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SIX KILLERS: LUNG DISEASE

From Smoking Boom, a Major Killer of Women

By [DENISE GRADY](#)

For Jean Rommes, the crisis came five years ago, on a Monday morning when she had planned to go to work but wound up in the hospital, barely able to breathe. She was 59, the president of a small company in Iowa. Although she had [quit smoking](#) a decade earlier, 30 years of cigarettes had taken their toll.

After several days in the hospital, she was sent home tethered to an oxygen tank, with a raft of medicines and a warning: "If I didn't do something, life was going to continue to be a pretty scary experience."

Ms. Rommes has [chronic obstructive pulmonary disease](#), or C.O.P.D., a progressive illness that permanently damages the lungs and is usually caused by [smoking](#). Once thought of as an old man's disease, this disorder has become a major killer in women as well, the consequence of a smoking boom in the 1950s, '60s and '70s. The death rate in women nearly tripled from 1980 to 2000, and since 2000, more women than men have died or been hospitalized every year because of the disease.

"Women started smoking in what I call the Virginia Slims era, when they started sponsoring sporting events," said Dr. Barry J. Make, a lung specialist at National Jewish Medical and Research Center in Denver. "It's now just catching up to them."

Chronic obstructive pulmonary disease actually comprises two illnesses: one, [emphysema](#), destroys air sacs deep in the lungs; the other, [chronic bronchitis](#), causes inflammation, [congestion](#) and scarring in the airways. The disease kills 120,000 Americans a year, is the fourth leading cause of death and is expected to be third by 2020. About 12 million Americans are known to have it, including many who have long since quit smoking, and studies suggest that 12 million more cases have not been diagnosed. Half the patients are under 65. The disease has left some 900,000 working-age people too sick to work and costs \$42 billion a year in medical bills and lost productivity.

"It's the largest uncontrolled epidemic of disease in the United States today," said Dr. James Crapo, a professor at the National Jewish Medical and Research Center.

Experts consider the statistics a national disgrace. They say chronic [lung disease](#) is misdiagnosed, neglected, improperly treated and stigmatized as self-induced, with patients made to feel they barely deserve help, because they smoked. The disease is mired in a bog of misconception and prejudice, doctors say. It is commonly mistaken for [asthma](#), especially in women, and treated with the wrong drugs.

Although incurable, it is treatable, but many patients, and some doctors, mistakenly think little can be done for it. As a result, patients miss out on therapies that could help them feel better and possibly live longer. The therapies vary, but may include drugs, exercise programs, oxygen and [lung surgery](#).

Incorrectly treated, many fall needlessly into a cycle of worsening illness and [disability](#), and wind up in the emergency room over and over again with [pneumonia](#) and other exacerbations — breathing crises like the one that put Ms. Rommes in the hospital — that might have been averted.

“Patients often come to me with years of being under treated,” said Dr. Byron Thomashow, the director of the Center for Chest Disease at NewYork-Presbyterian/Columbia hospital.

Still others are overtreated for years with [steroids](#) like prednisone, which is meant for short-term use and if used too much can thin the bones, weaken muscles and raise the risk of [cataracts](#).

Adequate treatment means drugs, usually inhaled, that open the airways and quell inflammation — preventive medicines that must be used daily, not just in emergencies. It is essential to quit smoking.

Patients also need [antibiotics](#) to fight lung infections, vaccines to prevent [flu](#) and pneumonia and lessons on special breathing techniques that can help them make the most of their diminished lungs. Some need oxygen, which can help them be more active and prolong life in severe cases. Many need dietary advice: [obesity](#) can worsen symptoms, but some with advanced disease lose so much weight that their muscles begin to waste. Some people with emphysema benefit from surgery to remove diseased parts of their lungs.

Above all, patients need exercise, because [shortness of breath](#) drives many to become inactive, and they become increasingly weak, homebound, disabled and depressed. Many could benefit from therapy programs called pulmonary rehabilitation, which combine exercise with education about the disease, drugs and [nutrition](#), but the programs are not available in all parts of the country, and insurance coverage for them varies.

“I have a complicated, severe group of patients, but I will swear to you that very few wind up in [hospitals](#),” Dr. Thomashow said. “I treat aggressively. I use the medicines, I exercise all of them. You can make a difference here. This is an example of how we’re undertreating this entire disease.”

