ADVENTURES OF AN OXY-PHILE

Written by:
Thomas L. Petty, M.D.
Professor of Medicine
University of Colorado Health Sciences Center
Denver, Colorado

Professor of Medicine
Rush-Presbyterian/St. Luke's Medical Center
Chicago, Illinois

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DEDICATION

This book is dedicated to the memory of the late Jo-Von Tucker. (See vignettes on pages 58 & 59. These represent her last writings.) Jo was internationally famous for her pioneering work in direct marketing. She won many awards for her unique methods and strategies.

Jo died December 17, 2003, from complications of diabetes and chronic obstructive pulmonary disease (COPD), two life-threatening illnesses that she had successfully battled for many years. Jo had just attended the First National COPD Coalition Conference in Arlington, Virginia in November. She was ill at the time, but wanted to add her voice and spiritual force to the movement to publicize COPD and get it recognized by government, Medicare, industry and payors who mostly have kept COPD on "the back burner." This was, in a sense, her last act of defiance against misinformation, inertia and simple sloth that have permeated the field for more than 50 years.

Jo wrote a book on her struggles with emphysema, "Courage and Information for Life with Chronic Obstructive Pulmonary Disease." She also wrote a book of poems entitled "Perspectives."

Jo was a "poster child" for modern ambulatory oxygen and genuinely shared the story of her life and struggle in advertisements and promotions of oxygen, which featured her engaging smile and indomitable spirit. Jo was the quintessential Oxy-Phile!

Thomas L. Petty, M.D.

PREFACE

Nearly four decades ago in 1965, we began our original scientific studies in long term home oxygen therapy. This has become known as LTOT. The true adventure begins on one snowy February day in 1965. Louise M. Nett, a nurse and now a respiratory therapist, and I (TLP) went to a dark basement where we were told to go find and fill some new oxygen equipment. This was the original Linde Walker & Reservoir prototype system that was shipped from New York to my mentor, the late Roger S. Mitchell. Roger assigned us to unpack the devices and get them to work. After reading the instructions, we carefully placed the canister upside down over the filling part of the reservoir to make a connection. A large hissing sound happened and scared us, so we backed out of the room. This was the normal sound of liquid oxygen being transferred to the ambulatory canister that could be carried by the patient. When the hissing stopped, we disconnected the walking device and pressed the start button that said 2L. We were pleased and surprised to hear oxygen flowing. We put a tubing attached to nasal prongs and breathed the oxygen for a few minutes. Later we began to plan our first pilot studies in six very hypoxemic patients, which we completed that year. We reported our preliminary results at the 8th Aspen Emphysema Conference in June 1965. Many in academia were stunned by our brazen behavior of giving oxygen to COPD cripples! We were warned by some of the senior doctors from New York that "everyone knows" it was dangerous to give oxygen to COPD patients because of the risk of severe carbon dioxide buildup. We never believed this was dangerous and already had done arterial blood gases that demonstrated that controlled low-flow oxygen not only corrected the deficit, but did *not* result in carbon dioxide buildup.

Over the years that followed, our group and others have established the scientific basis for oxygen therapy with an emphasis on ambulatory oxygen. We wrote our original articles on LTOT in the late 1960s.

In the mid 1970s we helped plan and conduct the Nocturnal Oxygen Therapy Trial (NOTT), which set the scientific basis for oxygen as it is used today in patients with oxygen deficits due to COPD and related disorders. The results of the NOTT were published in 1980 (see Appendix E). We have also been

involved in the development of new oxygen technologies from the very beginning right up to the present time. Thus, the Denver studies and more extensive multicenter trials gradually established the scientific basis for long-term oxygen therapy (LTOT). Today, LTOT is available in all modernized societies but is little used in large areas of the world. Ambulatory oxygen using modern low-weight devices is established as the standard of care.

Now following my third open-heart surgery and some complications that followed, I (TLP) am amongst the ranks of the LTOT users. Thus, I have a full perspective about oxygen, both from its scientific origins and its present day applications. In the final analysis, we are all "Oxy-Philes." That is, we literally love oxygen. In order to survive, oxygen allows for the energy possessed in all of the cells, tissues, and organs of our body. Oxygen allows us to live and pursue life to its fullest. This book is written for and by patients who have learned to adapt to the need for supplemented oxygen. I hope it will serve thousands of patients and their families, as well as other students of oxygen.

Thomas L. Petty, M.D. 2004

PRELUDE

Every cell of the body needs oxygen for high energy production. Oxygen is at the end of a complex energy electron transfer chain that allows the "wheels" of energy production to function smoothly. Thus, oxygen and the energy it produces enable the body to maintain the integrity of the cells of the body that comprise our tissues and organs. Without oxygen, these cells quickly die or, at least, are damaged until a repair process can take place. Current evidence indicates that early mild to moderate damage may be repaired by oxygen used in the home and in conjunction with exercise. A more detailed discussion of the scientific basis for LTOT is presented in Appendix D.

Humans can adapt to ascend to high altitude. Indeed, small communities can be sustained in the Peruvian Andes as high as 17,000 feet, where the oxygen saturation is about 75-80%, due to compensations. Even though a few mountain climbers have ascended to higher elevations and, indeed, have climbed Mount Everest, the highest place on earth, without oxygen, man cannot survive a sustained oxygen deficit equivalent to that found in our highest mountains. The first human being to receive oxygen in a hospital was a young man with severe bacterial pneumonia in York Hospital in 1885. Dr. George Holtzapple gave oxygen produced by chemicals similar to what Joseph Priestly, the discoverer of oxygen, had done over 100 years earlier in 1774 (see Appendix D). The young man survived. Soon after, beginning in about 1910, oxygen tents were used to treat pneumonia. The late Alvan Barach of New York invented a modern oxygen tent in 1920 (Figure 12).

Over the years, industry has developed an impressive array of new oxygen technologies. These began with high pressure compressed gas cylinders, which were the standard for hospital and home use until the early 1960s. Next came liquid portable oxygen, which is an inexpensive and practical oxygen supply for both hospital and home use. The advent of the liquid oxygen "walker" was a technological breakthrough first studied in 1965 and later more extensively evaluated by the Denver group. Later, the Nocturnal Oxygen Therapy Trial (NOTT) of the 1970s, published in 1980, created a sound scientific basis for LTOT ambulatory oxygen use being superior to stationary oxygen in these studies. This evolving research has led to evolu-

tionary changes that have improved liquid oxygen technology to the point that very practical modern ambulatory oxygen systems weighing slightly more than four pounds are now in common use.

Oxygen concentrators were introduced in the 1970s. Concentrators separate the oxygen from the nitrogen and other inert gases in the air. Today they are the most practical and efficient sources for stationary oxygen used in the home. But being homebound is not the goal of an Oxy-Phile.

Low-weight, high-pressure compressed oxygen tanks can be effectively used with ambulation and full activities of daily living, but they lack the convenience and efficiency of liquid portable systems and are not less costly if used in full activities of daily living.

A new battery-powered oxygen concentrator useful in travel and for limited portability has just been marketed. More details about oxygen, oxygen technologies, oxygen prescribing, and related matters are offered in the appendices.

This book is not just about the science and technology of oxygen; it is about the people who need oxygen and benefit from it. This book is written for all Oxy-Philes.

Thomas L. Petty, M.D. 2004

PERSONAL VIGNETTES

Vignette No. 1
EARLY EXPERIENCES AS AN OXY-PHILE

Following our original work with oxygen beginning in 1965 and our original report covered in the appendices, we became interested in certain personal side benefits of oxygen. In 1968, I first took a 9-pound "Linde Walker" on a hike up to a high mountain lake where I love to fish for trout. "How easy it was to walk at 12,000 feet," I thought to myself, having climbed these same mountains many times before with much more shortness of breath and effort than I experienced with the oxygen (Figures 1-4).

Figure 1

Figure 2

Figure 3

Figure 4

Later I took the growing Division of Pulmonary Medicine at the University Hospital on our first annual hike, which we initiated in August 1972. Figure 5 shows my outfit, which contains a liquid oxygen device, a leather bottle filled with wine, and my fishing rod and creel. It was easy to walk four miles from "The Fourth of July campground" at 7,000 feet to 12,000 feet at Dorothy Lake near the Continental Divide with the assistance of lightweight oxygen.

Later I tested out a prototype of a demand control system (oxygen conserving device), a forerunner of pulse delivery technology used in new ambulatory devices on another outing of the division as we climbed up to Diamond Lake from the same campground at nearly 11,000 feet in 1984. Figure 6 is a candid picture of a small cutthroat native trout in the foreground caught on a dry fly. (#16 Adams) Some of the fellows and faculty are seen in the background.

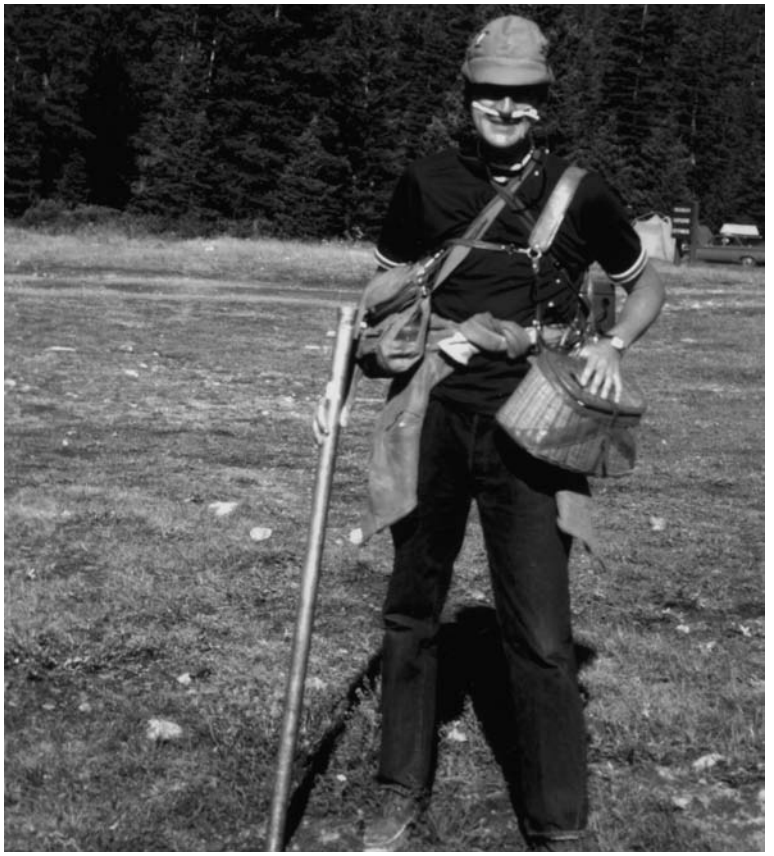

Figure 5

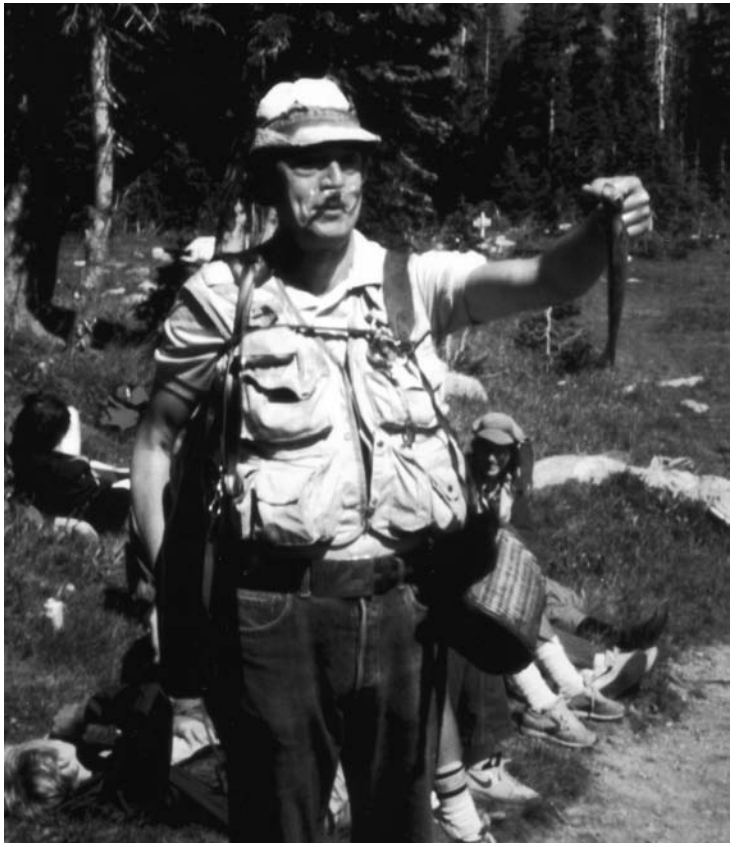

Figure 6

These early experiences gave me an inkling about what it is like to "wear oxygen" (Appendix A). I saw considerable advantages from using lightweight oxygen at the high altitudes frequently experienced in the Rocky Mountains, 9,000-14,000 feet above sea level. This modern experience in a simple way is reminiscent of how mountaineers used oxygen while attempting to climb the highest peak in the world, Mount Everest. George Mallory was seen disappearing into the clouds at approximately 28,000 feet, carrying oxygen, in 1924 in a failed struggle to reach the summit. He was never seen again. Sir Edmund Hillary and his loyal guide, Tensing, climbed Everest in 1953 with the assistance of oxygen. Subsequently, Everest has been climbed both with and without oxygen, but with great difficulty and the possibility of at least subtle degrees of brain damage (see Appendices). The human body simply cannot survive below a certain level of oxygen tension, and even moments on

top of Mount Everest with an oxygen saturation of about 45% (see Appendices) begin to take their toll.

Now that I am a regular oxygen user, because of a complex set of problems following my third open-heart surgery, and a severe reaction to dye used in CT scanning, I am looking at oxygen from the "other end of the stethoscope." Although my early research and personal experiences continue to serve me well, we need new and expanded ideas, more clinical research, and even better technologies to make greater progress.

The past nearly 40 years have provided marvelous evolution in the treatment for advanced stages of COPD and related disorders with oxygen, which is best provided by lightweight ambulatory systems, most commonly, ultra lightweight liquid oxygen containers, e.g., Helios, Spirit 300, and others.

Vignette No. 2
DO I REALLY NEED OXYGEN?

The answer is yes. Everyone needs oxygen to survive. If your oxygen level as measured by an oxygen saturation meter is less than 88% or a blood oxygen tension of less than 55 mm at rest, exercise or sleep, it is highly likely that oxygen will improve you (see Appendices). You need oxygen for energy production and for rehabilitation. Oxygen will help restore the structure and function of your critical tissues and organs. You will return to a feeling of health and adventure as you learn to explore new horizons.

If you were first prescribed oxygen following a severe illness with a hospitalization or emergency room treatment for sudden worsening of your condition, known as an exacerbation of COPD, you may not need supplemental oxygen in the long term. A sudden "setback" in the form of a pneumonia, an episode of bronchospasm, or need for surgery may *temporarily* reduce your lungs' ability to transfer oxygen from the air into the lungs. In these situations of acute illness, you should be retested by your doctor after 60-90 days. You should be tested off of oxygen for at least 20 minutes to get an accurate oxygen reading while breathing air. It is likely that your oxygen saturation is now well above 90% when resting or walking in the hallways of the office where indirect oxygen measurements are made with a simple device known as an oximeter attached to your finger.

By contrast, if oxygen was prescribed as a medical necessity because of low values while you were in a stable state, you most likely will need oxygen for your lifetime.

Many patients hate the thought of "having to wear oxygen" (Appendix A). They may equate the need for oxygen as a signal of impending death. This is the wrong idea. Oxygen prolongs life. Many of my patients have lived happily with LTOT for 10 or more years. The longest was 22 years. Appendix D answers common questions patients have about "wearing oxygen."

Vignette No. 3
WHAT WILL MY FRIENDS THINK?

Here is another adventure for all of us. Don't fear that the public will stare at you. Show off in front of your friends and impress them with what you are able to do. It is very likely that you can do more than you ever did before and, in many cases, more than your friends can do right now.

Challenge them to a walk and see how far you can go – see who gets tired first. Continue on your daily walks and be as active as possible. Show that the oxygen is no different from a crutch or wheelchair or, for that matter, any different from eyeglasses. It is a necessary compensation for a need. Many diabetics need insulin replacement to correct their blood sugar. Many patients with hormonal diseases need hormonal replacement, such as thyroid, estrogen, testosterone, etc. But what you need is supplemental oxygen to augment and enhance your life.

My guess is that your friends, like mine, will be impressed by your adjustment to the need for oxygen. You will be accepted with honor. Enjoy!

Vignette No. 4
CONSIDER IT COOL

You and I should both consider the use of oxygen as "cool." "Cool" means "groovy," "modern," "nice and easy," or whatever. The teenagers have their own definition, but it certainly is cool to be "cool," to be able to pursue life's lovely activities of daily living.

I can fish with oxygen and do almost everything else I want to do. However, I haven't ventured up to 12,000 feet in a long time. Most of my patients find it is "cool" to be able to golf, go to sporting events, the theater and restaurants. It makes their ordinary daily life possible. Yes, it is "cool."

The other way to look at cool is that it is important to keep your liquid portable canister out of high temperatures, which is a hot car or sunlight. The reason is that the technology of liquid portable oxygen is to have a well-insulated (thermos bottle) device that allows a small amount of liquid to vaporize, i.e., boil into the oxygen that you consume (breathe) at various liter flows up to five per minute. Most people only take two liters per minute during normal activities. External heat can warm the canister, causing excessive boil. Since there is a pressure pop-off in the device, which makes it possible to use the low-pressure system, high temperature creates an excessive boil-off and, thus, loss of oxygen. So you want to keep your system cool.

I like to tell the story of the grandfather who was celebrating his grandson's graduation from college as an engineer. Said Granddad, "I think the thermos bottle is the smartest device in the world!" "But, Granddad, a thermos container does not think," said John, his grandson. Grandfather replied, "Look, Johnny, you put cold stuff in it and it stays cold; or if you put hot stuff in it, it stays hot. How does it know?"

