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You and COPD: An Introduction

What Is COPD?

COPD means Chronic Obstructive Pulmonary Disease. It is an umbrella name covering *pulmonary emphysema* and *chronic bronchitis*. These are both chronic lung diseases that damage the air passageways, interfering with the lungs' capacity to breathe enough air in and out. These two diseases typically occur together, although one or the other often predominates.

Other general terms for these two diseases, all of which point to their chronic nature and their interference with getting air in and out of the lungs, include: Chronic Obstructive Airway Disease (COAD); Chronic Obstructive Lung Disease (COLD); Chronic Airflow—or Airway—Obstruction (CAO); and Chronic Airflow Limitation (CAL).

How to Use This Guide

If you have picked up this book to read, you know or you suspect that you or someone close to you is suffering from emphysema or chronic bronchitis. Perhaps a doctor has told you. Or perhaps changes you've noticed—like breathlessness when walking up stairs, a heavy cough that won't go away, or a lot of mucus from your lungs that doesn't clear up—have aroused your suspicions. (If you haven't mentioned these to your doctor, take a look at the questionnaire at the end of this chapter. Your answers will indicate whether you should see your doctor.)

Before you read further, you should know what you can—and cannot—expect from this guidebook. You cannot substitute it for a doctor. But you can use it to help find the best possible medical treatment. The book gives you an accurate and complete COPD education to help you: learn how to find the right specialists to diagnose and treat you; understand your disease so you can recognize appropriate treatment; know the variety of

medical and rehabilitation techniques that will control your symptoms, improve your health, and better the quality of your life.

Why is it necessary to know all this? Successful treatment of COPD combines a broad variety of specialized techniques from pulmonary and rehabilitation specialists. Common sense alone cannot tell you what's right for you. And it's very difficult to learn it all from your doctor. It's a fact of life today that few doctors have the time or staff to educate their patients—and patients' families—in any depth. And many have little practice in translating medical jargon into normal speech.

In addition, many doctors remain unaware of the profound benefits to be gained from lung rehabilitation programs. They mistakenly assume that anyone with a disease that's eventually going to get worse can't benefit very much from rehabilitation efforts.

So patients often have to go to bat for themselves. This book gives you the tools and ammunition you'll need. It combines everything you need to know about controlling your disease and improving your life, in language you will understand.

Turning Your Life Around

Here are a few concrete examples of what COPD patients can gain from education and rehabilitation.

Rosa M. had suffered with a mix of emphysema and chronic bronchitis for years. Her family doctor prescribed medication and encouraged her to be increasingly inactive, convinced he was helping her. Whenever one of her frequent respiratory infections became life-threatening, he hospitalized her promptly and gave her the best care. Rosa gradually grew breathless more and more easily. By the time she entered the N.Y.U. Medical Centers' Pulmonary Rehabilitation program, she was a pulmonary cripple who could no longer do any of the things she loved: travel, visit museums or art galleries, attend concerts, take leisurely walks, give dinner parties. At home, she had become frustratingly dependent on her husband.

An evaluation determined that Rosa's pulmonary resources were seriously limited, but not enough to justify the crippled life she was leading. This crucial knowledge guided the rehabilitation program we designed for her.

After conditioning her muscles, learning how to breathe more effectively and how to use her energy economically, Rosa gradually resumed her favorite activities and her participation in life at home. Learning how to avoid major lung infections made hospital stays a rarity. Rosa and her husband—both no longer frightened and depressed—now live with renewed pleasure, vigor, and hope.

Harry D. entered the Pulmonary Rehabilitation program with very moderate COPD that had wrecked his life. He was a 55-year-old skilled furniture refinisher who loved his work and enjoyed the comfortable income it had provided. But the various chemicals his work required, and the dust raised by sanding, were so irritating to his lungs that—even with a protective mask—he could no longer work.

Harry sat around at home, afraid of everything that made him breathless—and angry at the world. His ego was crumbling. The emotional consequences of unemployment accompanied by the pressures of a dramatically lowered income were also destroying Harry's marriage. Harry's doctor suggested he enter the N.Y.U. Medical Centers' Pulmonary Rehabilitation program.

