr. Hodder.

Research conducted by The Lung Association suggests that receiving timely information has a significant impact on people's ability to manage their COPD. Those who receive good advice from medical personnel and others shortly after the point of diagnosis are better able to accept and come to terms with the illness, adopt an illness management program and follow a path that typically leads to higher quality of life.<sup>4</sup>

Both The Lung Association and the CCA recognize that primary care providers, including family physicians, have a pivotal role to play in educating COPD patients and families, in developing strategies for stable management and prevention of exacerbations, and in providing information about community supports and long-term encouragement. Evidence shows, however, that many general practitioners could use help providing this information. Many do not have adequate time to provide enough education, while many others do not have material available for their patients.<sup>5</sup>

BreathWorks hopes to change that situation by becoming an effective part—at the earliest stage possible—of the continuum of care of people with COPD.

The telephone helpline, which will be staffed by COPD educators, is designed to be the backbone of The BreathWorks Program. The services provided by the COPD educator who responds to a call will be tailored to the needs of the individual patient and their family members. To support the helpline, a parallel initiative, supported by The Lung Association and being led by the CCA, is the formation of a national COPD educator certification program. While in the early phase of development, it is anticipated that the project will eventually enable health care workers to become certified edu-

### The BreathWorks PRIME Plan for COPD

The Lung Association has developed a five-point preventative maintenance program for those living with COPD.

The PRIME plan is based on the following five goals:

1. Prevent the progression of COPD.
2. Relieve symptoms.
3. Improve health and ability to be physically active.
4. Manage COPD by preventing and treating flare-ups.
5. Establish a COPD team, including a doctor, COPD educator, pharmacist, family, friends and The Lung Association.

## Meeting the Needs of People Living with COPD

The Lung Association's BreathWorks Program is based upon the recognition that there are many opportunities to make a significant and profoundly positive difference in the lives of those with COPD. The COPD challenge requires action on many fronts. People with the illness need:

**Knowledge:** to understand what COPD is and its implications, to know what options and programs are available to help them, to learn that they can live more normal lives, perform everyday tasks and remain engaged members of society.

**Motivation:** to overcome the shock and fear at the time of diagnosis, to begin and persevere with a disease management program covering the three critical areas of exercise, proper medication use and coping strategies.

**Access:** to information, services, programs and products that will enhance quality of life.

**Support:** from family and friends, health/home care professionals and health services organizations that can provide accurate information, understanding and assistance.

**Confidence:** in their own abilities and in the belief that a high quality of life with COPD is both possible and attainable.

cators in helping COPD patients with all aspects of disease management.

In addition, the CCA will present its third national conference in Halifax in November 2002. The scientific agenda for "Charting the Course of COPD" is being spearheaded by Dr. Paul Hernandez, a Halifax-based respirologist, and can be accessed at [www.lung.ca/cca](http://www.lung.ca/cca).

During the pilot phase of the BreathWorks Program, from October 2002 to March 2003, physicians in Saskatchewan, Ontario and Quebec will be able to direct their patients to the BreathWorks helpline by phoning 1-866-717-COPD (2673). The helpline services offered will be evaluated and, if necessary, altered before the helpline becomes available across Canada in mid-2003. Print materials, including The BreathWorks Plan, are available across Canada by phoning toll-free: 1-888-566-LUNG (5864) or by visiting [www.lung.ca](http://www.lung.ca).

The objectives of the helpline are to provide:

1. Information and education regarding COPD and its management via the telephone and with written materials, including The BreathWorks Plan and fact sheets.

2. Guidance regarding COPD management.

3. Links to other support services and programs locally, provincially and/or nationally.

4. Caring support, reassurance and "coaching" to those with COPD and their families.

The helpline will also act as a screen and provide advice about actions that should be taken—the caller may be advised to return to his or her family physician or go to the emergency department, for example. Callers will always be referred back to their medical practitioner if calling about their current medical condition. Medical advice will not be given. Information regarding COPD, symptoms, resources and links to other resources and support will be provided.

Based on theoretical frameworks and consultation with experts in helplines, COPD educators and other experts and individuals with COPD, a protocol has been developed for helpline staff to determine how to tailor the information and support provided to callers. The protocol is flexible enough to ensure a caller's needs will be met; the protocol

will not "box in" the caller. In other words, the caller will determine the flow and direction of the call. Both the protocol and the information it will provide are based on the best available evidence for the care of COPD. ♦

## References

1. The BreathWorks program was made possible through unrestricted educational grants from Boehringer Ingelheim, GlaxoSmithKline, Pfizer, Transamerica Life and ProResp, with a contribution from Health Canada's Population Health Fund.
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