"Common sense is not common." — Voltaire.

Vignette No. 5
GETTING HOOKED

A lot of my patients ask me, "What if I get hooked on oxygen?" My answer is, "Good." This means you are "living." I don't mean to be facetious here, but oxygen is required for the sustenance of life; and not only does it maintain the integrity of cell tissues and organs, but it provides the machinery for the generation of energy for exercise in the pursuit of life's daily activities. Thus, we are all hooked on oxygen. Some of us need supplemental LTOT.

But oxygen does not come in a pill or capsule. It requires a device that contains or produces oxygen. This is where oxygen tubing comes in.

The other issue about getting hooked is the following axiom.

If your oxygen tubing can possibly hook on something, "it always will." This might well be added to Parkinson's Laws. Thus, you should think about the extra tubing you have hanging around your waist, and put the excess in your pocket. The tubing might tangle around a doorknob or steering wheel or the shift indicator, without your realizing it. Watch out for banisters, coat hangers, or anything that juts out from a flat surface. You will be surprised at how many things can get you hooked. They seem to jump out at you! If you use oxygen while dressing, it will definitely hook on your clothes. Take off your oxygen tubing while dressing unless you are very short of breath. Thus, you are hooked on oxygen all right; but don't hook up in your tubing. It tends to destroy the bliss of the moment!

Vignette No. 6:
EFFICIENCY TRAINING

One of the things that most oxygen users do, and I also have learned, is to become more efficient. The modern lightweight liquid ambulatory devices contain on average an eight-hour supply with a demand system used at two liters per minute. That is great, but there are situations where you will want to conserve the amount of oxygen that you use. Also, there are ways to stretch your oxygen supply, if you know that your needs such as sitting, visiting, or working in the office are less than the average two liters. You can monitor this yourself with an oximeter (see Vignette No. 7).

It is important to plan ahead and consider what tasks you want to do and in *which order*. Consider the increased effort of multiple tasks. Around the home or office, most patients with COPD and related disorders who require oxygen simply don't want to waste energy "running back and forth." It is important to plan each task in its logical order to try to save extra steps. On the other hand, all activity is energy producing and, thus, in essence a good thing; but it is still better to become an efficiency expert. It may be a new discipline for you, but it will pay dividends!

Vignette No. 7
YOUR OXIMETER WILL KEEP 'EM HONEST

By "'em," I mean both you and them. An oximeter is a simple device that attaches to the fingertip to reflect the amount of blood containing oxygen, compared with the oxygen capacity of the blood. Expressed in a percentage known as saturation, oxygen saturation does not relate directly to oxygen tension, which is the partial pressure of oxygen in the blood. There is an S-shaped relationship between tension and saturation (see Appendix D).

We all need oxygen with a saturation of greater than 88%, because 88% is on the "steep part" of the oxygen-hemoglobin dissociation curve. This means that more tension means more oxygen. This means more oxygen saturation, and saturation means a greater amount of oxygen. By contrast, if you are on the flat part, i.e., over 90% saturated, adding more oxygen increases the pressure (tension) of oxygen in the blood but does not add much saturation (amount). (Amount relates to saturation – see Appendix D.)

So here's where the oximeter comes in. You can check yourself and see if your liter flow is adequate. If you are on a pulse-control flow system, see if the doctor's liter flow prescription is still correct under your normal living conditions at home. You should try to maintain an oxygen saturation of 88-90% or higher under all conditions if possible. Also, in the event of a "virus cold" that settles in your chest and you experience worsening shortness of breath with or without increased sputum, known as an "exacerbation of chronic bronchitis." you can check your oxygen to see whether the prescribed amount is still correct or maybe not enough. This may be the first indication that medications are needed, such as antibiotics and corticosteroids. Thus, knowledge of a falling saturation can keep both you and your doctor honest. You can go see him, and you have your own oximeter. The oximeter is a good investment and costs approximately $400. Spread over a lifetime, this is a great investment.

Vignette No. 8
ADVENTURES IN OXYGEN EXPERIMENTS IN THE HOME

You can do some interesting experiments with oxygen at home. Oxygen flows into your nose and is inhaled down into your lungs to the alveoli, where it is picked up by red hemoglobin (red blood cells) and carried by circulation controlled by the output of your heart (cardiac output) to the tissues, where it provides for energy production. The body does not store oxygen, but some oxygen remains in your lungs at the end of a normal breath, known as functional residual capacity (FRC) or the residual volume (RV), which is below the functional residual capacity. The residual volume is the air that you *can't blow* out of your lungs no matter how hard you try. The vital capacity is the air that you *can blow* out (called the forced vital capacity). The sum of the vital capacity and the residual volume is the total lung capacity (TLC). The forced vital capacity (FVC) and the forced expiratory volume in one second (FEV_1) are measured by spirometry. These two numbers are of great importance to you and your doctor in assessing responses to therapy and the progress of the disease. The FRC, RV and TLC are not measured by spirometry but are easily measured in a pulmonary function laboratory in the clinic or hospital's respiratory care department.

This background is necessary to be able to understand about the residual volume in that it tends to increase in COPD (it gets smaller in restrictive lung diseases). With COPD the normal residual volume of less than two liters often increases to five or six liters, or even more in rare instances. Thus, the residual volume becomes a small reservoir for oxygen.

Now do the following experiment. Adjust your oxygen flow so that you are fully saturated (i.e., above approximately 95%). Then turn off your oxygen and notice, with your watch, how long it takes for your oximeter reading to fall below 88% while you are just breathing air (normal is seven minutes or less). This may take 15 or 20 minutes due to the reservoir function of the expanded residual volume. Now you know that checking a "blood gas" or a saturation of oxygen in the doctor's office, when the oxygen is only off for five or 10 minutes, will be inaccurate. This will keep the doctors and technologists honest. It

often takes 20 minutes or more to washout, i.e., to consume or washout the oxygen in the residual volume.

Now do a second experiment. Take a full breath with oxygen running in the nose and hold it for about 15 seconds or longer. Now turn off the oxygen and notice the time to reach the low point in your oxygen saturation while breathing air. What you have done is add additional oxygen, filling the vital capacity; but, of course, it isn't completely full of 100% oxygen since the oxygen you are inhaling is a mixture of atmospheric oxygen (i.e., 21% oxygen) and that supplemented by LTOT. The fraction of supplemental oxygen that is inhaled into the lungs in most situations is low, i.e., on the order of 24-30% going into the mouth and airways.

These two experiments will teach you (and probably your doctor) a lot about oxygen "storage" and wash-out time to reach an oxygen saturation below 88%. Remember the 88% is not dangerous because many populations of people, such as in Leadville, Colorado, live in an atmosphere of 10,000 feet where 85-88% is normal. But these people tend to get more strain on the heart and more pulmonary hypertension.

Now do still another experiment. Let your oxygen level stabilize at its low point – whatever it is – 75%, 80%, and 85%. It won't hurt you at all to be at low levels for a few minutes. Then try pursed-lip breathing, i.e., inhaling slowly and then slowly expelling against pursed lips as in whistling. Watch your oxygen saturation rise on your oximeter during pursed-lip breathing. This will help give you a feeling of confidence if you run out of oxygen sometime and need to rely upon pursed-lip breathing. It is amazing how high people can bring their oxygen saturation level with this simple maneuver. You can probably think of some other experiments to do with your oximeter. You can become an expert in oxygen dynamics!

Vignette No. 9
BUBBLERS

It is common for oxygen suppliers to attach a water-filled device to the flow meter of the controls for the delivery of oxygen. This is called a "humidifier." This is a common misconception. Essentially no water is added to the tubing, as anyone with "common sense" can clearly tell. There is no precipitation of water in the hose under most circumstances. The bubbling device, however, is reassuring because it shows the patient that the oxygen is running. Many suppliers say, "My patients like the bubbles."

In fact, most bubbling devices get contaminated with bacteria, fungi, and molds. It is not good to be inhaling this stuff. There is absolutely no need for bubblers under ordinary conditions. Just hook the tubing directly onto the flow meter, and it will be delivered to your nasal cannula or transtracheal system (see Oxygen Cosmetics). How will you know that the oxygen is flowing? Taste it in the cannula about one-quarter inch in front of your tongue. You will feel the cool flow and it tastes salty because it stimulates the salt taste buds on the tongue. This will tell you that the oxygen is flowing, because your tongue is very sensitive to the "taste" of oxygen. You can even detect as low as 0.12 liters per minute, which is used in pediatric practice. Mothers can quickly learn to do this; and it beats the complexity, weight, and nonsense of the bubbler.

Vignette No. 10
OXYGEN COSMETICS & CONVENIENCES

The commonly used double nasal prongs, draped over the ears, are now recognized by many as a common way to deliver oxygen. This is because over one million people with COPD and related disorders take oxygen every day, and many go out in public by virtue of the availability of modern ambulatory oxygen. But there are ways to "spruce up" the appearance of the cannula.

Years ago, we did scientific studies that proved that the flow of oxygen into one nostril is equal to flowing it into both nostrils. We proposed attaching the cannula to ordinary eyeglasses. Now this has been done commercially, and it provides a very attractive device known as the Oxy-View (Figures 7a and 7b) and this can be used with any system.

Figure 7a

Figure 7b

The Helios or equivalent systems employ double delivery tubing. One tube is called a "J" tube because of its shape. It fits comfortably in one of the nasal passages. One tube is for sensing the need for flow and the other for the oxygen flow

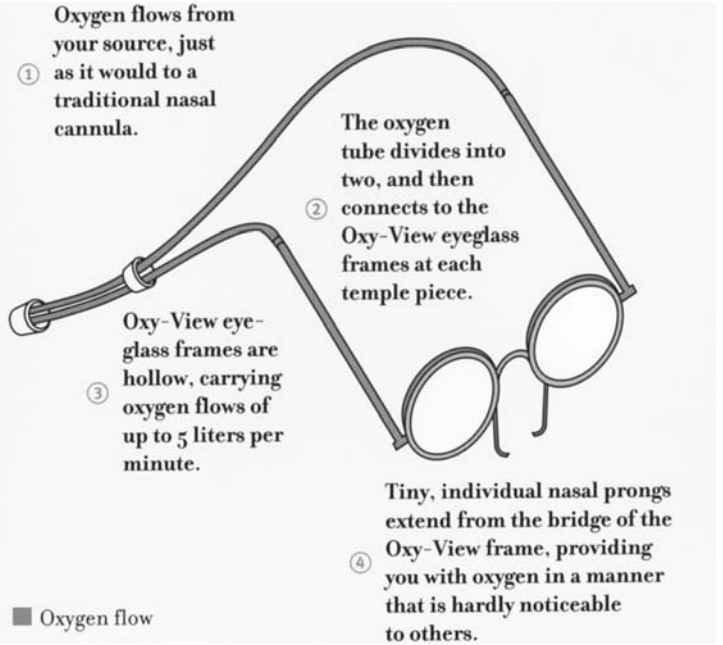

Figure 8a

itself. With the Helios, fuel oxygen flows into only one nostril. This actually has an advantage in the case of inside nasal congestion, a nosebleed, etc. All you have to do is switch the tubing and it flows into the other nostril. It is a trick that not many people know. The Spirit 300 flows oxygen into both nostrils because it uses a battery-powered demand system.

But you can't wear your glasses to bed, so we have designed "Oxy-Snooze" (Figures 8a and 8b). These come in two models. One is a headband that allows the J tube cannula to easily reach the nostrils. The other one, like eyeshades used on airplanes, also is equipped with a Velcro-controlled peep-

Figure 8b

hole to be able to see. Both are comfortable and good for oxygen delivery. I like the Oxy-Snooze eyeshade for daytime nap and the Oxy-Snooze headband for sleeping (available from Transtracheal Systems, Englewood CO, phone: 303 790 4766).

Reservoir nasal cannula are available from the oxygen concentrator manufacturer, CHAD Therapeutics of Chatsworth, California.

Another cosmetically pleasing way of delivering oxygen is by the transtracheal route. This is oxygen delivered directly into the windpipe, as shown in Figures 9-10. This has the advantage of total concealment of oxygen, if the patient desires. Of greater importance, however, is that the oxygen flow can be reduced by approximately 50%. In addition to the oxygen flowing directly into the windpipe, it provides some assistance to all this work of breathing. Thus, some patients experience remarkable relief from shortness of breath with oxygen delivered by transtracheal oxygen (TTO). TTO is required in very high-flow users, such as in the scarring diseases (fibrosis) of the lung. Nasal prongs can become pretty inefficient above four or five liters per minute. Four or five liters, or even more, delivered by TTO can be much more efficient and comfortable.

TTO is not just a cosmetic technique but also one with some interesting physiology behind it. TTO is also useful in helping to wean patients from mechanical ventilation. But

Figure 9

Figure 10

this goes a little far afield from this book. On the other hand, on recovery from an attack of acute respiratory failure requiring mechanical ventilation, TTO may be a "bridge" to being discharged home. Being home beats being in any hospital, in my mind and in the opinion of most of my patients. But we should return to the adventures of the Oxy-Phile, with a variety of different systems.

Vignette No. 11
UP IN SMOKE?

Believe it or not, a number of people who need oxygen still smoke cigarettes! To be honest, this is dangerous only if the nasal cannula are in place during smoking. Actually it takes the direct ignition of the plastic tubing to cause a fire. But horrible facial burns have happened. Some patients do continue to smoke because that is why most of them got to this stage of advanced COPD where oxygen was needed. My attitude as a physician has never been one of punishment. I know that patients with COPD can have a high level of anxiety, depression, and somatic symptoms that are unpleasant. They depend on nicotine in cigarettes and other tobacco products to be able to deal with depression and anxiety, as well as some strange feelings that occur in their body. Since smoking will continue to damage the lungs at a much faster rate than normal, smoking should stop in everyone, particularly in those who need oxygen.

It is silly, if not absurd, to have signs posted outside the home or in the workplace: "No Smoking – Oxygen in Use." Oxygen will not explode. It will only support combustion. It is safe to have a fireplace if you are not sitting next to it because of sparks. Thus, the only way to make things "go up in smoke" is to directly ignite the oxygen source. Nobody should be that stupid.

Vignette No. 12
COLLATERAL ADVANTAGES

Additional and unexpected advantages of being an Oxy-Phile should be recognized. For one thing, you can get a disabled parking sign, which gives you access to all of those large marked empty spaces reserved for the disabled. Certainly there are too many of these in some places, but not when you need one. Disabled signs come in handy when you really need them. You will then join the 8.5 million ambulatory disabled, but you won't have a cane or wheelchair to show for it.

Another advantage is that no one can (should) smoke in your presence. Obviously, this is a great advantage because by this time you are sick of cigarette smoking. Since the public is still somewhat frightened about oxygen explosions and fires, which won't happen unless the tubing is directly ignited, they will want to keep their distance.

Finally, you can have fun with kids when you are sitting in the park, enjoying the sunshine. When they come up and ask you what is that machine and what's in your nose, simply say that you are an alien from Mars and this is the way you get your food. They will giggle, laugh, and question you to no end. You can laugh, too – keep your sense of humor.

As in all of life, consider that every situation offers advantages. Consider the advantages of being an Oxy-Phile. We all are, of course!

Vignette No. 13
SEXUALITY

Hopefully, you will continue to explore sexuality as an adventure. Indeed, it is a most powerful expression and a key aspect of the human spirit. Oxygen will reduce your shortness of breath during playing and love-making. It doesn't replace hormonal function or mental desire. Remember that 80% of sexual functioning exists between your ears. The other 20% is between your legs. The oxygen, of course, will improve brain function and general health; and this, in turn, may lead to more interest in sex and better sexual function. Don't be afraid to explore new positions and better ways to be close with the person that you love so dearly.

One reason why patients with COPD have sexual problems is because they get out of breath easily. If both the patient and their sexual partner practice slower sex, they are more likely to enjoy their time together. The patient must also accept partial rather than complete sexual satisfaction with some sexual activities. Sexual activity, particularly for men, can be too hurried and feverish.

Orgasm causes faster breathing and faster heartbeats. Sex for COPD patients is more satisfying when it is done slowly, more deliberately, and leisurely. With thoughtful preparation and planning, satisfactory sex can be achieved, even for patients with serious lung disease. Some ideas on how to change behaviors leading up to and during sex include:

Desire and anticipate: Patients with long-term disease often need to begin preparing for sex an hour or two before it actually happens. When a desire for sex with a willing partner is noticed, take care of personal hygiene. Shower, shave, brush your teeth, and use the toilet. Try to plan a time and place where the encounter will not be interrupted for an hour or more.

Prepare and perform: Be rested. Take your bronchodilator medicine regularly. Be sure you take all recommended lung medicines before sex. Don't have sex after a large meal or at the end of a tiring day. Do have sex at home or where you feel most secure and confident. If you are strongest in the morning or early afternoon, that's the time for sex. Try different and more comfortable positions. One position for intercourse that often works well for individuals with COPD is with the woman

on her back with legs across the man's buttocks. The man lies on his side at a right angle to her. Both partners can maintain the position with little energy. Successful intercourse can happen without a full erection. For the patient with severe shortness of breath, taking a small dose of a relaxer (tranquilizer) or opiate drug before sexual activity begins may be helpful to lessen the sensation of shortness of breath.

Vignette No. 14
CARBON DIOXIDE: FRIEND OR FOE?

Carbon dioxide (CO_2) is known as the waste gas of metabolism (energy production). But some patients and even many physicians consider it a poison. Nothing could be further from the truth. A normal amount of carbon dioxide is necessary to create a balanced acid-base environment in the blood and lung (see Appendices). This is slightly on the alkaline side, due to the production of bicarbonate presence (like sodium bicarbonate) of the kidney. In fact, carbon dioxide is necessary to produce a bicarbonate. The level of carbon dioxide and bicarbonate is carefully balanced by the respiratory system, which controls the rate and depth of breathing, and the kidneys, which control the bicarbonate. Normal carbon dioxide pressure's tensions are 38 at higher altitudes and up to 44 at sea level.