In addition to a program like Rosa's, Harry was also scheduled for vocational and psychological counseling, and both Harry and his wife joined a support group. Harry discovered he has excellent accounting skills, loves the work, and can do it at home if he prefers. He and his wife have achieved a positive adjustment—including satisfying sex—to the unavoidable changes COPD brings. Harry's zesty optimism has returned, his wife's basic emotional strength is flourishing, and their marriage is now responding resiliently to the challenges of his disease.

Leon L. was participating in an experimental pulmonary rehabilitation program in our laboratory. Our initial evaluation of his lungs indicated moderately severe COPD. Several months into the program he was offered a very desirable job in Kingston, Jamaica. Medically, Leon was fully capable of handling the work. Yet he was going to turn down the opportunity because he was, in his own words, "afraid to let go of my safety net." Fortunately, we finally convinced him that his fears were out of line. When he returned to New York City after three and one-half productive years in Kingston, our evaluation showed that his pulmonary status had remained stable.

(You can read Leon's story in much greater detail—and in his own words—at the end of Chapter 13: how his disease developed, how frightening and incapacitating it became, how he learned to take care of himself, and how that turned his life around.)

The Downward Spiral

These examples stand out from among the typical COPD stories because of their happy endings. Sadly, the breathlessness—technically called

dyspnea—that becomes one of COPD’s hallmark symptoms leads a great many patients to fear a wide range of jobs and satisfying, health-promoting leisure activities—exercise, outings, trips, etc.—that are still within their physical capacity.

When dyspnea first begins, it initiates a downward spiral (see Figure 1.1). Patients so fear becoming breathless that they withdraw from activities they can still pursue. Then they start to lose shape—partly from their disease, *and partly from their reduced level of physical activity!* They are “deconditioning” themselves.

What happens when your physical conditioning starts to slide? Formerly easy activities become difficult. They leave you winded. But COPD patients are convinced it is only their disease making these activities dif-

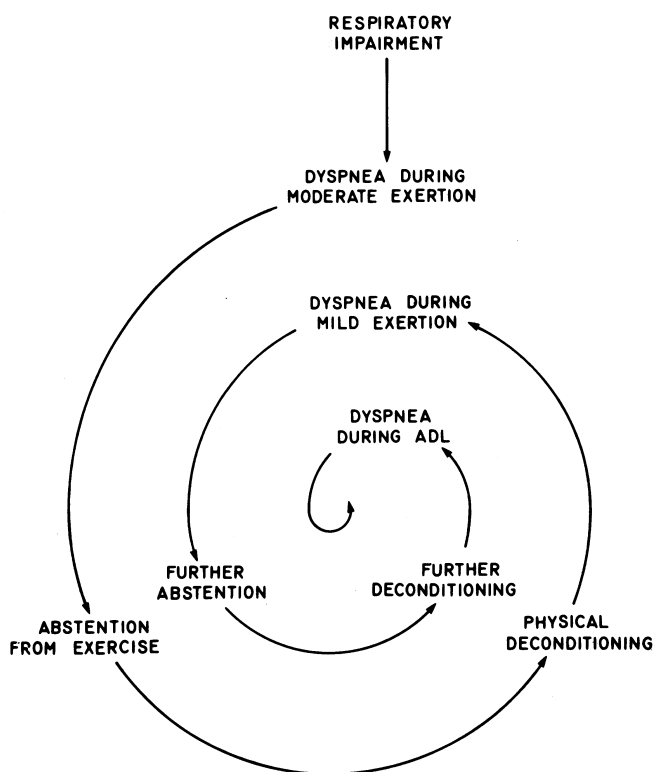


Figure 1.1 In chronic pulmonary disease, dyspnea from energetic activities can eventually result in such severe physical deconditioning that daily household and self-care tasks assume a difficulty out of proportion to what the patient’s heart and lungs are actually capable of undertaking.

ficult. Because they are terrified of feeling breathless, they drop those activities from their shrinking repertory, become more deconditioned, experience breathlessness with even lighter physical demands, give them up too, and so on. They react to everything through a filter of fatigue and anxiety. They see their lung disease as an inescapable prison, not realizing that they have helped to build it and lock themselves in.

These needless limitations prematurely turn COPD from a serious disease into a crippling one, significantly diminishing quality of life for the patient and his family. But the harm appears to go beyond emotional impoverishment. The growing view is that these needless limitations may also speed up the actual physical progress of the disease.

