Taking Her Breath Away





Executive Summary



Chron (COPE

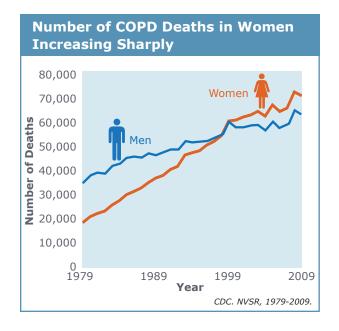
Chronic Obstructive Pulmonary Disease (COPD) is a progressive lung disease that slowly robs its sufferers of the ability to draw life-sustaining breath. It is the third leading cause of death in the United States, surpassed only by heart disease and cancer, and is not decreasing nearly as quickly as the other two. There is no known cure. Smoking is the primary cause of COPD. Because most people with COPD have a history of smoking, it was for many years thought of as a disease of older white men, who have as a group smoked at higher rates over a longer time than any other. But as gender roles and smoking behavior have changed in recent decades, so has the profile of COPD. The number of deaths among women from COPD has more than quadrupled since 1980, and since 2000 the disease has claimed the lives of more women than men in this country each year.1

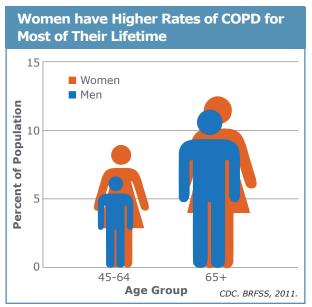
Today, more than 7 million women in the United States have COPD, and millions more have symptoms but have yet to be diagnosed.² Women have higher rates of COPD than men throughout most of their lifespan, although it appears that they are especially vulnerable before the age of 65. The profile of the "typical" woman with COPD is not that different from the "typical" man with the disease, and also looks a lot like the average smoker.

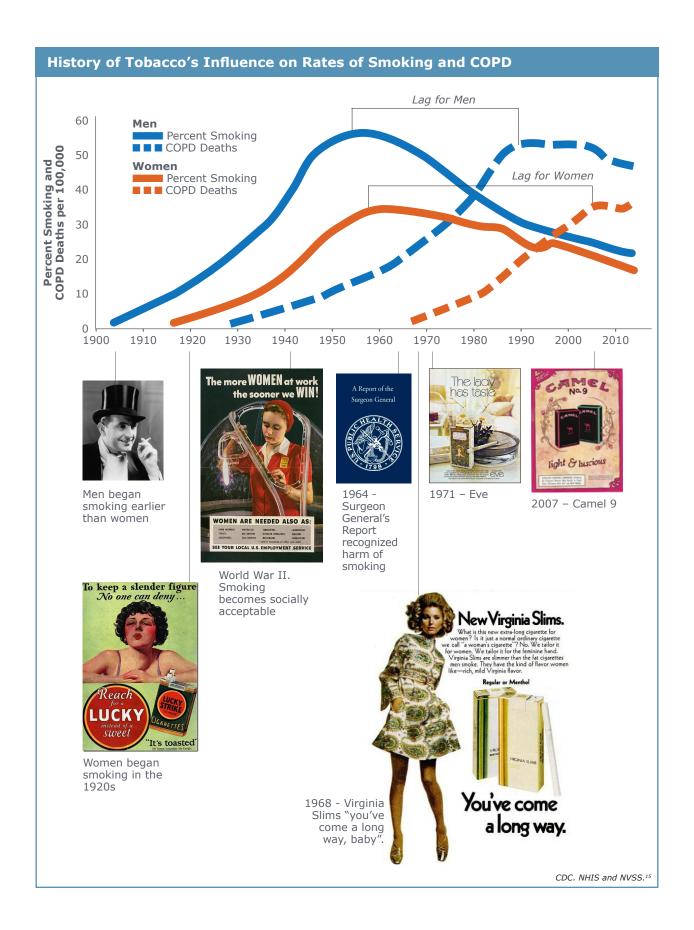
She is most likely to be white, to reside in a southeastern or Appalachian state and to have an income below the poverty level.³ A small number of people have a rare inherited form of COPD called alpha-1 antitrypsin deficiency, which occurs about equally in women and men.