Unfortunately, quite a few physicians believe or fear that oxygen use will cause the retention of carbon dioxide. This is generally not true. There is a complex physiology behind carbon dioxide buildup, which is far more complex that just the taking of oxygen. It has to do with how the lungs handle oxygen, and how they adjust air flow and blood flow.

The majority of patients use only a little supplementary oxygen just to correct the oxygen deficiency state, i.e., a saturation of above 90% but not greater than 96% will have no bearing on carbon dioxide level.

It is a fact that in late stages of disease, there is a gradual buildup of carbon dioxide. This is due to the wisdom of the body. The body will trade off higher CO_2 for less work of breathing. Thus, if it is a normal CO_2 of 40 (on average, at low altitudes goes to 80), each breath contains twice as much carbon dioxide. The kidneys compensate by generating an appropriate amount of bicarbonate; and, thus, the balance between carbon dioxide and bicarbonate is much like a scale that maintains a normal acidity/alkaline level. If carbon dioxide is higher than 80, it can still be compensated by the kidneys. This, of course, is only made possible with the use of oxygen.

One should never consider carbon dioxide a poison. After all, it is, in essence, the source of life. When carbon dioxide first became assimilated by evolving organic protein molecules in the sea, photosynthesis and oxygen production became possi-

ble. It is the source of the oxygen we breathe and the source of life for all air-breathing plants and animals.

Vignette No. 15
RECREATION WITH OXYGEN

Lightweight ambulatory oxygen allows for the pursuit of most previously enjoyed recreational activities. It is easy to take a portable system to the ballgame, a play, or a restaurant. You can conceal this fashionably, if you wish (see Oxygen Cosmetics). It is not necessary for most. You can garden with ease. You need a backpack or side pack in order to have both hands free.

You can golf without any impediment. You can go fishing. The oxygen that you carry will fit in your fishing creel, if you wish. But a backpack is better. You might want to take a few small "brookies" home for dinner.

The availability of truly ambulatory systems weighing four pounds or less has expanded the horizons of the Oxy-Phile immensely. But the use of ambulatory oxygen is more than just the pleasure of enjoying life to its fullest. By increasing the activities of living and increasing blood flow and cardiac output, more energy can be produced at the tissue level. We believe that this leads to restoration of organ system functioning. This is currently a matter of intense study, which I will participate in as a devout Oxy-Phile.

Vignette No. 16
ADVENTURES IN SLEEPING

Sleep is an adventure for some. Many have trouble falling asleep and others awaken startled. Sometimes, waking with a start is a sign of oxygen deficit. This is particularly true with people who have so-called sleep apnea, where there is actually obstruction of breathing during the act of sleep.

Patients with COPD tend to breathe at a more shallow level during sleep; and accordingly, they need more oxygen. Very commonly people need even more oxygen during sleep than their prescription at rest. We discovered this in the Nocturnal Oxygen Therapy Trial (NOTT).

Comfortable oxygen delivery systems such as the Oxy-Snooze options make sleeping with oxygen more comfortable. You will learn to manage the tubing in bed, and it won't be a problem. Enjoy your sleep because it refreshes. The energy being produced while you sleep with oxygen will make you feel vigorous on the next day. Get out and get moving!

At the end of life we will all approach our "eternal sleep." As the lungs finally fail, a gradual increase of CO_2, well above 100 or more, will occur. This is a very pleasant and narcotizing experience as many patients have told me after wakening from a "long sleep" of sometimes 24 hours or more. In these situations, the body awakens because the naturally occurring narcotics of the brain are released. Oxygen and carbon dioxide are also smooth muscle relaxants, and this may dilate arteries and airways. This leads to improved breathing. Now the patient feels euphoric and has a détente with death. Many such patients have lived several months or up to one year following a "long sleep." Life ends in what I prefer to call the "eternal sleep."

Vignette No. 17
ADVENTURES IN TRAVEL

"You can take it with you!" Oxygen, that is. It is a fact that modern portable and ambulatory systems can be effectively used when traveling. Things are improving immensely.

It has always been possible to take your oxygen tank, whatever its size, in your car. In the old days, even large K-cylinders were put in the back seat of cars by some of my patients in the 1960s and early 1970s. E tanks also work well in cars; but they are heavy and cumbersome. Their range (hours of use) is also short, i.e., four to six hours, and even with a conserving device is limited. I personally have very little use for E cylinders other than for emergency backup.

Liquid portable systems are fine for travel in cars; but, of course, you need to have a filling source (reservoir). A home reservoir is too heavy to put in most cars or even vans. Industry is now making lighter-weight portable liquid-filling systems that are suitable for automobile travel (e.g., Liberator 10 – CAIRE), and the systems that you carry your ambulatory oxygen in (e.g., Helios or Spirit 300) are excellent devices. When used conservatively, selecting the lowest possible flow based upon oximeter measurements or experience, Helios will last up to 10 hours between refills. This certainly handles a day's travel. But, of course, there is need for refill. At least one company, Apria, will arrange for delivery of the stationary liquid filling system to your hotel in most major cities. You can also get refills of your Liberator 10 at any Apria, CAIRE, or Lincare company as well as smaller independents listed in the Yellow Pages of your city of destination. This has worked well for me in recent months.

You can't take your oxygen system on airlines, and therefore, air travel is a real hassle. Oxygen needs to be prescribed by your physician, usually 48 to 72 hours in advance. The patient can take the ambulatory system right up to the gate, but then must leave it. Many large airports, such as Denver's, simply have a collecting system to return the ambulatory canister to the supplier. Oxygen is supplied by the airlines during flight. Unfortunately, few cabin attendants and almost no airlines understand much about oxygen. You pay a supplemental fee of approximately $100 for each leg of the journey. And, it is a nuisance if you have to wait between flights and need oxygen at all times.

Then, of course, you need to be met by someone with an oxygen system. All of this is very cumbersome and expensive, to say the least.

A new portable oxygen concentrator has just been marketed, which weighs 9.75 pounds. This device is used by a demand-inspiratory control system. It can be powered by either the 12v battery in your car directly into the power outlet or old-fashioned cigarette lighter assembly. It does not require special wiring. It is both internally and externally powered. The internal battery lasts about 45-50 minutes. But the battery is charging whenever external power is used. This can be 120v AC or 12v DC. There are even conversion units for use in Europe.

Considering the weight of 9.75 pounds, the concentrator can be used under almost all circumstances. It has effective output up to 10,000 feet, according to my own observations. It is relatively quiet and fits snugly in the car. It can be used wherever you go, including at night. It is probably not robust enough to be the only oxygen system you ever need, because of the light weight and maintenance needs of approximately every 3,000 hours of use. Today the device is marketed through dealers and must be purchased by the customer. Medicare and most insurance companies will not pay for two different oxygen systems.

One great drawback is an obnoxious alarm that sounds if the patient fails to take in a regular breath. This is a huge limitation in the case of mouth breathers.

One of the great advantages of the portable concentrator system is that it is *highly likely* that it will soon be approved for air travel. Since the oxygen concentrator carries no oxygen and only produces it from the cabin atmosphere, and since it has electronics no more complex than a computer, it poses absolutely no hazard. The portable concentrator is great on buses and trains. Recently, the FAA has finally agreed to something that is suitable and convenient for air travelers. The Department of Transportation now needs to give its "okay" that you can take your "medical device" onboard and receive your necessary supplementary oxygen during flight. A new battery pack will last up to four hours. Many airplanes are being equipped with 12 volt outlets so that you can use external power with your portable concentrator. At last the FAA may finally agree to something that is suitable and convenient for air travelers.

Great progress has been made in our ability to travel with oxygen. Yes, you can take it with you!

One more thing. Take some emergency supplies with you. The "nipple" that threads to the oxygen outlet may not be on the liquid reservoir that is delivered to your room. Also take at least two plastic connectors to splice your nasal cannula tubing to a 50 foot tube. Better also bring along another 50 foot tube and a spare cannula. By being prepared, you will avoid surprises! Bon voyage, everyone!

Vignette No. 18
TRAVELING IN STYLE

It has been wisely said that there are advantages to every situation. This is hard to believe when the situation includes a significant illness, which is always a setback to one's peace of mind and personal bliss. This is my lot these days, since I suffered some complications following recent heart surgery. In plain language, I just don't have the exercise capacity that I had before; and, in fact, I am now receiving continuous oxygen therapy. How ironic, since it is just 39 years since we started our original studies on ambulatory oxygen and the development of new oxygen technologies.

However, there *are* advantages. On a recent occasion when I needed to go to Vermont and later to Vancouver and Boise to participate in important conferences, I asked for a wheelchair in the airport. I had only done this one time before in Japan when, with severe sciatic pain, I needed assistance to get through Narita International Airport, which is a jungle in case you have not been there. Denver International Airport (DIA) isn't quite a jungle, but it is at least a large zoo and often has the longest wait lines in the country. So I let them wheel me through security, which had a short line and gave a thorough, but much quicker, search than if I had been in a queue that was estimated to be 50 minutes for those without any physiological impairment. My compensation for all of this was the feeling of "traveling in style." Here I was whisked to the trains that connect the concourses, delivered to my gate, and boarded first. There have to be some advantages to adversity, and the important thing is to find these and enjoy.

Vignette No. 19
ADVENTURES IN NEW OXYGEN RESEARCH

Even though we began our research in ambulatory oxygen in 1965, and have done extensive studies since, along with others, we really *don't even know exactly how oxygen works*! This seems like an astonishing statement considering all of the time that has passed and the energy that has been put into research.

There is no doubt that oxygen increases the length and quality of life. It increases exercise tolerance, stimulates appetite, restores muscle function and, in fact, probably has a restorative effect on all organs of the body such as the brain, heart, and lungs. Exactly what this mechanism is, is not well understood.

A simple explanation is that oxygen is required for the maintenance of all cell structures and organ system functions. Thus, organs and cells may be "stunned" due to lack of oxygen. Cells and tissues may "hibernate" until oxygen is restored; and thus, energy supply can be recovered.

The mechanism for how oxygen works may be even more complicated. It is known that there are genes that stimulate abnormal blood vessel responses in the lungs at high altitude. These are the "hypoxia genes." How these may be turned on in disease or an exposure to altitude and regulated or turned off with oxygen is a fascinating question. Much more research is needed at both the cellular and clinical levels.

I have long advocated for an extensive study comparing the outcome of patients using a truly ambulatory modern system compared with the more conventional stationary systems, which most commonly are a concentrator used alone or with a very cumbersome and inconvenient high-pressure compressed gas supply such as an E cylinder on wheels. This system, though technically portable or "schlepable" does not encourage ambulation and activity. Much smaller M6 cylinders are of equally light weight but do not offer the same duration of ambulatory oxygen supply during the day. The M6 cylinders are needed for full daily activities away from home. Lightweight liquid systems, e.g., Helios, Spirit 300, and others that allow for full activities of daily living, are far superior, not only from the standpoint of convenience and duration of supply, but because of important biological reasons yet to be further unraveled. It requires nearly continuous ambulatory oxygen to gain maxi-

mum benefit from oxygen used in full activities of daily living.

In the meantime, I believe it is wise for physicians to prescribe ambulatory oxygen earlier in the course of disease than they now do. By preventing the ravages of tissue breakdown through a shortage of oxygen, restoration or maintenance of organ systems may be sustained in the interests of good health.

It has been a real adventure studying oxygen for the past 39 years and now I am benefiting from it. I am, indeed, an Oxy-Phile.

Vignette No. 20
REMEMBER TO LIVE

This should probably be the first vignette of this little book. But, unfortunately, a lot of people wait until late in life to really begin to enjoy it. I still have the haunting memory of a woman who asked me some time ago, "Dr. Petty, why did I have to get advanced breast cancer before I could start to enjoy life?" What a poignant comment!

All too often we take life for granted. We don't adventure as much as we should. We get stuck in a rut of continuous day-by-day existence. We don't take enough time for our family, our friends, our faith, or ourselves.

I have had many patients tell me that on good days they are afraid to do anything for fear that the "feeling" will go away: "It will not last." Then on bad days, they hardly ever get out of bed. The important thing is to remember to live each day to its fullest. It takes a little courage to get up, get dressed, get groomed, and get out of the confines of the house. Adventuring forward adds zest to each day of life.

One definition of old age is failure of adaptation. As long as people can adapt to whatever disease they may have, they can stay young and be healthy and happy.

A disease is some alteration of an organ's structure or function. But a disease may not have any symptoms. An illness is the impact of that disease on the patient's well being and quality of life. The illness leads to the predicament. What does this illness mean to job, personal life, including family and future. And, at times, some people ask about the spiritual meaning of illness. Since suffering is part of the Christian tradition, suffering may be viewed as a necessary step in redemption. My own view is that we have all suffered enough to be saved. Let's just assume that we are saved based upon our faith in God and the promises of our religions.

So I end this section of the book with a high level of enthusiasm that becoming an Oxy-Phile can, indeed, extend life with further meaning, greater importance, and more profound meaning.

INTRODUCTION TO AMBULATORY OXYGEN: COMMENTS ABOUT THE LATE ALVAN BARACH

by Rueben M. Cherniack and Thomas L. Petty

Dr. Rueben M. Cherniack, my close friend and colleague in Denver since he joined the Denver Group, moving from Winnipeg, Canada in 1978, once worked with the late Dr. Alvan Barach of New York. Barach was the first to promote ambulatory oxygen, beginning in 1958 (see Figure 11). He sent me this cartoon shortly after we began our first ambulatory oxygen studies, using liquid portable oxygen for the first time in 1965. This little story related by Rueben Cherniack should be a guideline for all practitioners who take care of respiratory patients. This is an appropriate introduction to the following section, "Veteran Oxy-Philes Speak Out."

Figure 11

Al told the story of the very first oxygen patient he saw in practice, and he felt it was the hallmark of his success. When she entered the office and was comfortably seated, he asked her what her problem was. While she was reciting her problem, he thought that he had better remember the circumstances so he could perhaps write about this historic moment in the future. So he looked around the room mentally recording all the pictures on the walls, the bookcases, the distribution of the furniture, etc. Then he realized that she was finished and that he had missed her entire story. He then quickly said, "Mrs. Goldbloom, that is, without doubt, the most fascinating story I have ever heard. So that I won't miss anything, tell it to me again." Later she was responsible for many patient referrals and told everyone she had never seen a doctor who listened to any of her problems, whereas this one not only listened but asked her to repeat her story twice.

Al Barach (Figure 12) was one of the original oxygen pioneers. He championed the first oxygen tent used in the United

Figure 12

States for the treatment of pneumonia. He was an early proponent of ambulatory oxygen and pulmonary rehabilitation with breathing retraining. He was an inspiration to me from the day I first met him in 1966. All Oxy-Philes should know Barach's name and honor his pioneering contributions to our understanding of oxygen (see Appendix E).

VETERANS' ADVENTURES

"And Live She Did" (A Tribute to the Late Pat Chesbro by Thomas L. Petty, M.D.)

Pat was a patient of Kent Christopher, a former fellow. Because of her advancing COPD, Pat had required oxygen in the early 1960s. She was a pioneer at heart and a "sweetheart" to many. She hated the appearance and complications of nasal cannula, i.e., sore ears, runny nose, etc. She was an early recipient of the techniques of transtracheal oxygen, popularized by Kent and his partner, Brian Spofford. She was an active woman who lived in a lovely home and enjoyed the full support of her lifetime companion, her husband.

Kent, John Goodman of Transtracheal Systems, and I visited Pat in August of 2002. By now she had suffered the complications of advancing COPD and high work of breathing, with serious carbon dioxide retention. She had benefited from what is known as high-flow oxygen therapy through the transtracheal device, as illustrated in Figures 9, 10, and 13. One of the reasons why this "house call" was so important to me is that I had always been inspired by her optimism and charm.

She was a founding member and supporter of the National Home Oxygen Patients Association (NHOPA) and made many other civic contributions. She recovered from breast cancer

Figure 9

Figure 10

Figure 13

approximately one decade ago. On the occasion of this visit (captured in the Figures 9, 10, and 13), she was preparing for her third course of chemotherapy for metastatic colon cancer, which had been diagnosed a year earlier in inoperable form. Her enthusiasm for life, as observed in the figures, also illustrates the high-flow system that is useful in different stages of COPD, including weaning from mechanical ventilation and as an alternative to home ventilatory support in the most advanced stages of COPD.

A full discussion of high-flow transtracheal oxygen goes beyond the scope of this book.

Pat lived another year and ultimately died of the consequences of advancing COPD and colon cancer. She was 76 and had lived a full life. Would that we can all follow her adventurous spirit.

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A House Call by Thomas L. Petty, M.D.

I visited Clayton, a young man with advanced cystic fibrosis, on several occasions. He was in failing health and needed oxygen all of the time. He hated hospitalizations. He was a commercial artist with some skill, and I got him to do some illustrations for a short book I was writing on "Prescribing Home Oxygen for COPD," (Thieme-Stratton, New York, 1982). Figure 14 is a picture taken outside his home in a suburb of Denver. Notice that I am carrying his hospital charts, representing eight long hospitalizations. Ambulatory oxygen helped him live a productive life at home for two years before he died. He had only a brief hospitalization at the end of his life. I learned a lot from patients by visiting their homes.

Figure 14

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Story by Joan Breeden, Member COPD-Alert Group

I am a 71-year-*young* female with COPD. I had been struggling to breathe while walking around for a couple of years, all the while using albuterol to get me through a day.

Having to rely on Medicare to pay for medical equipment, I had to go without O_2 because I simply could not pass the required six-minute walk test for Medicare to approve O_2. The reason I could not pass is because I couldn't walk for six minutes! My pulmonologist would have given me a prescription for it, but I could not afford it.