Minimizing the Limitations

You should clearly understand that COPD ranges from mild, perhaps unnoticed, forms to severe, debilitating conditions. Whatever the stage of your COPD when it was first diagnosed, the essential goals are the same: (1) to gain a fundamental understanding of what has happened to your lungs, and (2) to determine what can be done to minimize the consequent problems.

These goals are reached via two paths taken simultaneously. One is appropriate medical treatment, which includes far more than pulmonary evaluation and medication. It must incorporate an extensive rehabilitation program involving social, psychological, and vocational counseling as well as physical measures. The other avenue is education. You must make every attempt to educate yourself about your disease. *With proper medical intervention and education, the progression of the disease can be significantly slowed.* Although existing damage cannot be undone, some of the negative effects may be reversible.

The information in this book is specifically intended to help educate COPD patients and their families. We hope that providing solid, comprehensive, understandable information and a realistic perspective about COPD will help our readers remove needless limitations from their lives. You can live calmly and confidently—and much more fully—with your condition.

Some COPD Facts

Emphysema and Chronic Bronchitis in a Nutshell

Our airways are structured like a many-branching, upside-down tree. The trunk (our *trachea*) receives air from our mouth and nose. It divides

into the main branches entering the lungs' five lobes. With each successive branching, these airways become more numerous and narrower. Each branched pathway finally ends in a cluster of *air sacs*. This is where the oxygen in fresh air passes into our blood while carbon dioxide passes from our blood into our lungs (to be exhaled).

In *emphysema*, overstretched and torn air sacs cannot hold much fresh air and cannot fully release their stale, carbon dioxide-containing air for expiration. In *chronic bronchitis*, chronic airway inflammation leaves them permanently swollen, which narrows them. The airway irritant causing the inflammation also makes them produce great quantities of mucus—which blocks them. Both types of damage limit the amount of fresh air coming in, and stale air going out.

Doctors refer to these two related lung conditions with the same term because of outstanding similarities. They are both typically (although not always) caused by smoking. They usually appear together in the same person (although the degree of each will vary). Most of the symptoms—and their treatment—are similar. And with both diseases, decades usually intervene between the start of damage and the point at which it progresses far enough to be noticed.

The net effects of these obstructive lung diseases include a chronic cough, often with heavy mucus production. In addition, the breathing effort needed to pull air in and push it out through narrowed airways requires a great deal more energy. This is experienced as shortness of breath. Eventually, the lungs' ability to transfer oxygen into the bloodstream and remove carbon dioxide from the blood is damaged. Within this general picture, differences emerge that depend on which disease predominates. (See Chapter 3 for a more detailed look at these differences.)

How Long Have We Known About COPD?

Emphysema was the first of these two chronic lung diseases to be formally recognized. The earliest medical descriptions appeared in the late 1600s. One example is the eminent British physician of that era, Sir John Floyer, describing his examination of the lungs of a “broken-winded mare”:

In the thorax, the Lungs appear'd very much swelled or puffed up, and appear'd much bigger in the Broken-winded mare than usual. . . . I blew up some Lobes of the Lungs and found the Air would not come out again, nor the Lungs subside by themselves; by which it was plain, that the Bladders of the Lungs had been extended or broken . . . that caused a continual Inflation of the whole Lungs . . . which causes a continual Dyspnoea [breathlessness], in which the external Air can't pass freely thro' the Trachea and its Branches

in Inspiration and Expiration; and this difficulty occasions the great Labour and Nisus [physical effort] of the Respiratory Muscles.

But roughly 150 years passed before emphysema was fully described and defined. Laennec, the great French physician—and inventor of the stethoscope—achieved this in the 1820s. Anatomists of his day first pinpointed the lungs' damaged air sacs and the air that becomes trapped inside them as the typical physical evidence of emphysematous lungs. Laennec mistakenly thought that persistent cough and breathlessness recurring during the winter months—the primary symptoms of chronic bronchitis—were also due to emphysema's structural damage. Now we know that it is a separate, although related, lung disease. So although the symptoms of chronic bronchitis have been recognized as an irreversible lung disease since antiquity, an accurate understanding of the pathology underlying them is quite recent. No medical writings, however, indicate when Laennec's mistaken view was revised.

How Common Is COPD?