Women with COPD experience the disease differently than men, in ways that increase their burden. COPD is a disease that brings with it a heavy burden on patients and families. It often means years of poor health, lost productivity and costly healthcare expenses. Women with COPD have more frequent disease flare-ups, which are a sudden worsening of COPD symptoms that are often caused by a cold or other lung infection. These bouts of illness may require urgent care or emergency department visits, and sometimes hospitalization. Each flare-up accelerates the progressive loss of breathing ability, eventually leading to long-term disability and death.

The rise of COPD in women is closely tied to the success of tobacco industry targeting. Cigarette smoking was rare among women in the early 20th century, but started increasing in the late 1920's after the brand Lucky Strike launched its "Reach for a Lucky Instead of a Sweet" campaign. In 1968, Philip







Morris introduced Virginia Slims, the first cigarette created specifically for women. With the advertising slogan "You've Come a Long Way Baby," Virginia Slims was massively appealing to women's new-found sense of liberation. By 1973, less than six years after the introduction of Virginia Slims, the rate of 12-year-old girls who had started smoking increased by 110 percent.4 Since that time, nationwide anti-tobacco campaigns and policy changes have successfully decreased smoking rates for both women and men. But sadly, the old TV ads that declared to women "you've got your own cigarette now" are still resulting in new cases of COPD and other tobacco-related illness in those women as they have aged.

Women are more vulnerable than men to lung damage from cigarette smoke and other pollutants. Female lungs and airways are smaller than men's, and have less respiratory muscle to move air in and out. As a result, cigarette smoke and other lung irritants get more concentrated when they are inhaled, and can cause more damage. The female sex hormone estrogen also plays a role in worsening the

lung damage from smoking by altering the way nicotine in the body is broken down into harmful compounds. The fact that women with COPD are 1.5 times more likely to have never smoked than men with COPD is a good indication that they are also at greater risk from other causes of the disease, such as secondhand smoke, harmful workplace exposures and outdoor air pollution.²

Women are definitely underdiagnosed and under-treated. It is tragic to hear our patients express disappointment that they suffered so long before their disease was recognized.

Chris Garvey, RN is a clinician and researcher focusing on the impact of pulmonary rehabilitation on the health and well-being of people living with COPD. She has published numerous journal articles and chapters on chronic lung disease, and serves on several professional and non-profit boards.



For women with COPD, getting a proper diagnosis can be a problem. Because COPD has long been thought of as a man's disease, many doctors still do not expect to see it in women and miss the proper diagnosis. When a woman goes to her doctor with breathing problems, they typically discuss physical symptoms and her history of exposure to risk factors. Even though the answers to these questions are valuable indicators of COPD, doctors tend to diagnose asthma due to similar symptoms. The recommended way to diagnose COPD is a breathing test known as spirometry. Unfortunately, spirometry is not widely used, especially in primary care practices. Women are also less likely to be given a spirometry test than men with the same smoking history and disease symptoms.5

Effective treatment of COPD is complicated, and women don't always get the kind of care that meets their needs. Women with COPD tend to require more interpersonal connection and social support to cope with their disease, and they are less likely than men to feel that they are getting adequate time and attention from their doctors. They are also more likely to say that they get information about COPD from sources other than their doctor.⁶ Quitting smoking has more of a positive impact on the health of COPD patients who are still smoking than any other type of treatment, and women with COPD actually benefit more than men.⁷ But women have more trouble quitting successfully and staying smoke-free. Pulmonary rehabilitation is another important program for COPD patients. It combines exercise training, self-management education, and counseling. Despite its proven effectiveness, only about 2 percent of COPD patients have access to an existing rehab program.8 Experts recommend that disease management services like smoking cessation and pulmonary rehabilitation are most likely to be effective if they are tailored to meet the specific needs and concerns of women, including social support.^{9,10}

Exercise not only lets me live, it enables me to have a life.

Patient advocate Jean R. was diagnosed with COPD in 2000 after 15 years of breathing problems. After being hospitalized with respiratory failure, she determined to turn her life around with weight loss, exercise and careful attention to her treatment plan. She feels like a new woman, and devotes some of her considerable energy to fighting for clean air and healthy lungs for all.