I had a double mastectomy in February 2001, and after surgery my "sats" would not go above 84 with any movement. I was finally approved by Medicare and sent home with oxygen, 2 LPM at rest and 3 LPM while exercising. I cannot tell you how much better I have done since having oxygen. What a difference it makes! I have LOX at home and M6 gas portables that satisfy my needs just fine.

The first time I ventured out in public with my "nose hose," I felt as if the entire world was looking at me; but after two to three times out, I no longer feel that way and, in fact, enjoy telling inquisitive youngsters and adults why I need O_2. It gives me a great opportunity to tell the young folks what smoking can lead to.

The major problem I had with my O_2 at home was vacuuming my floors and getting my O_2 hose all tangled up with the vacuum cord. I solved that by strapping my portable unit onto the vacuum—no more tangled-up hose and cord. Now, if I could just get my children and grandchildren to keep their feet off my O_2 hose when they visit, I would be A-OK. They are forever standing on it and cutting off my air supply.

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Cruising with Oxygen by Mary Burns, RN, BS

Did you know that back in 1984 medical oxygen was considered hazardous cargo and not allowed on cruise ships? We

didn't when we naively planned our first cruise for oxygen patients. Three weeks before sailing, when we rechecked with the cruise line, we found to our horror that the tourist agency had told them nothing about our plans to take oxygen on board. The cruise was off. Our tourist agents, eager not to lose the commissions from our group of 50, encouraged us to "sneak on board" or "run past the ticket taker at the last minute." Visions of our patients running up gangways pulling their oxygen and pursued by ticket agents were not what we had in mind for this dream trip!

After inundating them with safety information and a powerful letter from Dr. Petty darkly hinting at the evils of discrimination, we finally convinced the reluctant cruise line to allow us on board with oxygen *IF* we could get Coast Guard approval! Everyone was sure we would never budge that bureaucracy. But, miracles really do happen, especially when you work very hard to achieve them. In a frantic three-week period, all obstacles were overcome. On June 11, 1984, we sailed from San Pedro, California, to Ensenada, Mexico. For the first time in history, passengers with oxygen were allowed on a cruise ship! Oxygen-dependent passengers have been cruising ever since.

Wonderful things began to happen in that ocean air. Patients who had hated upper extremity exercises in pulmonary rehabilitation would play the "one-armed bandits" by the hour, with nary a complaint. Those who "couldn't" handle stairs managed very nicely, with their portable oxygen, to climb the half flight up to the casino.

Back in those days, portable liquid oxygen wasn't very common. All of our patients, however, were supplied with liquid portable systems for this trip. One of the other passengers, puzzled by the units pulled by our oxygen users, was heard to comment, "Look at all those little vacuum cleaners. This is the cleanest ship I've ever seen!"

One night at dinner, a white-faced steward anxiously hurried me and the other nurse, Maureen Finnerty, out of the dining room. He told us an oxygen unit was about to blow up and the ship with it. Courageously, two stewards had dragged the unit to an outside deck while another had cordoned off that area of the ship. Maureen and I couldn't suppress giggles as we beheld the steaming oxygen unit, attached to a frozen portable, surrounded by a pile of "snow." Some hot water poured over the

frozen connection remedied the problem caused by a patient unaccustomed to using a liquid system. We complimented the men on their bravery, while reassuring them that hair dryers would work next time if they didn't want to get the carpet wet.

The frozen portable was one of a series of events caused by our problem patient. Though accompanied by his "girlfriend," supposedly a nurse, he was always in some kind of mischief. He was a wiry little gnome of a man, probably smaller than 5 feet with long white hair and a long, stringy white beard. His favorite trick was to hide behind a potted palm, sipping Bloody Marys, while checking out the ladies walking by. He liked ladies. Whether it was the Bloody Marys or his love of ladies, we don't know. But something prompted him to enter the ladies' restroom when he "had to go," as he put it later. Seconds after he snuck in, a shrieking, hysterical woman come tearing out. She tripped over the riser in front of the restroom door, almost falling in her haste to escape. She was babbling loudly about being invaded by a little space man with green tubes in his nose. (Did you know that oxygen tubes used to be green?) Our "space man" was confined to quarters until his "nurse" promised to make sure that all his beverages were non alcoholic and that he limited his restroom visits to those that said "Men" on the door.

Another amusing dinner episode occurred on our last night. Lights were lowered and waiter after waiter paraded into the dining room, each carrying a flaming Baked Alaska to one table after another. Our group was last. Our Alaskas got about 100 feet away, and then stopped long enough for everyone to admire them, *if* they had good distance vision. The flames were carefully extinguished before the non-flaming Baked Alaska came any closer to our tables. We gave our waiters an extra large tip to compensate them for their "hazardous duty" in waiting on our tables.

How times and attitudes have changed! What *hasn't* changed is the fun people have when cruising. Some of our group found that oxygen was no deterrent to swimming and learned to enjoy the pool. Others again discovered dancing. One of our group parked his portable oxygen on the deck and swung into Swing steps, joined by his gyrating wife. Their audience burst into appreciative applause.

Our entire group attended the Captain's Dinner Dance. They were resplendent in evening clothes and proudly posed, with their oxygen on, for the inevitable picture by the boat photographer. Who said being on oxygen was the end of a fun life? They didn't! They danced, carrying their own oxygen or having their partner carry it. It didn't matter, they were having fun! So, the next time those of you on oxygen go on a cruise, don't take it for granted. Remember the adventures of our pioneering group, way back in the dark ages of 1984, and enjoy!

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Story by Starion

I was diagnosed with "idiopathic," non-A1-AD emphysema and severe COPD in December of 2000 at the ripe age of 43, never having smoked or been around any lung irritants. I live at sea level and have never required supplemental oxygen. I was increasingly concerned about my oxygen saturation rates because my six-minute walk tests at altitude (5,000 feet) showed that I desaturated to 90% when I was walking at a slower than normal pace. In 2003, I purchased a personal pulse oximeter to monitor my oxygen saturation levels and learned that I desaturated from 94% to 86% from ANY mild exertion on the airplane and while lying down to rest at altitude (5,000 feet). I told the nurse when I went to see my pulmonologist, and a six-minute walk test revealed that I was indeed desaturating while I was walking around at altitude and, further, that my personal pulse oximeter readings correlated very closely with the medical center's. I was given liquid oxygen and sent for another six-minute walk test to titrate my oxygen level. When I saw the pulmonologist, he determined that we had reduced my inhaled corticosteroids (Qvar) too much, as well as my Atrovent, which caused me to desaturate more than in past trips to altitude, so he increased my prescription for both medications; and my oxygen saturation rates improved so supplemental oxygen was only needed for sleeping rather than sleeping and activity. My pulmonologist and I agreed that as long as I kept my O_2 SATs at or above 90 on my personal pulse oximeter, I didn't need supplemental O_2 while awake but needed O_2 if I were having ANY difficulty maintaining at least 90-91% saturation rates.

It was great to be given that flexibility.

I was pleasantly surprised that adjusting my medications made a difference because I have never read or heard that our dose of inhaled corticosteroids and Atrovent affects our oxygen saturation rates. Of course, I'm delighted that I have less frequent need for supplemental oxygen now with my medications adjusted. I still have difficulty getting used to prongs in my nose while sleeping at altitude, but perhaps someday...

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Story by Sharon B of Florida

My father, God rest his soul, was the best "jury-rigger" I ever knew. So when he became ill with COPD and ultimately had to use O_2 and the concentrator, he had to deal with a couple of things. First off, hard of hearing as he was, the noise of the concentrator disturbed his sleep. So he got extra line so he could put the unit in the hall closet. Secondly, although he was fond of sitting in front of the tube, he didn't like HAVING to sit there because he couldn't drag the thing around . . . so he got MORE extensions. But he'd trip on the hose, so he installed hooks above the doors throughout the house and in the garage so he could loop the hose over the hooks as he came and went – and voila, no more threat of breaking his hip or ripping the hose out of his nose because he tripped over or stepped on the hose. He was proof that necessity is the mother (or in this case, father) of invention.

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Story by Don Soderstrom, Albuquerque, New Mexico

After smoking between three and four packs of cigarettes a day for a little over 40 years, I now have severe emphysema and have been on oxygen 24/7 ever since February 17, 2002. Even though my mother died of emphysema and had been on oxygen for several years before her death, I never gave any thought that I would someday end up having to use oxygen to breathe.

Living on oxygen has been a very interesting learning experience, to say the least. My wife and I can no longer burn wood in our fireplace. She can no longer burn her collection of scented candles or wear perfume. We can no longer fly anywhere together as the cost of oxygen aboard a plane is cost prohibitive. For example, her brother is an executive with UPS in Louisville, Kentucky. They had invited both of us to fly out to celebrate his 50th birthday. When we found out that it would cost an additional $150 every time we got on a different plane, plus $150 for the waiting period in between flights at the air terminal, we decided that my wife would fly out and I would stay home. It would have cost an additional $900 for the oxygen.

Rather than sitting at home feeling sorry for myself because I now have to survive on oxygen 24/7, along with all the other medications and inhalers, I decided to take this negative and turn it into a positive. Consequently, I have been a volunteer for the local VA Hospital's Smoking Cessation classes. And my wife and I also volunteer with the American Lung Association's Smoking Cessation classes, and we are starting to work with the youth in the local schools. I have an oxygen tank cart that I put a horse head on, and you should see the looks I get from mid-schoolers when they see it.

Probably the most difficult issue to deal with, for my wife and me, is making sure I have sufficient oxygen supply whenever we leave the house to go somewhere. After we had gone out to dinner one time, about a year ago – while we were still getting accustomed to my being on oxygen – we decided to go to a movie. After purchasing our tickets and going inside the theater, I suddenly noticed that my oxygen tank was down on reserve. I asked my wife if she would go get my reserve tank. Guess what? I had put an empty tank in the back of our car thinking it was a full tank. Boy, did we have fun driving back home. My wife never ran stop signs or stop lights in her life before. She did this time so she could get me home and hooked back up to oxygen.

###

Story by Mary Jane Diskin

One of the worst and funniest things that happened to me is the day my husband stepped on my O_2 tubing, and it disconnected. I was having a fit, and he was at a loss for words. We both discovered the tubing off the concentrator at the same time and bumped heads trying to fix it.

Also, I found out that other people's dogs love to chase the tubing as you walk around; and if you are not careful, puppies like to cut their new teeth on the tubing.

###

Story by Saundra Roberts

He constantly assured me . . . NO PROBLEM, I CAN DO IT. Peacock Hubby. Told him if I couldn't breathe or turned purple or grey to call an ambulance. If I pumped my forefinger up and down, I needed a shot of albuterol as I was in distress. He said, NO PROBLEM.

I was weak and was having to move from bed to wheelchair to go to RR. We have put a D oxy tank on back of a chair to keep from having to undo the BiPAP, mask and oxy tubing: just take off face mask and put on oxy tubing and cannula from chair. Great and easy idea. All going great, I was so happy and proud of him; and so was he, and beginning to strut a little.

The D tank is empty. NO PROBLEM, he says, I know how to change it out, regulator and all. OK, great. So he goes for it. Gets an empty one off chair, connects regulator to new tank and is in process of lifting it to back of chair when he thinks he saw a spider crawling on side of tank (possible as they are kept in the garage), so he lifts it way up to check it out. No spider. BUT then he dropped it. Next thing I know, I open my eyes, I am slumped over in the chair. Strutting Peacock is holding my hand and hollering my name, shaking my shoulder. I am quite dazed but begging to realize what just happened. HE KNOCKED ME OUT! Asked for how long and he said "not even for a minute really." Well good for that – I mean I am fighting to live as long as I can with this COPD. I certainly don't need any of my precious minutes robbed from me by being unconscious. Decided I was really OK and would just wait and see if anything started to act peculiar before calling for medical help. Never had a problem.

I did not get back in the chair until after the tank was changed from then on out. I am a little faster learner (lol). I still want my minute back though (lol).

###

Story by William R. Probstfield

It was just a few weeks after I was prescribed full-time supplemental oxygen. I was trying to breathe through my nose as a life-long mouth breather and struggling with oxygen-dried and very sore nose. My daughter was coming to visit me on my birthday, bringing a boyfriend and, quite frankly, I was still a bit self-conscious using my full-time "scuba tank."

My daughter and her boyfriend arrived with her special home-made cookies for my stash and a beautifully decorated birthday cake. I have passed 60 birthdays so had gotten accustomed to having too many candles for the cake. It was March in Northwest Oregon; I had a stand-up collar shirt and my favorite cotton sweater on with a pair of faded jeans. I was ready to party. I decided to enjoy this part of my birthday without my oxygen and put my cannula aside and turned my concentrator off for the moment.

My daughter put my birthday cake in front of me at the kitchen table, lit the candles and everyone gathered around. She asked me to make a wish, and I was thinking. "Dad!" my daughter exclaimed, "You are on fire; smoke is coming out of your shirt collar!" she shouted. She ran to my side for a closer look. I did not feel the heat but could smell the smoke and saw the smoke out of the corner of my eye. My daughter quickly removed my cotton sweater over my head as I began to feel heat on my neck from where the smoke was coming. Her boyfriend, Paul, grabbed my shirt, pulling and jerking at the collar and down my chest while I watched every button pop off my shirt.

It took a few minutes to realize that I was not burned. My guests and I had seen no flames, just smoke. We were all puzzled and amazed. What magic had caused the smoke? It was indeed a mystery. My investigation took many weeks before I found my answer from a friendly COPD e-mail list.

Moments before the candles were lit on my cake, I had been using oxygen that had accumulated some vapors under my cotton sweater and shirt. As I sat very close to the cake candle flames, they ignited the residual oxygen under my shirt collar and burned because of the small amount of oxygen fumes that had accumulated there. I was thankful I had turned my concentrator off for the party. I had learned one more lesson in using long-term oxygen therapy. On that day, all had a hot time.

###

Story by Jo-Von Tucker[1]

As a 24/7 supplemental oxygen user for more than 14 years, I've had lots of stories to tell about it … some good, some not so good. But here is a funny one.

I was sitting in a chair waiting for a fasting blood test for my diabetes the other day. My chair was in a long line of chairs lined up against the wall. There were probably 20 or more of them, and they were all full. Some folks had brought their morning newspaper to read while waiting, as I had. Others had paperback books, hand-held computer games, etc. But it was a pretty quiet assemblage.

The lady sitting to my left was deeply immersed in a book. She appeared to be about my own age, 60s, and like everyone else, was keeping mostly to herself and her book. All of a sudden, she dropped the book to her lap, looked at me and politely but quietly inquired, "Are you beeping?" I just smiled and answered "Sure." As if this were a question I was asked every day, and as though the answer should have been obvious to her.

Of course, I was not beeping. It was the little "chirp chirp" sound my Helios portable makes as I intake a breath. Most of us know that the Helios is an on-demand conserver system that emits a puff of oxygen (resulting in a "chirp" sound) each time we take in a breath.

Moral to the story… I felt no need to further explain the "beeping" sound to my neighbor at the lab. Granted my Helios was carried on my right side, extended from the belt around my

[1] See Dedication at front of book

waist. So I'm sure my inquisitive neighbor did not see the oxygen equipment. But even if she had, I questioned her right to put me – or any other person wearing oxygen equipment – into a situation demanding an explanation. "Sure" was a good enough answer for me. Hope it worked for her, too. Maybe she will think twice about asking rude questions next time.

###

Story by Jo-Von Tucker[2]

During my 14 years as a supplemental oxygen user, I've known so many other patients who felt embarrassment being seen in public with their O_2 equipment. One lady I knew in our support group simply would not be seen wearing/using her oxygen equipment outside of her home, period. She would place the oxygen portable unit on the floor of her car (covered with a blanket!) if she were driving. And each time she came to a stop at a signal light, she would quickly remove the nasal cannula from her face so that the people in the car next to her would not see it.

It's funny, I never have felt the embarrassment that others seem to experience. It simply has not been an issue with me. I do realize the help that my body gets from the supplemental O_2. And I firmly believe that my 24/7 use, as prescribed for me all those years ago at National Jewish Hospital in Denver, has extended my life.

Now that we have the jazzy, sophisticated little oxygen delivery units like Helios, my quality of life is much improved. The portable unit is so small and lightweight, making it easy for me to remain active, both in my business and socially. It is wonderful to have both hands free, whereas I used to have to drag around a portable unit on a set of wheels, because I didn't have the strength to carry it on my shoulder.

People who use oxygen should not feel that there is a public stigma attached to it. The only public stigma is one of ignorance, where people just don't understand what the equipment is for and how it helps us. I guess I am a poster child for long-term oxygen therapy. I wear my equipment as others might

[2] See Dedication

wear a knee brace or use a cane. I am neither ashamed of it or the fact that I need it. Rather, I am thrilled that state-of-the-art equipment allows me to work and play with maximum mobility.

My advice to those patients who try to hide their O_2 equipment and usage? Get over it! Vanity has nothing to do with living life at its fullest.

###

Story by Margo Holmberg

Let me introduce Harvey, my portable oxygen system. He is my traveling buddy and my constant companion. I refill him from a large 100 "Big Bertha" supplier tank in my bedroom. I cannot get along without Harvey, yet I find I cannot get along with him either.

I call him Harvey after a very famous six-foot rabbit who many years ago shook Broadway theaters with pleasurable enjoyment and surprise. Some of you readers may be too young to know about Harvey, the invisible six-foot rabbit. I wish my Harvey was also invisible like his namesake, so that is why I named him Harvey.

Harvey came into my life in December 1994 after my doctor diagnosed me with COPD. I resisted with great force against taking Harvey into my life. I had many questions and insurmountable apprehensions. I continued to resist, but to no avail for I soon discovered there were no other alternatives if I was to enjoy the rest of my life.

Harvey and I have what you would call a love/hate relationship. I call him my friend; but he really is not my friend when I trip over his cord, forget to turn him on, and, consequently, become quite dizzy and breathless. I often find Harvey a drag in our lives if we go out to dinner and, being placed under the restaurant table, he tips over and sings a loud and screeching song. Sometimes he misbehaves and gets tangled up in the market shopping cart and pulls merchandise off the shelves. Even in the car he will become tangled up in the door handles and seat belt. I find that if I slow down and talk very softly to Harvey, he will listen and soon begin to behave.