The frequency of chronic bronchitis and emphysema has risen so dramatically during the past 50 years that they now constitute a major health problem in industrialized countries—and the rate is still increasing. In the seventeen years from 1979 to 1996, the estimated number of Americans with chronic bronchitis and/or emphysema increased from 9.5 million to over 16 million (from roughly 4.0% to 6.0% of the country's population).

But these figures probably underestimate the actual total. It is suspected that a significant number of COPD patients do not report their condition in national health surveys.

Who Gets COPD?

Because COPD develops slowly—usually requiring 20 to 30 years of smoking before symptoms prompt a person to seek medical help—most patients are in their 60s or older. The typical COPD patient is, or has been, a long-term cigarette smoker.

Because smoking is far and away the single most important risk factor for COPD, the social pressures determining who smokes also influence who is most likely to develop COPD. One factor is sex. For many decades, smoking was far more acceptable for men. So today's COPD patients are predominantly male. But the social acceptance of women smokers that developed after World War II is beginning to erase this extreme imbalance.

The other factor is socioeconomic class, which influences how much smokers typically smoke, and how strong these cigarettes are. Blue-collar workers, for example, tend to smoke stronger cigarettes and more frequently than white-collar workers do. That explains why in England and Wales over the last 50 years, the bronchitis-related mortality rate for the lowest socioeconomic class has been six times higher than for the highest; and why in the United States, the COPD-related mortality rate among unskilled and semiskilled laborers is twice as high as among professionals.

Socioeconomic class also influences how a COPD patient does once his disease develops. Families with lower incomes can usually afford only a small—often overcrowded—house or apartment. Overcrowding makes respiratory infection more frequent, as well as encouraging a premature return to work after illness. Both situations speed up lung damage in COPD. The poorest families also tend to live in more polluted neighborhoods, providing an additional constant and inescapable respiratory irritant. And adding insult to injury—patients in this lower income bracket frequently do not have access to the best medical care.

Family Clustering In both high-risk groups, COPD tends to cluster in families. This means that the vulnerability to COPD is inherited. Heredity—the genetic element—was first considered important in COPD's development back in the 19th century. Recent research confirms that genetic factors predispose people in certain families to the development of chronic obstructive lung diseases when the causes are present.

We now know that: (1) relatives of bronchitis patients (compared to relatives of other types of patients) have a much greater likelihood of developing bronchitis; (2) siblings of bronchitis patients, compared to their husbands or wives are also more likely to have bronchitis; (3) airflow measurements are much more alike between siblings (who share genetic material) than between their parents (who do not), although they all live in the same environment; (4) identical twins (who share the same genetic material) are much more likely both to have COPD than are fraternal twins (who are like non-twin siblings in terms of shared genetic material).

But these research results only tell us that heredity usually determines who will develop COPD given the right circumstances. In most cases we don't yet know what physical differences create this predisposition.

The one clear-cut family scenario involves a known inherited enzyme deficiency. Men and women lacking enough of this enzyme are predisposed to the rapid, early development form of emphysema, which hits them in the decades before their 50s. (In this form of emphysema, the enzyme—*alpha₁-antitrypsin (AAT)* or *alpha₁-antiprotease (AAP)*—that

normally prevents loss of the lungs' elastic fibers is not produced in sufficient amount.) Yet even this inherited condition interacts with the harmful effects of smoking. In one study of COPD patients suffering from AAT deficiency, the average age at which shortness of breath was first noticed was 44 years for nonsmokers and 35 years for smokers.

Not everyone with this deficiency, however, develops COPD. Also, emphysema can occur, although rarely, in nonsmoking families with normal *alpha*₁-antitrypsin production. Obviously, other as yet unidentified hereditary factors must also increase risk for COPD.

How Serious Is COPD?

The seriousness of any disease must be gauged from the answers to three separate questions: Is it life-threatening? What is the economic impact on the family and/or society? How does it interfere with your ability to live your life as you would like? A disease can be considered serious in regard to one aspect, even though it is negligible as far as others are concerned.

Threat to Life

COPD causes 4.7% of all deaths in the United States, making it the fifth most common cause of death here. In 1997, for example, this meant that at least 110,000 deaths were caused directly by COPD and its related medical problems. That year COPD also made another 160,000 Americans too weak to survive other, unrelated medical conditions. So 270,000 COPD-related deaths in 1997 is a far more realistic figure.