Little-Known Epidemic

Researchers say there is so little public awareness of how common and serious C.O.P.D. is that the O might as well stand for “obscure” or “overlooked.”

The disease may not be well known, but people who have it are a familiar sight. They are the ones who cannot climb half a flight of stairs without getting winded, who have a perpetual smoker’s [cough](#) or wheeze, who need oxygen to walk down the block or push a cart through the supermarket. Some grow too weak and short of breath to leave the house. [The flu](#) or even a cold can put them in the hospital. In advanced stages, the lung disease can lead to [heart failure](#).

“This is a disease where people eventually fade away because they can no longer cope with life,” said Grace Anne Dorney Koppel, who has chronic lung disease. (Ms. Dorney Koppel, a lawyer, is married to [Ted Koppel](#).) “My God, if you don’t have breath, you don’t have anything.”

Most cases, about 85 percent, are caused by smoking, and symptoms usually start after age 40, in people who have smoked a pack a day for 10 years or more. In the United States, 45 million people smoke, 21 percent of adults. Only about 20 percent of smokers develop chronic lung disease.

The illness is not the same as asthma, but some patients have asthma along with their other lung problems. Most have a combination of emphysema and chronic bronchitis. In about one-sixth of cases, emphysema is the main problem. Women are far more likely than men to develop chronic bronchitis, and are less prone to emphysema. Some studies have suggested that women's lungs are more sensitive than men's to the toxins in smoke.

Worldwide, these lung diseases kill 2.5 million people a year. An article in September in *The Lancet*, a medical journal, said that "if every smoker in the world were to stop smoking today, the rates of C.O.P.D. would probably continue to increase for the next 20 years." The reason is that although quitting slows the disease, it can develop later.

Cigarettes are the major cause worldwide, but other sources are important in developing countries, especially smoke from indoor fires that burn wood, coal, straw or dung for heating and cooking. Women and children are most likely to be exposed. Outdoor air pollution plays less of a part: it can aggravate existing disease, but is believed to cause only 1 percent of cases in rich countries and 2 percent in poorer ones. Occupational exposures in cotton mills and mines may contribute.

Researchers have differed about whether passive smoking plays a role, but a *Lancet* article in September predicted that in China, among the 240 million people who are now over 50, 1.9 million who never smoked will die from chronic lung disease — just from exposure to other people's smoke.

Many patients with lung disease have other illnesses as well, like heart disease, [acid reflux](#), [hypertension](#), high [cholesterol](#), sinus problems or [diabetes](#). Compared with other smokers, those with C.O.P.D. are more likely to develop lung [cancer](#) as well. Researchers suspect that all the ailments stem partly from the same underlying condition, widespread inflammation, a reaction by the immune system that can affect blood vessels, organs and tissues all over the body.

Lung disease can creep up insidiously, because human beings have lung power to spare. Millions of airways, with enough surface area to cover a tennis court, provide so much reserve that most people would not notice it if they lost the use of a third or even half of a lung. But all that extra capacity can hide an impending disaster.

"If it comes on gradually, the body can adjust," said Dr. Neil Schachter, a lung specialist and professor at [Mount Sinai Medical Center](#) in New York. "Some of these patients are at oxygen levels where you and I would be gasping for breath."

People adjust psychologically as well, cutting back their activities, deciding perhaps that they just do not enjoy sports anymore, that they are getting older, gaining weight or a bit out of shape. But at some point the body can no longer compensate, and denial does not work anymore.

"It's like trying to breathe through a straw," Dr. Schachter said. "It's very uncomfortable."

By then, half a lung might be ruined. On a [CT scan](#), he said, the lungs may look "moth-eaten," full of holes where tissue has been destroyed.

Often, the diagnosis is not made until the disease is advanced. Even though breathing tests are easy to perform and recommended for high-risk patients like former and current smokers, many doctors do not bother. People

who do get a diagnosis frequently are not taught how to use the inhalers that are the mainstay of treatment. Access to pulmonary rehabilitation is limited because [Medicare](#) has left coverage decisions to the states. Some programs have shut down, and there are bills in the House and Senate that would require pulmonary rehabilitation to be covered by Medicare. Medicare may also reduce coverage for home oxygen.