We felt our traveling days were over, but this was not to be. Harvey took the wind out of our sails for a while, but my husband and I were determined to make the most of this newcomer in our lives. We have taken him on trains, planes and boat rides, plus many driving trips. Harvey appears to be enjoying himself, and we are also.

###

From the "Energizer" Bunny

Loaded my Helios at 9 a.m. That gave me between five and six hours of O_2, as long as I was seated. Called a car service and proceeded to Pennsylvania Station in NYC. It took us only a half hour to get there and another 45 minutes to try to find the redcaps with the wheelchairs. Since we couldn't find them, I asked to be dropped off at the corner of 8th Avenue and 33rd Street. I wheeled my suitcase behind me and took the escalator down. At the bottom, I was completely out of breath and had to rest. My train leaves at 10:35, and the Amtrak personnel were w-a-y across Penn Station. By the time I finally had the strength to make my way to them, it was already 10:15. When they saw me they gave me a wheelchair and called a redcap to take me to the train. So, with six minutes to spare, I was on the train – and would make it. Whew!

So I found a seat next to a nice young gentleman who was going home to Baltimore, Maryland, after being at a conference in NY. Naturally, I was in a seat that didn't recline. But that was an easy thing to overcome. The train was lovely and very full. A gentleman across the aisle got off at Newark Airport; and I knew his seat reclined, so I changed seats.

I guess we were getting close to Baltimore when I was awakened by a message that there was a tree down on the tracks. The next message was that three men tried to move it and couldn't. So we were now waiting for the tree to be removed. At this point, I decided to check my O_2 tank and see what was left. We were supposed to be in Baltimore at 1:30 and then Washington at 2:00. The time was already 2:00, and I knew I only had another hour's worth of O_2. The man sitting next to me asked me what liter flow I used. And I immediately asked him if he were a doctor. He said no, but I could turn my flow down to 2 since I was at rest and I should calm down and breathe slower. As it turned out, he was a respiratory therapist

in Long Island, NY. Wow – was I lucky or what!!? His name is Alan Lurie, RRT. The next announcement was that they had gotten a chain saw, cut the tree and removed it from the tracks. Relief!!

That is, until right after we passed Baltimore, when the train lost its signal. We slowed down to about 2 mph. We passed a town called Odenton, MD, and there was nothing but woods and swamp on either side of the train. Time was just about out for me, so I asked the conductor (Barbara) if she could arrange to have O_2 waiting for me in Washington, DC. She said she would call ahead and make arrangements. A little while later the train came to a complete stop. This time there was a tree down over the electric line, and the train could not proceed. I still didn't panic – but I was very nervous!

Okay, so this time the train was backing up!! There were two trains behind us, and all the trains had to back up to the last station to switch tracks because that tree could not easily be moved. Now panic was setting in. I was just about out of O_2 and only using 2 Lpm!! So Alan remained in charge and together we asked Barbara if they could get O_2 to me very soon. She said there would be an ambulance waiting for me at Odenton. So I asked her where they would take me and she said wherever I wanted to go…All right now.

Turned out not to be true. They would take me to a hospital nearby. So, of course, I lost my cool at that point! Imagine being stuck in the middle of nowhere with no place to load my Helios! How would I get out of that town – or state, for that matter?! Fortunately for me, I had Barbara Rogers' cell phone number with me. (Barbara Rogers is the President of COPD Resource Network.) She made all the arrangements from that point on. I was in Maryland, and the conference was in Virginia! Poor Bill Grimm had just walked through the door of the hotel and was whisked away in a taxi to come get me with a full Helios!! That cab ride was over $100. If it weren't for Barbara Rogers, I would have been stuck in Odenton for the rest of my life – and missed the convention – good grief!!

It took a couple of hours for him to reach me, so I just waited in the ER waiting room. The rest of the trip was uneventful (lucky for me). I had a wonderful time at the conference and, by the way, the train wound up being 3-1/2 hours late!! I never would have made it, were it not for Alan, Barbara, Barbara, and Bill. I just want to say a big "thank you" to all of them for saving me!

The trip home was great. Alan and I shared a seat again, so I felt very relaxed. And the trip was perfect: on time, no trees, went very smoothly. The redcap was at Penn Station with a wheelchair for me, and he took me to a cab. The hardest part of the trip home was trying to shlep my luggage up the 19 stairs to my apartment. After that it was a breeze. I am at home with my pets and feel very fortunate that I got to make the trip to Washington at all.

###

Story by Claire McGrail of Rochdale, Maine

I had five years of oxygen therapy 24/7 and have just recently been able to stop it. I'll miss lugging my oxygen to restaurants only to be asked if I wanted to sit in the "Smoking" or "No Smoking" section. How obtuse.

I am an almost-66 years old woman, wife, mother of seven, grandmother of 11, with dermatomyositis, thankfully in remission. The dermatomyositis affected my lungs, and hence the O_2.

It wasn't an easy adjustment for me, but I much preferred it to the alternative. I got used to sweeping the floor, dragging my cord through the dust—so frustrating, but funny when you think about it. We had to keep our little grandchildren from standing on the cord or squeezing the cannula.

I was self-conscious, thought everyone was staring at me out in public. Even the children seemed to stare when I was riding around the supermarket in that wonderful cart.

I had a funny thing happen when I tried a new cart in a grocery store. It was a new-fangled one and, as my husband preceded me through the automatic doors, I almost crashed into them as I hadn't figured out how to stop it. People were very nice and helpful at other times when I had stalling carts.

I loved my shower chair when I could shower without exhaustion. A friend of our son's asked, "Why do you have a diving board in your tub?" We got a real kick out of that.

My last anecdote was when I had a girl come from the Nursing Association to give me my shower when I'd first come home from the hospital. She was from Poland, and we couldn't understand

each other at all – very hard to distinguish the words "hot," "cold," "start," and "stop."

Also, with my first shower after my first hospitalization, I became so scared because I had so much trouble breathing that I was overcompensating; and all I had was the aide with me. I was sent to a nursing home for rehab; and I bless those wonderful, talented, patient respiratory, physical, and occupational therapists. I found I could take my time washing and dressing and not let the nurses' aides rush me. I ballooned up to double my weight with my initial dose of 50 mg of prednisone, which also masked my pneumonia and mitral valve infection; but I know my fibrosis had to be attacked aggressively. My pulmonologist is wonderful — Dr. Morris Spierer of Fallon Clinic in Worcester, Maine — and he did a great job of tapering my prednisone and testing my PFTs and encouraging me. My success in breathing well again without my O_2 is a miracle to me, and my doctor agrees. But if I should have to be on it again, I know I can live very well with it, especially with my husband's help and my children.

###

My Adventures As an Oxygen User, by Susan W. Landers

I was diagnosed with alpha-1 antitrypsin deficiency in 1996. Alpha-1 is a genetic form of emphysema, and symptoms in adults begin at middle age or younger. Alpha-1 can affect people as a lung or liver illness. I am lung affected.

I will not bore you with the details of having an illness that has no cure. I am sure you can imagine the fear and hopelessness someone must feel.

I am what people call a "gutsy woman." I try to face reality with a positive attitude and thought I had done that with alpha-1. After being diagnosed, I went to my first support group meeting in North Carolina. This meeting was huge; and when I walked in, I almost passed out—people, lots of people, were using oxygen. I told my husband that we must be in the wrong meeting–these people are really sick and use OXYGEN. I stayed for the whole meeting because I was embarrassed to walk out. When it was over I headed straight for the door, and when I got to the car I was hysterical.

That was several years ago, and I still remember the fear of wearing oxygen. As with most illnesses that have no cure, I have had a slow but steady decline. When I became shorter of breath and my doctor did some testing, the thing I feared most happened. I was told I needed to use oxygen. I started using it at night, and I felt so much better that I was glad I had it. When the need for daytime use came, that was a different story. I got all the equipment and said, "Okay, I can do this!" The truth was I didn't want to do this. I would rather have been short of breath than wear the oxygen in front of people.

I want you to know that I grew up in a family that believed how you looked was what you were. I was considered a pretty woman; and I believed my successes in life were due to my looks, not my brains. I dressed beautifully on a daily basis, had a haircut every three weeks, and my nails done weekly. I am sure you get the picture; it was where my self worth was. If my Mother were alive she would have been horrified that I had to wear O_2.

I will move ahead a few years and tell you that in spite of my own vanity and fears, I now wear O_2 all of the time. When I realized that my heart was working so hard to help me breathe and that I was rushing my own death, my intelligence finally kicked in and I gave in.

In 2000 I went to work for the Alpha-1 Association as Community Services Director, and I loved my job. I worked from my home in Florida, but our main office was in Minnesota. I helped support groups to begin and stay active, and we always did a large yearly conference. There were board meetings and educational meetings all over the country; and I wanted to go, and I did—with oxygen. The plane trips were expensive because of the oxygen, and the oxygen company sometimes made mistakes at my destination; but it always worked out. If I were low on O_2, there was always someone at a meeting who had a spare tank. I was proud of myself for doing the right thing and not being afraid what others might think. I know you are thinking that I was in a comfort zone with others who understood, and you are right.

I grew a lot from my two-year employment with the Alpha-1 Association. My self-confidence grew stronger, and I learned so much from people who were in situations that made my life look like a piece of cake.

I decided that I needed a vacation and I wanted my daughter and my best friend to go on a cruise with me. WE WENT! With a cabin full of oxygen tanks and a concentrator we went to Mexico and had a wonderful time.

I have a nine-year-old adopted son, and I am raising him as a single parent. He wants to see and do all of the things the other kids do, so I try to do what I can. We went to the Tampa Zoo, and I was exhausted afterward; but I held on to a friend's baby carriage for support. We went to Epcot Center in Disney and I needed a wheel chair this time, but I went. If I had not relaxed and decided to use my oxygen, I would not have been able to go with my son to these places.

My greatest hope is that I can go to Ireland with my daughter, Erin. I have been sick with pneumonia for the past six weeks, but I will get my strength back and I hope we can go on this trip next year.

I have tried to write my experiences with oxygen for you because it is a hard journey to accept things that we so dislike. It is hard to put aside our vanity, and it is hard to pretend we are not sick with a "nose hose" as our best friend.

Oxygen has made me able to continue my life style in many ways. Yes, people do stare, and kids do ask questions, and it is all right with me. If one person sees me and thinks, "I will quit smoking," or if someone gets the courage to wear their O_2 because they saw me, that is terrific.

###

Story by Bill in Virginia

Hi, my name is Bill Poplett, an alpha-1 antitrypsin deficiency patient who was put on O_2 in August 1996 until I was blessed with a donor who provided me a new lease on life with his right lung. My "lung brother" received the left lung. There are many tales of life with O_2 hose in the nose lifestyle that I experienced and had shared with others experiencing the joys of O_2.

My most memorable one of my sister Sharon, also an alpha-1 patient (now deceased), was during my visit to her home in California. She had her O_2 hose running through the house on a 75-foot hose with swivel connectors in hopes it would help prevent the hose from tangling up…which was a lost cause.

Sharon was sitting at the kitchen table, having just finished her neb treatment, while I watched and interrupted her treatment with my talking and asking questions. Soon I realized my error and told her to finish up as I pulled up a chair to wait. Not long after, she started going into distress, color from her face started to darken, and I got concerned — leaning over to try to hear what she was saying. Her voice was raspy as she squeaked out, "Get off my damn hose before I pass out!"

Another funny story was my "Alpha Sis," as I call her, who related a story to me. She, as many of us, used our O_2 to hook up to our nebulizers. Well, Darcy was en route to an appointment or something so she hooked up her neb to the O_2 and was tooling down 164 when a Virginia state policeman pulled her over. Walking up to her car, they both had a good laugh as he'd assumed she was doing some other form of inhaling from the pipe.

The O_2 has served countless times as an educational tool for children, especially in explaining the need to keep their lungs healthy.

###

Story by Karen VonKaenel of Dover, Ohio

Years ago when I first started wearing oxygen, I was tethered to a concentrator. I had a lot of ground to cover in my home so I had a couple of 25-foot hoses connected together. My problem was that this connector got stuck everywhere and I was always getting jerked backward. I gained a whole new respect for dogs on leashes.

One day I had a brainstorm and decided to cut a small hole in a tennis ball and stick the connector in that. Well, that worked really well until one day my Rottweiler decided to fetch the ball and took off with it! WHAT A RIDE!!!

Today, I use the Helios so I don't have to worry about being tethered anymore.

###

Story by Helen Vanholsbeeck, Chiang Mai (TH)

I am Helen and I live deep in the paddy fields in the north of Thailand. I was diagnosed with COPD in 1997 and since then have been living and learning how to live with my emphysema with an oxygen tube in my nose for company all day and every day. Some days are good, and on the others I have learned to accept the rules and keep a low profile. Without the help and encouragement of the online support groups, I don't think I would still be here.

I have always been a "traveler;" and the first trip I took after I had recovered from the shock and the fear of having COPD and spending the rest of my life attached to an oxygen bottle, was to the heart of the Golden Triangle. There is a hotel there I had known and enjoyed in "the good old days." It sits at the point where Burma, Laos, and Thailand converge.

We stowed my liquid oxygen reservoir in the van and very cautiously set out for the four-hour drive. For days I had been very apprehensive about this trip; but as soon as the initial anxiety had worn off and I was breathing comfortably, I settled down to enjoy the scenery. The next day I really got adventurous… clutching my O_2 portable and my little ultrasonic nebulizer, I clambered aboard a tiny boat that was willing to battle the currents of the "mighty Mekong" river. Full speed ahead and it was wonderful to feel the cool, keen wind rushing into my lungs and feel the adrenalin surge of a slightly dangerous ride. I felt truly alive again for the first time since my diagnosis three years earlier.

We made it over the river into Laos and disembarked – no passports involved, just one official-looking person very busy looking the other way!! At this stage I was still very conscious of the hose in my nose but no one gave me a second look. We stayed for several hours around the embankment villages until the boat man started to get a bit nervous, the light was fading, and the needle on my portable was ambling towards the red zone.

This day was the turning point in my COPD career. At last I felt positive and comfortable with my situation. Since then I have had unilateral lung volume reduction surgery; and slowly, slowly I can now function quite well. I swim every day and am able to do so without O_2. This is a major bonus.

A final note to my little saga. We do not have oxygen suppliers here. If you want oxygen you must drive out to the factory

and buy it. I have my tank filled about every 17 days now, but three years ago it was every 10 days. I intend to keep going on the end of my user friendly O_2 tube for a long time.

###

Oxygen Gave Me a Second Chance at Life, by Ron Peterson

I was diagnosed with emphysema at age 44 after smoking cigarettes since age 12. Along with the diagnosis came, at my insistence, this grim prediction: You have, at most, a five-year life expectancy if you continue smoking.

I had been trying to quit since age 14 (after starting at age 12 for a new thrill) when the first Surgeon General's Report linking cigarette smoking and disease was issued and was not able to quit during all that time. I wasn't able to quit for another eight years after the diagnosis. I finally was able to quit then, when I blacked out from coughing whenever I had just one drag from one cigarette. That got my attention!

After my diagnosis, I decided to take my own life. Fortunately, after I had already bought a book on how to do it, the required equipment, and done a "dry" run, I was inspired to learn what God had to say about my plan. On page 1000 of my 1020-page Bible (I started at the beginning), in First John 5:16-18, I learned that everlasting life is not possible for those who commit suicide. The price of suicide was too high for me; so I changed course and, instead, attempted to do all I could to help my peers who had lung disease. Helping my peers immediately led me to Internet support groups where I was actually helped more than I helped.

One of the first lessons I learned from my peers was the ability of supplemental oxygen to minimize the probability of a heart attack for those with "end-stage" (which I had!) emphysema when they choose to maintain their health with exercise.

When I quit the bad habit of smoking, I intuitively replaced it with the good habit of exercise and was routinely walking an hour a day, every day. One of my Internet support group buddies (Jim Fairchild) told me I was in real danger and asked me to get evaluated for supplemental oxygen therapy.

When I requested from my pulmonologist to be evaluated for the need for supplemental oxygen while exercising, he slapped an oximeter (a medical device that fits on your finger like a clothespin that measures the amount of oxygen in your blood) on me and had me walk for five minutes. Then he checked my blood oxygen level and said, yes, I needed supplemental oxygen to exercise and wrote the script that allowed me to walk safely on 2 liters of oxygen per minute. Thank God!

One of the first ways that oxygen helped me was to allow me to enter and complete a 5K walk/run on oxygen. It was the first time in history that this had been done by someone on supplemental oxygen. I wrote an article entitled, "Facing my Fear," which describes the experience. The article originally appeared in the journal *Airways* in 1997. *Airways* is published by the Second Wind Lung Transplant Association. The fear I faced was to be seen in public using supplemental oxygen. Now it seems irrational; but at that time it was real, and I was able to face it and eliminate the fear. Good advice, in my opinion, in general.

From that competition, I moved to a six-week, 7,000-mile truck camper tour of the eastern half of the U.S., which produced a video entitled, "Maintaining your Health with Lung Disease," which has an introduction by Dr. Tom Petty, the individual who originally led the research and development that gave the world supplemental oxygen therapy.

I used E tanks with compressed oxygen on the tour. No problems with suppliers while I toured; in fact, all were most supportive and helpful! Eighteen peers with lung disease, whom I had "met" on the Internet support groups and who were doing especially well, were interviewed on camcorder during the tour.

Next I traveled to Columbus, Ohio, for the 1998 transplant games and interviewed the strongest lung transplant recipients and produced the video entitled, "Advice from the Transplant Game Athletes" with an introduction by Dr. Cooper, the "father" of lung transplantation.

In February of 1997, I was evaluated as a lung transplant recipient and accepted into the Barnes lung transplant program in St. Louis, Missouri. Shortly afterwards, my oxygen supply was changed from the heavy, bulky E tanks of compressed gas to the lighter liquid oxygen tanks, which allowed me to continue walking outside an hour each day.