From 1970 to 2000, the likelihood of COPD's, being a direct or contributing cause of death has tripled. This increasing likelihood of dying from COPD is even more pronounced for women than for men. In 1970, COPD killed 4.3 men for each woman. By 1983 this ratio had decreased dramatically to 2.4 men for each woman, reflecting the post-World War II upsurge in women smokers. By 1997 it had fallen even farther, down to 1.5.

Economic Impact

The proportion of COPD patients whose disease limits their activities is the highest of all major disease categories! Over 50% report some degree of limitation. More than one-half of this group is confined to bed at least part of the time.

In 1990, the estimated total annual economic drain produced by COPD was a staggering \$15 billion. Only a small fraction of this was spent on actual medical costs. It overwhelmingly reflects disability

payments and the premature loss of earnings. Thousands of COPD patients each year reach a degree of impairment that forces them to leave work and rely on disability payments. In 1983 and 1984 alone, more than 16,000 each year were awarded first-time disability benefits. During the 1980s, both health care costs and the number of COPD patients escalated, dramatically deepening the annual economic drain. By 1990, COPD was the cause of 16.2 million doctor's visits and 1.9 million hospital days. This translates to an estimated annual cost of \$7.6 billion spent on COPD patient care along with \$8.6 billion lost from reduced productivity due to disability and premature death.

Effect on Lifestyle

Although there are no statistics describing COPD's impact on the ways in which patients shape their professional lives and leisure time, the many anecdotal reports from patients illustrate the potentially serious impact of these diseases even in their milder states. The three COPD portraits we sketched earlier in this chapter give a sense of the destructive impact COPD typically has on the lives of patients and their families. Jobs, favorite leisure activities, and independence are forfeited. Income is suddenly limited. Close relationships are undermined. Fear, anxiety, loss of self-esteem, depression, and anger replace the anticipated satisfactions of one's later years.

Minimizing This Impact

But COPD's impact in terms of lives diminished and then lost can be substantially lessened. Even though this disease is usually quite advanced by the time patients become aware of a serious health problem, it does not have to be such a frequent killer. Patients with COPD are *not* inevitably fated to deteriorate and die from this disease.

With the kind of medical help stressed in this guide, many patients are able to slow their disease enough and cope with their symptoms so effectively that they live longer and fuller lives. Their eventual death is from an unrelated cause.

QUESTIONNAIRE

	Yes	No
1. Do you get winded more easily during exertion than you did one year ago?	<input type="checkbox"/>	<input type="checkbox"/>
2. Do you worry about your shortness of breath?	<input type="checkbox"/>	<input type="checkbox"/>
3. Have you been bothered for the past several years by a cough that takes about three months to shake?	<input type="checkbox"/>	<input type="checkbox"/>
4. Do you have roughly a three-month period each year when your lungs produce a lot of phlegm (also called "sputum" and "mucus") that you bring up?	<input type="checkbox"/>	<input type="checkbox"/>
5. If you are bringing up phlegm now, is it colored (milky white, gray, yellow, green)?	<input type="checkbox"/>	<input type="checkbox"/>
6. Do you regularly find blood in your phlegm?	<input type="checkbox"/>	<input type="checkbox"/>
7. Does your breathing sound noisy?	<input type="checkbox"/>	<input type="checkbox"/>
8. Do you snore at night and feel tired in the morning?	<input type="checkbox"/>	<input type="checkbox"/>
9. Do you need more pillows than you used to sleep comfortably?	<input type="checkbox"/>	<input type="checkbox"/>
10. Does it feel easier to breathe if you bend forward and lean on your arms?	<input type="checkbox"/>	<input type="checkbox"/>
11. Do you tend to purse your lips when you breathe out?	<input type="checkbox"/>	<input type="checkbox"/>
12. Have you recently developed a bluish tinge in your lips and/or under your fingernails?	<input type="checkbox"/>	<input type="checkbox"/>
13. Have you been smoking for about 20 years, and have never seen a doctor?	<input type="checkbox"/>	<input type="checkbox"/>
14. Do your ankles swell fairly regularly?	<input type="checkbox"/>	<input type="checkbox"/>
15. Did either of your parents die from pulmonary disease before age 60?	<input type="checkbox"/>	<input type="checkbox"/>

If you answered "Yes" to any of these questions, we suggest you see your doctor and tell him what you have been experiencing. Although in your case it may be nothing to worry about, these symptoms can indicate the presence of significant respiratory disease.