Meanwhile, billions are spent on treating exacerbations, episodes of severe breathing trouble that are often caused by [colds](#), flu or other respiratory infections.

A recent study of 1,600 consecutive hospitalizations for chronic lung disease in five New York hospitals found that once patients were in the hospital, their treatment was generally correct, Dr. Thomashow said. But “most upsetting,” he said, was that the majority had been incorrectly treated before going to the hospital.

For many, trying to control the disease, rather than be controlled by it, is a daily struggle. Diane Williams Hymons, 57, a social service consultant and therapist in Silver Spring, Md., has had lifelong problems with [bronchitis](#), [allergies](#) and asthma. In the last five or 10 years, her breathing difficulties have worsened, but she was told only three years ago that she had C.O.P.D. It motivated her to give up cigarettes, after smoking for more than 30 years.

“I have good days, and days that aren’t as great,” she said. “I sometimes have trouble walking up steps. I have to stop and catch my breath.”

She is “usually fine” when sitting, she said.

Her mother, also a former smoker with chronic lung disease, has been in a pulmonary rehabilitation program. Ms. Williams Hymons’s doctor has not recommended such a program for her, but she has no idea why. They have discussed surgery to remove part of her lungs, which helps some people with emphysema, but she said no decision had been made yet because it is not clear whether her main problem is emphysema or asthma. She is not sure what her prognosis is.

A Risky Approach

Ms. Williams Hymons has been taking prednisone pills for years, something both she and her doctor know is risky. But when she tries to cut back, the disease flares up. She has many side effects from the drug.

“My bone density is not looking real good,” she said. “I have cramps in my hands and feet, weight gain and [bloating](#), the [moon face](#), excess facial hair, [fat](#) deposits between my shoulder blades. Yes, I have those.”

She has broken two ribs just from coughing, probably because the prednisone has thinned her bones, she said. She went to a hospital for the [rib pain](#) last year and was given so much asthma medication to stop the coughing that it caused [abnormal heart rhythms](#). She wound up in the cardiac unit for five days, and now says “never again” to being hospitalized.

Her doctor orders regular bone density tests.

“I know he’s concerned, like I’m concerned,” Ms. Williams Hymons said, “but we can’t seem to kind of get things under control.”

A recent study of 25 primary care practices around the United States treating chronic lung disease found that most did not perform spirometry, a simple breathing test used to diagnose or monitor the disease, even when they had the equipment to do so. The test takes only a few minutes, but doctors said there was not enough time during the usual 15-minute visit. Similarly, the practices did not offer much help with smoking cessation.

The author of the study (published in August in *The American Journal of Medicine*), Pamela L. Moore, said many of the doctors felt unable to help smokers quit, and believed that as long as patients kept smoking, treatments for lung disease would be for naught. But Dr. Moore said research had found that people are more likely to quit or start cutting back if doctors recommend it.

Labeling the disease self-induced is “an unbelievably painful concept,” Dr. Thomashow said. “Patients blame themselves, their family blames them, we even have evidence that health providers blame them.”

Shame and Blame

Indeed, a patient at a clinic in Manhattan, with nasal oxygen tubing attached to equipment in a backpack, said, “This is one of the evils you must suffer for the things we did in our life.”

Smoking also contributes to heart disease, Dr. Thomashow said, and yet people “don’t waste time blaming the patient.”

“This disease quite frankly has an image problem,” said Dr. James Kiley, the director of lung research at the National Heart, Lung and Blood Institute, which started a campaign last January to educate people about the disease.

In one way or another every patient seems to have encountered what John Walsh, president of the C.O.P.D. Foundation, calls the “shame and blame” attached to this disease.

It is a familiar theme to Ms. Dorney Koppel, who agreed to become a spokeswoman for the institute’s education campaign. She was surprised to be asked to help, she said, because the campaign needed a celebrity, and she is merely married to one. She asked the person who invited her, whether there were no famous people with C.O.P.D.

“I was told, ‘None who will admit it,’” she said.

Ms. Dorney Koppel, who is candid about being a former smoker, calls the illness the Rodney Dangerfield of diseases.

“You don’t get no respect,” she said. “I have to pay publicly for my sins. I have paid.”

Like many patients, Ms. Rommes has both emphysema and chronic bronchitis, along with asthma. She had symptoms for years before receiving the correct diagnosis.