At age 56, I was fortunate enough to obtain a life-saving (my lung function was about 9% of normal at transplant) lung transplant. As I write this, I am now 1,120 days later, in excellent health and have devoted my life to eliminating the most common cause of lung disease – youth cigarette smoking initiation and subsequent addiction.

In 1999, I decided to help prevent youth from following in my footsteps by producing and distributing tobacco prevention videos and formed the non-profit Prevention Video Corporation (preventvideo.com) which is made up of those with lung disease. To date, we have produced four videos and distributed them extensively—globally as well as nationally.

Without supplemental oxygen therapy, I would not have been able to exercise safely and be told by the Barnes lung transplant center doctors that I healed faster than any of the 552 previous lung transplant recipients in their program. I was the last transplant in the Barnes program of the millenium with a transplant date of December 27, 2000. When I asked why I healed so quickly, the doctors explained, "Healing rate is directly related to fitness level; the more fit you are, the faster you heal." They asked me to think of a professional ballplayer who is in top physical condition, who heals overnight from injuries a normal person would take six weeks to heal from.

The point here is that the oxygen allowed me to safely exercise to be in the best shape of any pre-transplant patient. (I walked an hour on the day of my transplant and another hour on the day following my transplant; this was unheard of previously.)

Although I left supplemental oxygen behind me on the second day after transplant, I recognize how much it has helped me and would like to salute the many thousands of hardworking health care professionals who make its use possible. Thank you.

In the early '80s, I purchased wilderness land at an elevation of 9,000 feet in the Rocky Mountains of Colorado, about 30 miles west of Denver. The land was a five-acre mining claim called the Boxer. With the help of many friends, I built a home there that I call The Observatory. It is a hexagon—seven feet to the side with the three southerly facing walls being mostly window. Although it is only 203 square feet, including the half loft, it seems larger because of the open feeling and ease of observ-

ing nature from the windows. I often see deer, eagles, and many other forms of wildlife there and feel like I am an observer of nature. I was forced to sell the Boxer and Observatory in 1998 when I got so disabled that I could not breathe well enough there at the 9,000-foot elevation to function. After my lung transplant, I contacted the owner and asked if he was interested in selling the property back to me; and he agreed! Lucky me. I now live there whenever I am not touring or promoting youth tobacco prevention, and I am thankful to be able to do so with my new lung.

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APPENDIX A: WEARING OXYGEN[3]

Oxygen from the air is necessary for your body's efficient energy production. Oxygen itself does not contain energy, but it allows your body to produce energy by the burning (metabolism) of food. Oxygen allows for the transfer of a series of body chemicals and electrons through a chain of chemical reactions that fuels your body's system function. Without oxygen, critical cells of the body begin to die within a few minutes. The percentage of oxygen in the air is 21%, and this percentage stays the same regardless of altitude. At sea level, the air is thicker, more compressed and contains more oxygen because of the higher atmospheric pressure that concentrates or thickens the air.

The oxygen level in your blood depends both on the atmospheric pressure in the air that concentrates oxygen and pushes it through the lungs into your blood and the capacity of your lungs to take up the oxygen. People with normal lungs can have very low levels of oxygen at high altitudes where the atmospheric pressure is low and the air is thin. People with normal lungs who live at high altitude compensate for lower oxygen levels in their blood by pumping more blood through their lungs and raising red blood cell levels in the blood to increase the amount of oxygen the blood carries.

Chronic obstructive pulmonary disease (COPD) reduces breathing capacity and, in advanced stages, limits the ability of the lungs to transfer oxygen into the blood. A patient with milder COPD has some reduction in the oxygen level in the blood similar to the reduction seen in someone with normal lungs who breathes thinner air at an intermediate altitude of 5,000 to 7,000 feet. A patient with more severe COPD may have a more severe decrease in the blood oxygen level comparable to the reduction seen in someone with normal lungs breathing thin air at altitudes above 10,000 feet. Even at sea level, many patients with more severe COPD have oxygen levels low enough to put a strain on the heart, increase the blood hemoglobin level, and decrease brain and kidney function.

The following are common questions often asked by patients who are prescribed oxygen by their doctor.

[3] Source: Reproduced by permission for *Frontline Advice for COPD Patients, Snowdrift Pulmonary Conference*

How Is the Level of Oxygen Measured?

The oxygen level in your blood is measured directly by drawing a sample of arterial blood. Arterial blood has just passed through the lungs and carries a replenished oxygen supply. The arterial "PO_2" should be above 80 in normal people at sea level. The oxygen level in the blood can also be measured as the "arterial oxygen saturation" using an oximeter device that fits on a finger or an ear. Oximetry reports the percentage of red blood cells that are carrying oxygen. An oximeter does not require drawing a blood sample. Normal people have an oxygen saturation above 95% at sea level.

How Will My Doctors Know When I Need Oxygen?

Your need for oxygen is guided, in part, by measurement of the arterial blood oxygen level. A PO_2 level of 55 measured by arterial blood gas or a saturation of 88% measured by an oximeter qualifies a COPD patient for home oxygen (see Appendix D, Figure 17). Patients with normal oxygen levels at rest may qualify for home oxygen if the oxygen level falls significantly with exercise or if nighttime monitoring shows a fall in oxygen level with sleep.

I Have COPD and I'm Short of Breath. Why Does My Doctor Say I Don't Qualify for Oxygen?

Shortness of breath does not necessarily indicate a need for oxygen. There are many other factors that contribute to shortness of breath other than a low oxygen level. Oxygen is only prescribed and effective if your oxygen is low at rest, with exercise, or with sleep. Many of the most short-of-breath COPD patients have normal oxygen levels and, therefore, do not qualify for oxygen therapy. Many patients are less short of breath when wearing oxygen, but some are not. Many patients who are not short of breath have low oxygen levels and need home oxygen. Patients, of course, are more likely to wear oxygen if it makes them feel better when the oxygen is on. Medical insurance requires documentation that patients have a low oxygen level before it will pay for oxygen.

Will I Become Addicted to Oxygen?

Many patients fear that oxygen is "addicting" and that the more it is used, the more it will be needed. Oxygen is a requirement for life, but the use of oxygen does not lead to an addiction or increasing need for oxygen. Oxygen is needed continuously by the body; and when the lungs are not able to keep up with the body's oxygen needs, it is a good thing that modern medicine can supply patients with the extra oxygen that they need to assure good function of the body's organs. When COPD patients need oxygen, the need continues regardless of if or how much a patient wears oxygen.

If I Start Using Home Oxygen, Will I Ever Get Off of It?

Some patients who are started on oxygen during times of acute worsening will improve over a short period of time to where they no longer require oxygen. Most COPD patients who have low oxygen levels when their disease is stable will require lifetime home oxygen.

How Long Will I Have To Use Oxygen?

Unfortunately, the body can't build up a large storage supply of oxygen. The oxygen level falls back to a low level within 15-20 minutes after oxygen is stopped, regardless of whether the oxygen has been worn for an hour or 12 hours.

Will I Need More Oxygen As Time Goes By?

Not usually. Most COPD patients require two or, at most, three liters of oxygen per minute. They don't require increasing amounts of oxygen over time. Some patients will need more oxygen with exercise and may be instructed to increase their oxygen flow with activity.

Do I Have To Wear My Oxygen All the Time?

If your oxygen level is low off of oxygen, the more time that you wear it each day, the better. Medical studies have shown that patients with low oxygen, who wear oxygen 12 to 15 hours a day, do better than patients who don't wear any oxygen. Patients who wear oxygen 18 to 24 hours a day do better than patients who wear oxygen only 15 hours a day or less.

What If My Oxygen Falls Off During the Night?

Usually nothing happens. Patients who are less short of breath with oxygen will be more short of breath when off oxygen.

Most COPD patients have a mild reduction in the oxygen level that takes a toll on the body over time but doesn't cause an immediate danger. Some patients with more severe symptoms and lower oxygen levels can tell immediately when they are off of oxygen. These patients are careful to wear their oxygen all the time. Some patients will awaken immediately if their oxygen falls off at night. Even if the oxygen falls off for a good portion of the night, it usually does not cause any problem.

What Will People Think When They See Me Wearing Oxygen in Public?

There are nearly a million people in America who wear home oxygen, so most people are used to seeing people wearing oxygen in public. Patients are sometimes sensitive to anything that detracts from how they appear to other people; but today people are used to seeing fellow citizens with many different assistive devices such as crutches, wheelchairs, and motorized carts, and think little or nothing unusual about someone wearing oxygen.

How Will I Get Oxygen at Home?

Your doctor will order oxygen through a homecare company. That company will deliver your oxygen equipment to your home. Most patients on home oxygen use an oxygen concentrator. This is a device that filters and concentrates oxygen out of the air using a dry sieve. It is electrically powered. You will have a large reserve oxygen cylinder to use in case the power in your home goes off or the concentrator stops working. You will also receive small portable oxygen cylinders to use when walking or when away from home. Some patients may receive liquid oxygen systems. These systems combine a large reservoir of liquid oxygen kept in the home and lightweight portable containers for activities away from the home reservoir. Liquid oxygen has been somewhat more expensive to supply in the past. It has been less available in recent years because of shrinking government reimbursement. However, newer liquid oxygen systems cost the supplier about the same as concentrators and small high-pressure tanks that are wheeled outside the home. Some patients may use a combination system with a concentrator for home use and a liquid portable system.

How Can I Wear Oxygen Comfortably Away from My Home?

There are many lightweight portable oxygen systems that allow you to be active while wearing oxygen away from your main oxygen supply. Portable oxygen systems vary in size, weight, and convenience. Table 1 below shows a variety of available portable oxygen systems.

Table 1. Portable Oxygen Systems

Type	Weight (pounds)	Duration at 2 Liters Continuous Flow (hours)	Duration at 2 Liters Pulsed Flow (hours)
Compressed Gas Cylinders			
E-Cylinder	11.00	4.5	10.0
D-Cylinder	7.50	3.0	6.0
M9-Cylinder	5.00	2.0	2.0
M6-Cylinder	3.50	1.0	2.0
Portable Liquid Oxygen Systems			
Puritan Bennett Mark 5	8.00	7.0	NA
Puritan Bennett Mark 6	5.50	4.0	NA
Puritan Bennett Mark 7 (Pulse dose)	5.50	NA	8.0+
Puritan Bennett Helios System	4.25	NA	8.5+
CAIRE Spirit System	4.25	NA	8.5+
Pentax Escort System	4.25	NA	8.5+

E-cylinders and other heavier devices are usually carried on a lightweight wheeled cart. Lighter units can be carried on a shoulder strap or concealed in an over-the-shoulder bag. Oxygen-conserving pulse devices that supply oxygen only when a patient breathes in can extend the duration of portable oxygen tanks. Pulse devices may not give an adequate oxygen supply to all patients but do extend the duration of portable tanks for those patients who can use them.

A Friend of Mine Has Oxygen That Goes into His Neck. You Can't Tell That It's On. Should I Consider That Kind of Oxygen?

Oxygen can be given directly into the windpipe or trachea using a catheter. This is called transtracheal oxygen (Figures 9, 10, & 13). Transtracheal oxygen requires a procedure to place the catheter in the neck. The catheter is more expensive and complicated to maintain than regular oxygen. Transtracheal oxygen is appealing to patients because the oxygen is not worn on the face and can be concealed under a shirt collar. Transtracheal oxygen doesn't work well in COPD patients who produce a lot of secretions, as the secretions can gather on the catheter and create large plugs of mucus.

What Will Happen if I Smoke with My Oxygen On?

Oxygen is not explosive or even flammable. It does support combustion and will make any fire burn more brightly. If you smoke with your oxygen on, you run the risk of igniting your oxygen tubing and sustaining burns to your face. No one should smoke cigarettes around you when you are wearing oxygen. You should stay at least eight feet away from any open flame. Do not use oxygen around any open gas flame such as a gas barbecue.

How Can I Prevent My Nose and Ears from Getting Sore When I Wear Oxygen?

Many patients who start oxygen therapy develop a sore nose. This usually gets better over a fairly short period of time. Sometimes, water-based lubricants such as KY Jelly help. Many patients notice drying in their nose from oxygen, even at low flow rates. This may be improved with the addition of a water bubbler humidifier device to your oxygen system. You can hold your oxygen in your mouth to rest your nose for short periods of time. Foam tubing placed around your oxygen tubing where it crosses the ears often helps protect the ears (also see Figures 7 and 8 – Oxygen Cosmetics and Conveniences).

I Breathe Through My Mouth When I Sleep or Exercise. Will My Oxygen Still Work if I Wear It in My Nose?

Yes. Oxygen running into your nose fills the nasal cavity and back of the throat with oxygen that gets drawn into the lungs even if you breathe through your mouth. The physical principle that draws the oxygen down into the lungs is called the "Venturi Effect."

Oxygen Is Expensive. Can I Afford Oxygen?

Your medical insurance will cover most of the cost for your oxygen. For example, a Medicare patient with supplemental insurance who is renting a concentrator and portable system usually pays nothing for oxygen. Patients with Medicare, but no co-insurance, may be required to pay 20% of the oxygen charge, which is usually around $30 or $40 a month. Most insurance plans fund oxygen on a rent-to-own basis. After a certain period, you own your equipment. Insurance usually doesn't cover the cost of electricity required to run an oxygen concentrator.

Will I Be Able To Travel with Oxygen?

Many patients travel long distances in their cars using larger compressed gas cylinders or liquid systems (see Liberator 10, page 37) that are supplied by their homecare company. Most airlines will supply oxygen for you in airplanes, but there is an additional charge not covered by insurance. Your airline may help arrange oxygen for you in the airport, or your homecare company may need to arrange oxygen for you in the airport before you board the plane. Arrangements for oxygen on airplanes need to be made well in advance of planned travel. Oxygen is widely available nationwide. Your homecare company can help arrange oxygen supplies for you at your destination so that the supplies are in place and waiting for you at your destination.

APPENDIX B: PRESCRIBING LTOT

Indications for LTOT

Table 2 lists the commonly accepted indications for LTOT and the requirements for oxygen prescription from the Centers for Medicare and Medicaid Services (CMS), formerly known as Health Care Financing Administration (HCFA) and certain insurance plans. When daytime normoxia is present, but sleep-related hypoxemia has been established by continuous nocturnal monitoring of oxygen saturation, oxygen can be prescribed during the hours of sleep when there is clinical evidence of harm from the consequences of hypoxemia, i.e., morning headaches, clinical evidence of pulmonary hypertension and erythrocytosis. Similarly, if exercise-related hypoxemia is demonstrated by pulse oximetry, ambulatory oxygen can be prescribed and is particularly appropriate if it can be demonstrated that improved exercise-tolerance results are from ambulatory oxygen therapy.

Table 2. General Prescribing Guidelines for Home Oxygen Patients with Advanced COPD

Patient Selection Criteria
• Stable course of disease on optimum indicated medical therapy, e.g., bronchodilator, antibiotics, corticosteroids
• At least two arterial blood gas determinations while breathing air for at least 20 minutes
• Room air PO_2 consistently 55 or less, or consistently 55 to 59 + cor pulmonale clinically diagnosed, or hematocrit 55% or greater
• Normoxic patients, when less dyspnea and increased exercise tolerance are demonstrated with oxygen
Oxygen Dose
• Continuous flow by double lumen nasal cannula
• By demand system with demonstration of adequate oxygen saturation
• Lowest liter flow to raise PO_2 to 60 to 65 or oxygen saturation to 88% to 94%
• Increase baseline liter flow by 1 liter/min. during exercise and sleep
Expected Outcomes
There are many benefits of LTOT for patients who require it. Some of the most noted and well-documented outcomes are:
• Improved tolerance of exercise and other ambulatory activities
• Decreased pulmonary hypertension
• Improved neuropsychiatric function
• Decreased erythrocytosis and polycythemia
• Reduced morbidity and mortality
• Increased length of life

APPENDIX C:
TYPES OF HOME OXYGEN SYSTEMS

Long-Term Home Oxygen Therapy (LTOT)

Massive technological advances have changed the expanding applications of LTOT. Beginning historically, high-pressure cylinders, liquid portable systems, and oxygen concentrators have all evolved (see Table 3 below). Today, high pressure

Table 3: Comparison of Attributes of Available Home Oxygen Systems

Liquid Portable	Concentrators	Compressed Gas
Advantages:		
1. Light weight	1. Lower cost in general (cost may equal liquid in continuous use situations)	1. Higher cost
2. Long-range portable canister	2. Convenient at home	2. Widespread availability
3. Most practical ambulatory system	3. Attractive equipment	3. Not a practical ambulatory system with E-cylinders. Better with multiple low-weight compressed gas cylinders, such as M6
4. Valuable for pulmonary rehabilitation	4. Lower cost concentrators (compressed gas)	4. Only low-weight M6 tanks good for exercise
5. 100% oxygen at all flow rates rates	5. Not 100% oxygen; usually about 95% at higher flow rates	5. 100% oxygen available at all flow
Disadvantages:		
1. More expensive than concentrators used alone	1. Electricity required 2. Stationary system	1. Multiple tanks necessary for ambulation unless transfilling can be done at home
2. Not available in some small or rural communities	3. May need back-up tank system for electrical failure	2. Frequent deliveries needed
	4. Not portable; does not assist in ambulation or pulmonary rehabilitation	3. Heavy and unsightly tanks; not as effective in pulmonary rehabilitation
	5. Noise	

cylinders are not commonly used as the primary home source of LTOT. A series of smaller tanks offer various degrees of "portability;" and even the smallest may be useful in promoting ambulation, the key to the physiological and restorative benefit for LTOT. Said another way, it is not just the oxygen that corrects blood oxygen deficits (i.e., saturation and content), but the ability to improve the delivery of energy-producing oxygen to the tissues of the body that is key.