Many women with COPD struggle with quality of life and emotional well-being, which takes a toll on their health. The quality of life for women with COPD is impaired at an earlier age, and is worse overall than that of men with similar severity of disease. 11,12 The feeling of shortness of breath is a key contributor to poor quality of life for COPD patients, and women experience more problems with shortness of breath than men. Women with COPD also suffer from anxiety and depression at very high rates, but less than one third of patients with anxiety and depression receive adequate treatment.¹³ All this puts women with COPD at risk of being caught in a downward spiral. Poor quality of life and increased anxiety and depression make it more difficult to follow a treatment plan, quit smoking, stay active and get the social and emotional support they need. This increases the likelihood of disease flare-ups, more frequent emergency visits and significantly more relapses. Frequent symptom flare-ups in turn further decrease quality of life and hasten the progress of the disease.14





My mother would often say to me, "You don't know what it is like to not be able to breathe. You don't know how hard it is," and I was sad because I just wanted to know what I could do for her.



Lynn S. is the daughter of Marilyn K. who lost her battle with COPD in January 2013. Marilyn was born in 1925, and like many of the "modern" women of her time started smoking right after World War II. She had an active, vibrant career and family life even after she started needing supplemental oxygen in 2006. She leaves a legacy of perseverance and love of learning for many.



There is much to be done to make a difference in the health and well-being of the millions of women at risk from COPD.

It is critical that our leadership in government and health care at the national, state and local level embrace a sense of urgency and a can-do attitude about COPD. This will benefit both women and men living with COPD, as well as their loved ones and their communities, all of which are suffering from this terrible disease. The American Lung Association calls for the following action steps:

> Strengthen the public health response to COPD.

Despite being the third leading cause of death, COPD is largely overlooked by federal and state public health systems, planning and programs. The Centers for Disease Control and Prevention must create and support a comprehensive COPD program similar to what is already in place for other major public health problems. States should increase the standardized collection of COPD-related data, in order to better track disease trends and allocate resources.

Increase investment in gender-specific COPD research.

Up until the mid-1990s, little of the research on the safety and effectiveness of medications included women, and there is still much to be learned about gender differences in how COPD medications work within the body. Researchers should continue to increase the number of women in clinical trials, and analyze and report on any differences in results between men and women.

> Expand efforts to protect everyone from harmful exposures that cause COPD.

The best way to address the problem of COPD is to prevent as many cases as possible. Decision-makers at all levels must continue to enact policies that discourage youth from starting to smoke and provide proven-effective programs to help smokers who are ready to quit. Federal, state and local governments should enact and enforce laws that protect the public from secondhand smoke, and reduce harmful levels of outdoor air pollution.

Implement healthcare systems changes to improve the timeliness and quality of COPD care.

Health care providers should adopt policies and practices that improve diagnosis and treatment of COPD in women, including spirometry, screening and referral for depression, and linkage with community programs for social support.

> Break the silence.

Women's health advocates and women living with COPD must speak out about the toll that COPD is taking on their lives, and the importance of making the disease a priority. This will mean learning more about COPD and how it affects them; advocating for their own best care, including the disease management services and social support that they deserve; and becoming a voice for themselves and other women with COPD in their community.

American Lung Association Support for Managing COPD



If you or a loved one has COPD, there are steps to help cope with the lifestyle changes this disease brings. Knowing more about COPD and its treatment can help you feel more in control. For more than 40 years, the American Lung Association has offered community-based Better Breathers Clubs to patients and their caregivers who are living with chronic lung disease. These support groups meet regularly and are led by trained facilitators. Patients and their

loved ones learn ways to live better with COPD while getting support from others who share many of the same struggles.

You can also call the Lung HelpLine, a toll-free telephone service staffed by nurses, respiratory therapists and quit smoking specialists. Call 1-800-LUNGUSA (1-800-586-4872) from 8 a.m. to 12 midnight Eastern Time.



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- 15. Figure is based on NHIS or related data since 1965 and NVSS since 1981. Earlier years are estimated based on summation of multiple sources, including cigarette consumption data, age-specific cohort trends, estimates of lag times and vital statistics summaries of the United States.

For More Information

Find the full report "Taking Her Breath Away: The Rise of COPD in Women", as well as other information at www.Lung.org/copdinwomen.

About the American Lung Association

Now in its second century, the American Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease. With your generous support, the American Lung Association is "Fighting for Air" through research, education and advocacy. For more information about the American Lung Association, a holder of the Better Business Bureau Wise Giving Guide Seal, or to support the work it does, call 1-800-LUNGUSA (1-800-586-4872) or visit www.Lung.org.

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Our Mission: To save lives by improving lung health and preventing lung disease.

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