She began smoking in college during the 1960s, when she was 18. People whom she admired smoked, and it seemed cool. She smoked for 30 years.

When she quit in 1992, it was not because she thought she was ill, but because she realized that she was

organizing her day around chances to smoke. But she almost certainly was ill. She was only 50, but climbing a flight of stairs left her winded. From what she found in medical dictionaries, she began to suspect she had lung disease.

By 2000 she was so short of breath that she consulted her doctor about it.

He gave her a spirometry test. In one second, healthy adults should be able to blow out 80 percent of the total they can exhale; her score was 34 percent, which, she knows now, indicated moderate to severe lung disease.

“I honestly don’t know whether he knew,” she said of her doctor. “I suspect he did, but he didn’t call it emphysema.”

“He put me on a couple of inhalers and he called it asthma,” Ms. Rommes said. “I sort of ignored the whole thing, because the inhalers did make me feel better. I started to gain some weight, and things got progressively worse.”

She cannot help wondering now if she could have avoided becoming so desperately ill, if she had only known sooner what a dangerous illness she had.

The turning point came in February 2003 when she tried to take a shower and found that she could not breathe. The steam all but suffocated her. She managed to drive from her home in Osceola, Iowa, to her doctor’s office, struggle across the parking lot like someone climbing a mountain and collapse, gasping, onto a couch inside the clinic. Her blood oxygen was perilously low, two-thirds of normal, even when she was given oxygen. The hospital was next door, and her doctor had her admitted immediately.

Fear and Anger

She had [Type 2 diabetes](#) as well as lung disease, and her doctor told her that losing weight would help both illnesses. But she said, “He made it pretty clear that he didn’t think I would or could.”

Motivated by fear and anger, she began riding an exercise bike, walking on a treadmill, lifting weights at a gym and eating only 1,200 to 1,500 [calories](#) a day, mostly lean meat with plenty of vegetables and fruit.

“I kind of came to the conclusion that if I didn’t, I probably wasn’t going to be around,” Ms. Rommes said. “I wasn’t ready to check out. And my husband was beginning to show the signs of [Alzheimer’s disease](#). I knew that if I couldn’t continue to manage our affairs, it wasn’t going to work out.”

By December 2003, her efforts were starting to pay off. She went from needing oxygen around the clock to using it only for sleeping, and by January 2005 she no longer needed it at all. She was able to lower the doses of her inhalers and diabetes medicines. By February 2005, she had lost 100 pounds.

The daily exercise also helped her deal with the [stress](#) of her husband’s illness. He died in June.

“I had no clue that exercise would do as much for ability to breathe as it did,” she said, adding that it helped more than the drugs, which she described as “really pretty minimal.”

She is hooked on exercise now, getting up every morning at 5 a.m. to walk for 45 minutes on the treadmill. She

goes at it hard enough to break a sweat, wearing a blood oxygen monitor to make sure her level does not dip too low (if it does, she slows down or uses special breathing techniques to bring it up). She walks outdoors, as well, and three times a week, she works out with weights at a gym.

“Exercise is absolutely essential, and it’s essential to start it as soon as you know you have C.O.P.D.,” she said.

Exercise does not heal or strengthen the lungs themselves, but it improves overall fitness, which people with lung disease need desperately because their shortness of breath leads to inactivity, [muscle wasting](#) and loss of stamina.

“Both my pulmonologist and my regular doctor have made it really, really clear to me that I have not increased my lung capacity at all,” Ms. Rommes said. “But I’ve improved the mechanics. I’ve done everything I know how to do to make the lung capacity as efficient as possible. That’s the key for me; I know there are lots of people with this disease who don’t exercise, who I guess just give up.”

She realizes that she has two serious chronic diseases that could shorten her life. But it does not worry her much, she said, because she figures she is doing everything she can to take care of herself, and would rather spend her time enjoying life — work, reading, opera, traveling, children and grandchildren.

“I will tell pretty much anybody that I have emphysema,” Ms. Rommes said. “They say, ‘Did you smoke?’ I say, ‘Yes I did, for 30 years, and I quit in 1992.’ Maybe it’s why I’ve attacked this the way I did. O.K., I did it to myself, and so I better do everything I can to get out of it. We all do things in our lives that are stupid, and then you do what you can to fix it.”

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