The original liquid portable device, first called "The Linde Walker," weighed just over nine pounds and provided four hours of oxygen at two liters per minute with constant flow. Now, three extremely lightweight ambulatory devices are available: the Helios, Spirit, and Escort, which weigh slightly more than four pounds when full and deliver oxygen for eight hours per filling or more at very low flow rates.

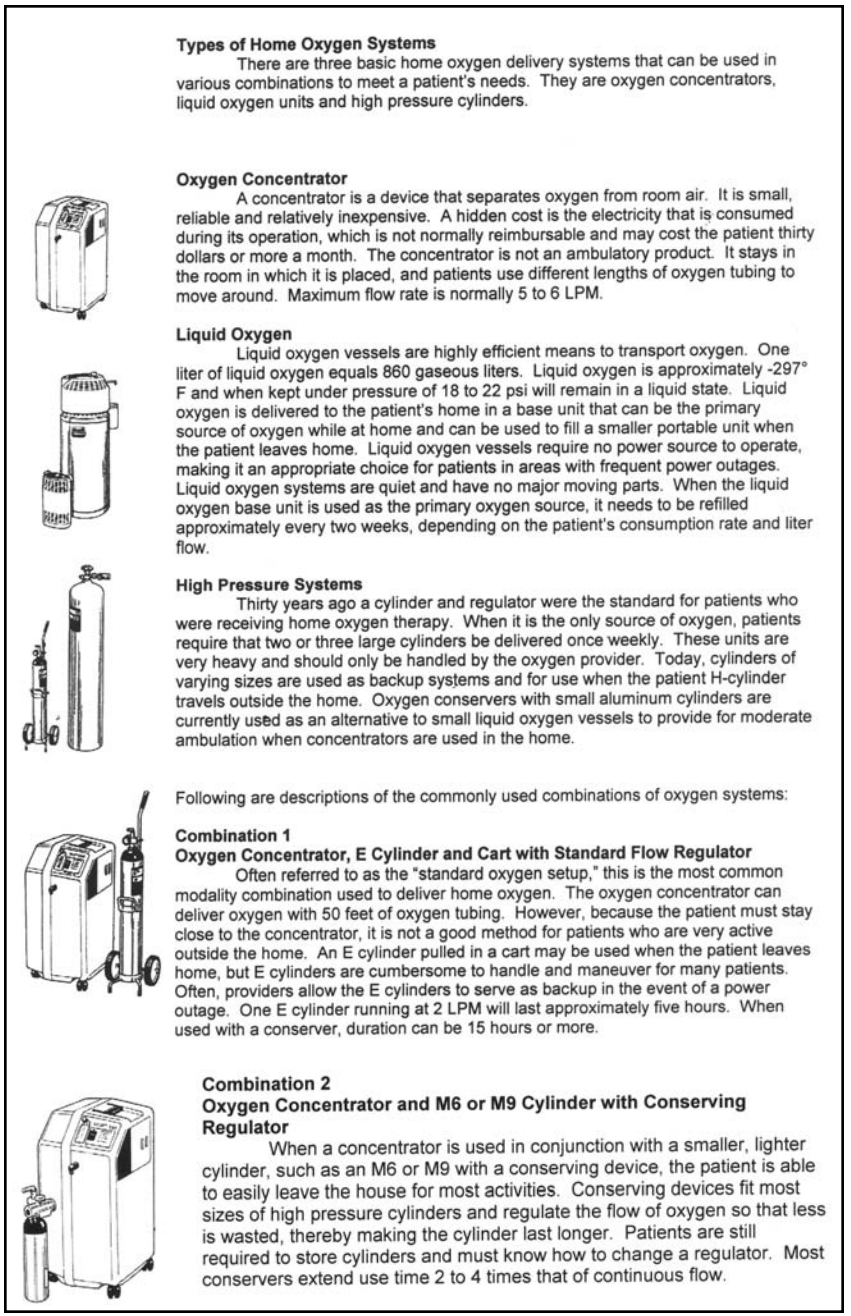
Concentrators have been improved and made less bulky and more efficient. The first of the new generation of portable concentrators weighs slightly less than 10 pounds. Battery life and alarm noise are significant drawbacks. But used with auxiliary power for AC and DC, these devices are soon to be a boon for travelers and where small liquid systems are not commonly available. Newer portable oxygen concentrators are soon to be introduced.

Oxygen conserving devices (OCD) are commonly used to control the flow of oxygen during inspiration only. These limit the amount of oxygen per breath and the efficiency of conserving oxygen while still providing adequate oxygenation of the arterial blood.

Figure 15 offers sketches of the oxygen systems that have been in most common use in the United States until recently. The availability of oxygen technologies varies greatly by country. Better systems are now available, and Figure 16 gives sketches of the newest and most efficient light-weight ambulatory oxygen devices. Also, portable oxygen concentrators (not shown in Figure 16) are being introduced.

Table 4 lists the patient interface options that can be used with ambulatory/stationary liquid systems, concentrators or high-pressure cylinders. By far, nasal cannula are used most often, either alone or with other oxygen convenience (cosmetic) systems. See Oxy-View glasses and Oxy-Snooze masks (pages 24-27).

LTOT use is growing in the United States. Today. approximately one million patients use LTOT. New oxygen systems are being developed to meet the needs of younger and more



Types of Home Oxygen Systems

There are three basic home oxygen delivery systems that can be used in various combinations to meet a patient's needs. They are oxygen concentrators, liquid oxygen units and high pressure cylinders.

Oxygen Concentrator

A concentrator is a device that separates oxygen from room air. It is small, reliable and relatively inexpensive. A hidden cost is the electricity that is consumed during its operation, which is not normally reimbursable and may cost the patient thirty dollars or more a month. The concentrator is not an ambulatory product. It stays in the room in which it is placed, and patients use different lengths of oxygen tubing to move around. Maximum flow rate is normally 5 to 6 LPM.

Liquid Oxygen

Liquid oxygen vessels are highly efficient means to transport oxygen. One liter of liquid oxygen equals 860 gaseous liters. Liquid oxygen is approximately -297° F and when kept under pressure of 18 to 22 psi will remain in a liquid state. Liquid oxygen is delivered to the patient's home in a base unit that can be the primary source of oxygen while at home and can be used to fill a smaller portable unit when the patient leaves home. Liquid oxygen vessels require no power source to operate, making it an appropriate choice for patients in areas with frequent power outages. Liquid oxygen systems are quiet and have no major moving parts. When the liquid oxygen base unit is used as the primary oxygen source, it needs to be refilled approximately every two weeks, depending on the patient's consumption rate and liter flow.

High Pressure Systems

Thirty years ago a cylinder and regulator were the standard for patients who were receiving home oxygen therapy. When it is the only source of oxygen, patients require that two or three large cylinders be delivered once weekly. These units are very heavy and should only be handled by the oxygen provider. Today, cylinders of varying sizes are used as backup systems and for use when the patient H-cylinder travels outside the home. Oxygen conservers with small aluminum cylinders are currently used as an alternative to small liquid oxygen vessels to provide for moderate ambulation when concentrators are used in the home.

Following are descriptions of the commonly used combinations of oxygen systems:

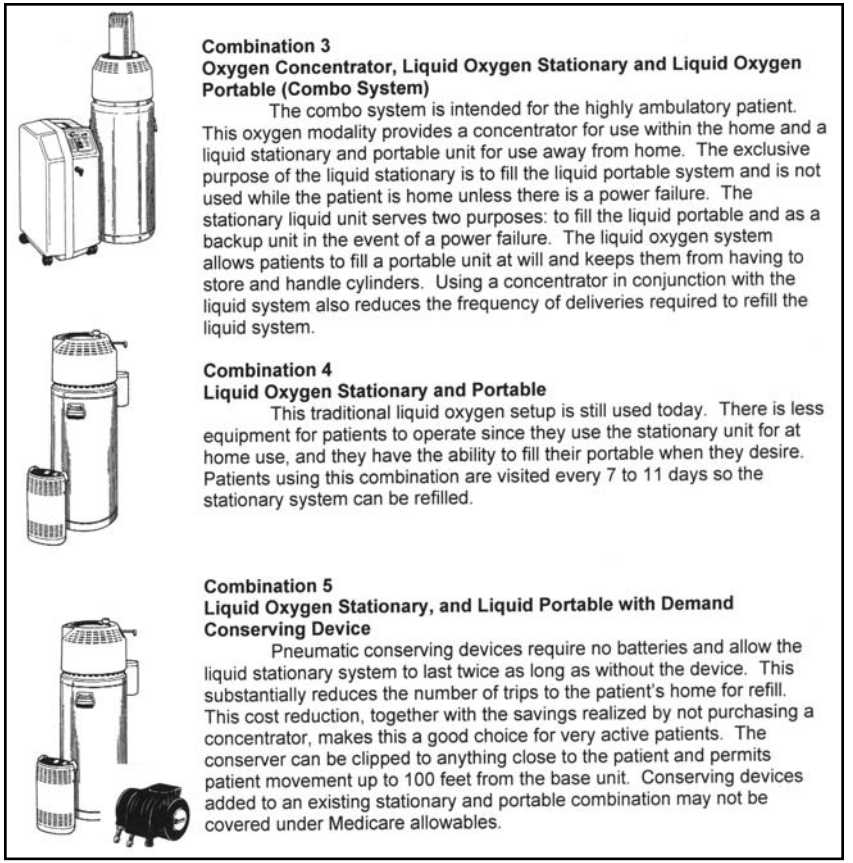
Combination 1
Oxygen Concentrator, E Cylinder and Cart with Standard Flow Regulator

Often referred to as the "standard oxygen setup," this is the most common modality combination used to deliver home oxygen. The oxygen concentrator can deliver oxygen with 50 feet of oxygen tubing. However, because the patient must stay close to the concentrator, it is not a good method for patients who are very active outside the home. An E cylinder pulled in a cart may be used when the patient leaves home, but E cylinders are cumbersome to handle and maneuver for many patients. Often, providers allow the E cylinders to serve as backup in the event of a power outage. One E cylinder running at 2 LPM will last approximately five hours. When used with a conserver, duration can be 15 hours or more.

Combination 2
Oxygen Concentrator and M6 or M9 Cylinder with Conserving Regulator

When a concentrator is used in conjunction with a smaller, lighter cylinder, such as an M6 or M9 with a conserving device, the patient is able to easily leave the house for most activities. Conserving devices fit most sizes of high pressure cylinders and regulate the flow of oxygen so that less is wasted, thereby making the cylinder last longer. Patients are still required to store cylinders and must know how to change a regulator. Most conservers extend use time 2 to 4 times that of continuous flow.

Figure 15. Different Types of Historical LTOT Techniques (page 1 of 2)



Combination 3
Oxygen Concentrator, Liquid Oxygen Stationary and Liquid Oxygen Portable (Combo System)

The combo system is intended for the highly ambulatory patient. This oxygen modality provides a concentrator for use within the home and a liquid stationary and portable unit for use away from home. The exclusive purpose of the liquid stationary is to fill the liquid portable system and is not used while the patient is home unless there is a power failure. The stationary liquid unit serves two purposes: to fill the liquid portable and as a backup unit in the event of a power failure. The liquid oxygen system allows patients to fill a portable unit at will and keeps them from having to store and handle cylinders. Using a concentrator in conjunction with the liquid system also reduces the frequency of deliveries required to refill the liquid system.

Combination 4
Liquid Oxygen Stationary and Portable

This traditional liquid oxygen setup is still used today. There is less equipment for patients to operate since they use the stationary unit for at home use, and they have the ability to fill their portable when they desire. Patients using this combination are visited every 7 to 11 days so the stationary system can be refilled.

Combination 5
Liquid Oxygen Stationary, and Liquid Portable with Demand Conserving Device

Pneumatic conserving devices require no batteries and allow the liquid stationary system to last twice as long as without the device. This substantially reduces the number of trips to the patient's home for refill. This cost reduction, together with the savings realized by not purchasing a concentrator, makes this a good choice for very active patients. The conserver can be clipped to anything close to the patient and permits patient movement up to 100 feet from the base unit. Conserving devices added to an existing stationary and portable combination may not be covered under Medicare allowables.

Figure 15. Different Types of Historical LTOT Techniques (page 2 of 2)

mobile patients. There is currently a general lack of knowledge of the needs, applications, and use of existing oxygen systems, which makes improvements for LTOT difficult for manufacturers and providers. The wide array of options in oxygen therapy is confusing to both physicians and patients. It is not possible in this brief section to give all of the details about the various oxygen technologies and common use, let alone about those on the drawing boards. Suffice it to say that things are rapidly changing.

Helios Personal Oxygen System
Weight 4.25 lbs full
Flow: Continuous: 0.12, 0.25, 0.50, 0.75 L/M; Intermittent at 1.0, 1.5, 2.0, 2.5, 3.0, 3.5, 4.0 L/M
Range: 6-8 hours

CAIRE's Liberator 10.
Designed for Travel
Capacity: 10.7 L (liquid)
26 pounds, (11, 8 Kg) (empty)
52 lbs full
8,881 L (gaseous)
Selectable Flow Rates (LPM): Intermittent 1, 1.5, 2, 3, 4, 5; continuous 2L

CAIRE's Spirit 300
Liquid Capacity: 0.3 liters
Weight: 3.5 lbs (1, 6 kg) empty
4.3 lbs (1, 95 kg) full
Range: 9 hours at 2 LPM & 16 BPM;
7 hours at 2 LPM & 20 BPM
Approximate battery life of 500 hours

(Not Shown)

Combination 6
Liquid Oxygen Stationary, Liquid Portable and Small Concentrator

This combination is most useful for traveling by car. The small concentrator can be plugged into the car power source to conserve the liquid system for ambulation and sleep. The small liquid unit can be refilled from the Liberator 10 liter, CAIRE, unit.

Figure 16. Newest and Most Practical Liquid Oxygen Portable Systems

Table 4. Home Oxygen Options: Patient Interfaces

Device	Flow	FIO_2	Appropriate Use
Nasal Cannula	1/4-8 LPM	22-45%	Long-term oxygen therapy patients
Transtracheal Catheter	1/4-4 LPM	22-45%	Patients who don't accept cannula, high flow requirements
Reservoir Cannula	1/4-4 LPM	22-35%	LTOT patients
Simple Mask	6-12 LPM	35-50%	Acute short-term therapy requiring moderate FIO_2
Reservoir Mask	6-10 LPM	35-60%	Emergencies, acute hypoxemia, moderate FIO_2
Non-Rebreather Mask	10-15 LPM	80-100%	Emergencies, respiratory failure

It must be *emphatically stated* that there is no one system or device that meets the needs of all patients. Thus the oxygen prescription and patient's understanding about the goals and objectives of oxygen therapy are key. Unfortunately, many physicians and patients alike find oxygen use in the home confusing, conflicting, and formidable. This leads to inadequacies of oxygen use, misunderstanding of manufacturers and suppliers, and ambiguity and antipathy on the part of most payors, i.e., CMC (formerly HCFA). The flat statement that "oxygen is oxygen" is a cop-out. Sure, one oxygen molecule is the same as another oxygen molecule no matter what its source. But how it is delivered to the patient, how it can be delivered and administered most efficiently and conveniently is a very complex issue. Today, it is a fact that CMC considers oxygen reimbursement as "modality neutral." The history behind this inadequate concept is too complex to relate in a few pages. Suffice it to say that this "is the law." But, if reimbursement is really modality neutral, why do some suppliers only offer concentrators and E-cylinders as the basic home oxygen unit? The answer is that they make more profit from concentrators and E-cylinders than from modern ambulatory systems. They often offer inadequate reasons for the need for LTOT. The "right thing" is to be honest about the fact that there are many advantages to various different oxygen systems.

"One size" is not appropriate for oxygen therapy. Things really get complex with the newer evolving technologies, which involve oxygen conserving devices that allow for the greater length of life of canisters, i.e., liquid or gaseous oxygen, limiting the flow of oxygen to the act of inspiration.

Concentrators have been improved and made less bulky and more efficient. The first of the new generation of portable concentrators weighs slightly less than 10 pounds. Battery life and noise from the alarm system on one early unit were significant drawbacks. Newer batteries last up to four hours; but used with auxiliary power for AC and DC, these devices are a boon to travelers where small liquid systems are not commonly available.

Oxygen conserving devices are commonly used to control the flow of oxygen during inspiration only. These limit the amount of oxygen per breath and the efficiency of conserving oxygen while still providing adequate oxygenation of the arterial blood.

Technologic differences between the newest devices that are available on a growing number of ambulatory systems are too complex to recount on these pages. Suffice it to say that "the bottom line" is that adequate oxygenation is judged by the pulse oximetry under conditions of rest, exercise, and during sleep. This requires appropriate monitoring by the health team, patients, and, at times, by the supplier.

Finally, it is certain that oxygen technologies will continue to evolve, perhaps even before this book goes to press. The possibility that oxygen reimbursement curbs "competitive bidding" threatens to limit both technologic advances and reimbursement for truly ambulatory systems. This should not be allowed to happen, and a vigorous attack on arbitrary constraints in oxygen use would and should be a challenge to all Oxy-Philes!

APPENDIX D: OXYGEN

Oxygen is the most common element in the earth's crust. Thus, it is obviously part of God's plan. Most oxygen, however, exists in the form of oxygen involved in mineral and rocks. The oxygen that we breathe does not come from this source. It comes from the process of photosynthesis, which is the conversion of carbon dioxide to oxygen that only plants can do. The vast majority of photosynthesis occurs in algae in the sea. Carbon dioxide originally came from the atmosphere, which probably resulted from "the big bang." In any case, carbon dioxide and photosynthesis create oxygen.

Joseph Priestly, a Unitarian minister, first isolated oxygen from chemicals and breathed (along with two mice) this mixture in 1774 .

"Who knows, but in that time this pure air (Priestly's word for oxygen) would become a fashionable article of luxury." How prophetic. Yet oxygen is not a luxury; it is a necessity of life. Priestly's American home in the borough of Northhumberland, Pennsylvania, at the branch of the Susquehanna River, is preserved as a museum and should be visited by all Oxy-Philes.

As all energy on earth can be traced to the sun's energy, it is appropriate to trace the evolution of oxygen to the sun because the earth's original oxygen was most likely formed by the photo–dissociation of water by ultraviolet light from the sun. The amount of oxygen produced this way was small and probably of the order of magnitude of about one-thousandth the oxygen concentration presently in our atmosphere. In fact, the amount of oxygen was probably fixed until the development of life itself because it is a living process, photosynthesis, that creates most of the oxygen in the atmosphere. Photosynthesis began approximately a billion years ago when early traces of algae were formed from water, carbon dioxide, and ammonia that were available in the primordial sea that bathed most of this planet. First came a series of more complex organic compounds and finally the first primitive photosynthesis cells that were crucial to the evolution of all life. Briefly the process of photosynthesis is the reaction of $CO_2 + H_2 + UV + chlorophyll = O_2 + by\text{-}products$.

At this point in the evolution of the earth, the atmospheric oxygen concentration increased rapidly to a new order of mag-

nitude. The final concentration became stabilized by the fact that the increased production of oxygen encouraged respiration and the consumption of oxygen, which in turn reduced the amount of oxygen available. Thus, by about a half a billion years ago there was very active photosynthetic life and the evolution of multicellular organisms in water. However, it took many millions of years for enough ozone to be generated from oxygen to be released into the atmosphere, which in turn would screen out the ultraviolet light to a sufficient degree to permit life to exist on land. These steps in the evolution of oxygen are intimately intertwined with the evolution of life itself and the transition of life from sea to land. Once an atmospheric "steady state," meaning a balance between production and consumption of oxygen, was achieved, terrestrial life and further evolution became possible.

The concentration of oxygen in the air is 20.9%; and this concentration has remained constant during the evolution of higher forms of life. including man. Somewhere in this evolution, the oxidative enzymes developed together with the mitochondria that are necessary factors to maintain the cellular integrity and function of aerobic organisms. Mitochondria are dedicated to energy production. Most of the oxygen that reaches the mitochondria is "handled" in the production of high-energy phosphate bonds (ATP). Oxygen functions as an electron acceptor and allows energy to be produced by electron transfer from hydrogen activation from foodstuffs. Thus, living systems made of matter must be driven by energy; and oxygen is essential in this energy cascade! Oxygen is also used by enzymes called oxygenases that are necessary in the development of neurotransmitters that control the functional integrity of the intact organism. Thus, oxygen, which is one of the most common elements in the earth's crust (as water or part of the matrix of minerals, but in this form unavailable for respiration) is an essential ingredient for aerobic life. Oxygen consumption is central to the process of energy development, much of which is used for the maintenance of cellular and, thus, tissue integrity as well as the functional control of integrated organ systems. Without this, there could be no life as we understand it.

So much for the history of the evolution of oxygen — a colorless, odorless, tasteless gas upon which we depend so absolutely and completely. Yet oxygen is essentially taken for granted unless it becomes in short supply!

The oxygen is breathed, thus traversing the upper and lower airways by the process of ventilation, and is then transmitted across the alveolocapillary membrane barrier by diffusion to the hemoglobin and carried to the tissues for the process of high-energy metabolism in the mitochondria. The oxygen tensions (pressures available for gas movement) in each of these steps are depicted in Figure 17, based upon sea level values. The concentration of oxygen in the atmosphere, of course, is fixed at 20.9% but the amount of oxygen in the inspired air is inversely proportional to altitude in a fairly linear fashion as illustrated in Table 5.

The arterial oxygen tension in relation to altitude is not perfectly linear because of ventilatory compensations caused by the response to hypoxemia. With augmented ventilation, the alveolar and, thus, the arterial oxygen tension are slightly increased due to the reciprocal relationship between alveolar PO_2 and PCO_2 in the alveolar air (Figure 18). This affects the resulting arterial oxygen and carbon dioxide tensions (Table 5).

Table 5. Oxygen Tensions of Various Altitudes (mm Hg) Inhabited by Man

Meters	Feet (Approx.)	Barometric Pressure	PIO_2	PaO_2	SaO_2	$PaCO_2$
0	0	760	149	95	98	41
1,500	5,000	630	122	67	92	38
2,500	8,000	564	108	60	89	37
3,000	10,000	523	100	53	85	36
3,600	12,000	483	91	52	83	35
4,600	15,000	412	76	44	75	31
5,500	18,000	379	69	40	71	29

Also, because of the shape of the oxygen hemoglobin dissociation curve, Figure 19, a significant reduction in inspired and, thus, arterial PO_2 can occur with little effect on oxygen amount (i.e., oxygen saturation). Oxygen saturation refers to the amount of oxygen carried by hemoglobin compared to the capacity for oxygen carried under ideal conditions expressed as a percent (Figure 19). This is why the oxygen tension can fall from a normal of 80 to 100 at sea level to 60 to 70 at Denver with essentially no difference in the oxygen saturation of hemoglobin as dictated by the oxyhemoglobin dissociation curve.

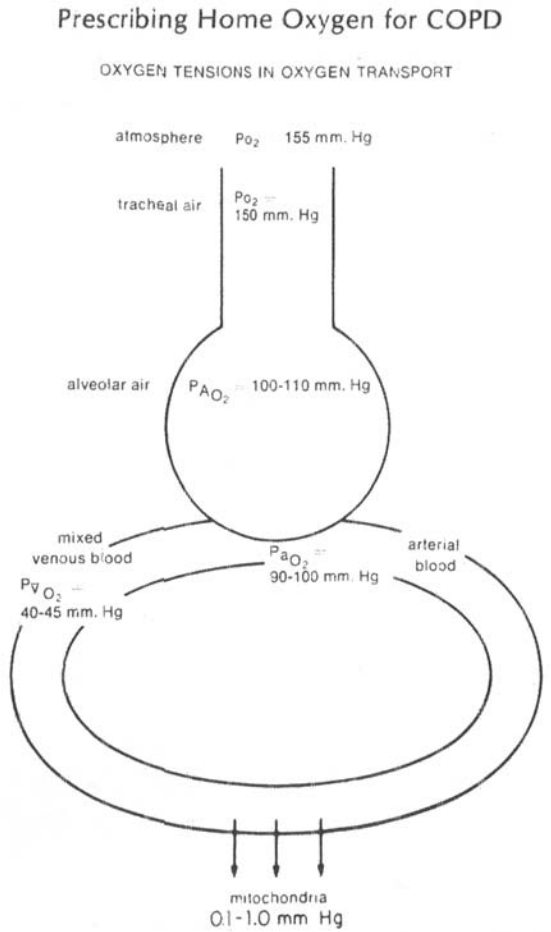


Figure 17. Oxygen tensions in the transport of oxygen to the tissues beginning with atmospheric tension. Tracheal air oxygen tension, alveolar air oxygen tension, arterial oxygen tension, probable oxygen tension at the mitochondrial level where metabolism takes place and normal mixed venous oxygen tensions are listed.

Greater altitudes begin to stress the system; but compensations of increased cardiac output, adjustments in red cell mass with shifts in the oxyhemoglobin dissociation curve to the left to carry more oxygen, and some fancy biochemical adjustments that will allow for the unloading of oxygen at the tissue level to be more efficiently increased (2, 3-diphosphoglycerate), allow for adaptation to high altitudes.

Thus, man can exist for at least short periods at the highest reaches of our planet. Mt. Everest, for example, has been

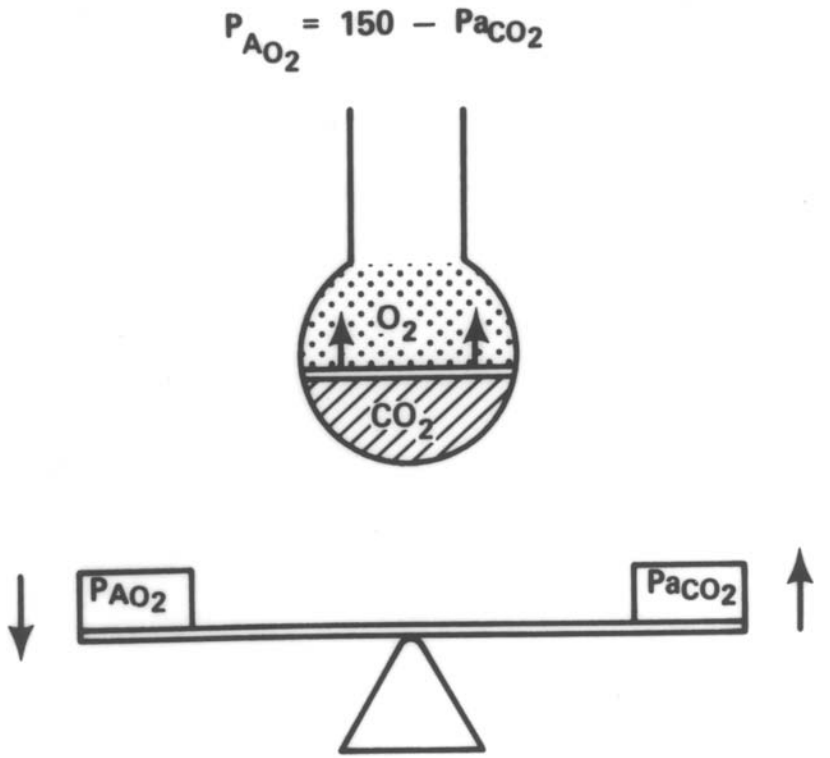


Figure 18. Graphic representation of the reciprocal relationship between alveolar oxygen tension and CO_2 tension. An assumption is made that arterial and alveolar CO_2 tensions are the same, which is essentially true in health. A modified alveolar air equation makes the same assumption (top of figure).

ascended recently without the aid of supplemental oxygen! This almost unbelievable feat, however, is only possible by virtue of exquisitely responsive compensatory mechanisms that include cardiac output, red cell mass, biochemical alterations of blood favoring delivery of oxygen to tissues, and probably the tolerance of a low level of oxygen, which if sustained could not support life. Figure 20 reproduces the oxyhemoglobin dissociation curve and indicates the oxygen tensions where man has lived or climbed!

When we return to the purpose of this brief monograph — which is the use of oxygen in patients with COPD and related disorders i.e., "oxy-philes" — we must be constantly mindful of the fact that the individual patient with hypoxemia is not endowed with athletic compensatory mechanisms. Thus, they

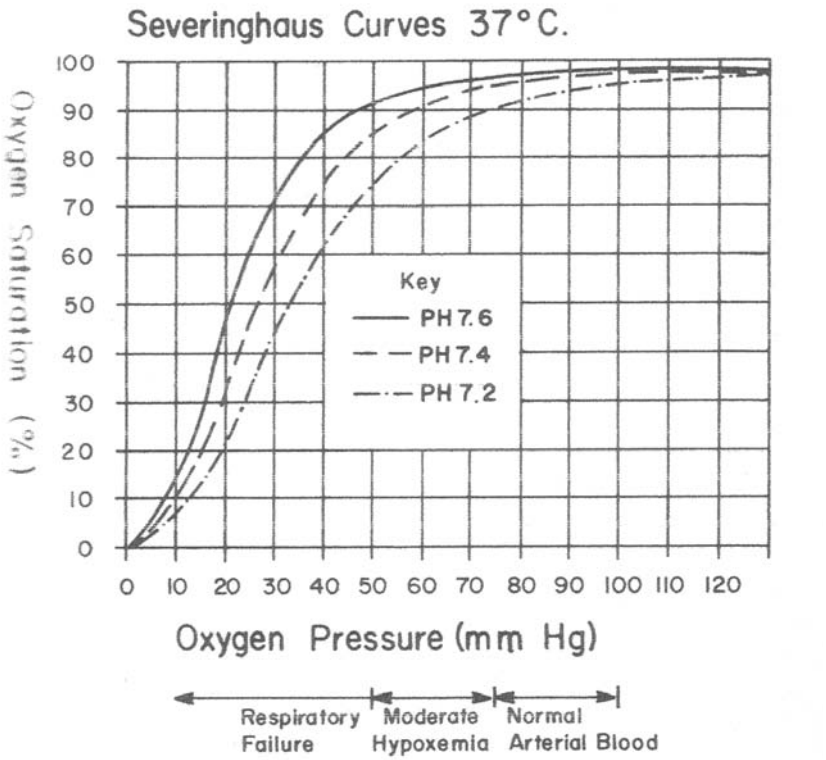


Figure 19. Classic Severinghaus oxyhemoglobin dissociation curve relating oxygen saturation to oxygen tension. Effect of pH change is indicated.

may suffer severe consequences of hypoxemia such as pulmonary hypertension, right heart strain, cerebral dysfunction, and possibly other organ system dysfunction at *higher levels* of arterial oxygenation than do normal people with these compensations. Indeed, and perhaps more importantly, the patient with COPD, usually older and less physically fit and having been exposed to many years of hypoxemia, finally succumbs to the ravages of oxygen lack. This usually occurs at a sustained arterial oxygen tension of 55 or less. It must be admitted, however, that there is considerable individual variation in a patient's ability to tolerate hypoxemia. Many normal individuals can live comfortably and productively at high altitudes, as high as 17,000 feet, in the Peruvian Mountains with oxygen tensions in the high 30s and no apparent damage. In fact, some patients with COPD and chronic levels of severe hypoxemia (e.g., PO_2 40 to 50) seem to tolerate this partly anaerobic state very well

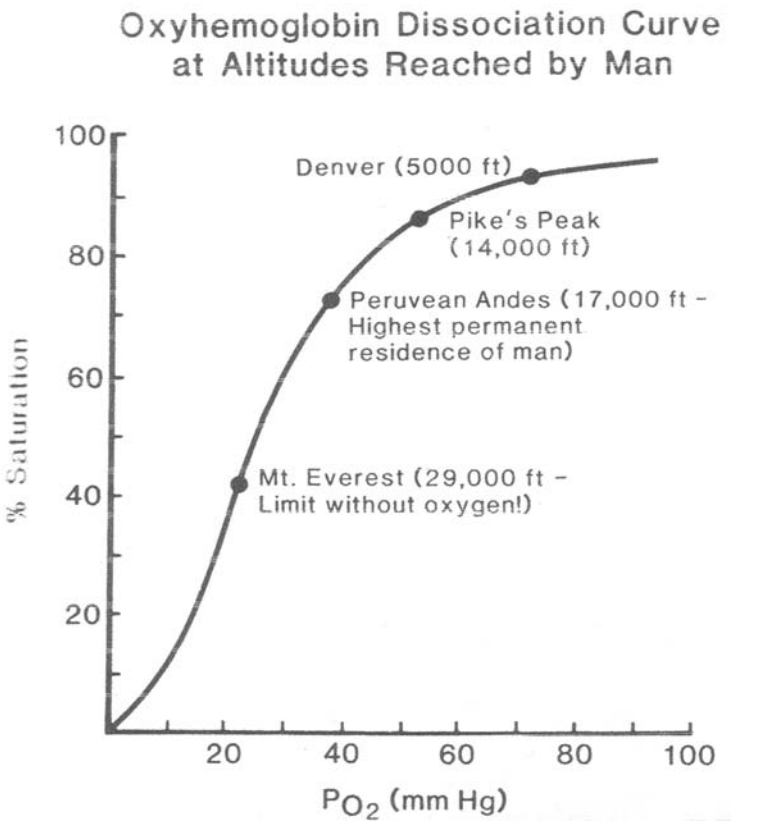


Figure 20. Oxygen saturation in relation to altitudes achieved by man.

for reasons that are not entirely understood. Thus, man can live in relative comfort at a barometric pressure that is reduced by nearly one-half and with what clinicians would view as alarming hypoxemia; but this is only possible by major compensatory mechanisms that are not present in most patients with advanced COPD.

This book deals with the COPD patient and others who are candidates for oxygen, and the value of oxygen therapy, particularly ambulatory oxygen; approaches to the therapy that may return the patient to a functional optimum. The focus is on oxygen therapy, which is often an important step in preserving health and functioning and preventing or forestalling premature morbidity or mortality from COPD and related disorders. It also focuses on the various evolving oxygen systems and their respective advantages in certain clinical situations.

APPENDIX E: SUGGESTED ADDITIONAL READING

A. Books (for the Layman)

1. Petty TL, Nett LM: Enjoying Life With COPD. 3rd Ed (1995). Laennec Press, Cedar Grove, NJ 200 p. (Available from Barnes & Noble)
2. Good JT Jr, Petty TL (eds): Frontline Advice for COPD Patients. 99 p. Snowdrift Pulmonary Conference 2002 (Available from Boehringer Ingelheim Pharmaceutical Representatives, worldwide. Also free of charge by downloading at www.NLHEP.org)
3. Gorby JP. Breathin' Easy Travel Guide (contains more than 2,500 listings throughout the world, over 1,700 cities in USA and Canada). Updated annually. Toll Free 888 699 4360; FAX 707 252 3028.

B. Articles (Scientific Literature)

1. Ward MR. Everest 1953, First Ascent: A Clinical Record. High Altitude Medicine & Biology 2003;4:27-43.
2. Petty TL: Home Oxygen – A Revolution in the Care of Advanced COPD. Med Clin North America 1990;74:715-729.
3. Petty TL: Historical Highlights of Long-Term Oxygen Therapy. Respir Care 2000;45:29-38.
4. Petty TL, Bliss PL: Ambulatory Oxygen Therapy, Exercise, and Survival with Advanced Chronic Obstructive Pulmonary Disease. (The Nocturnal Oxygen Therapy Trial revisited). Respir Care 2000;45:204-213.
5. Nocturnal Oxygen Therapy Trial Group: Continuous or Nocturnal Oxygen Therapy in Hypoxemic Chronic Obstructive Pulmonary Disease. Ann Intern Med 1980;93:391-398.

C. Books (for Clinicians and Scientists)

1. Barach AL: Principles and Practices of Inhalational Therapy. Lippincott, PA, 1944, 315 p.
2. Petty TL: Prescribing Home Oxygen for COPD. Thieme-Stratton Inc., NY 1982, 121 p.
3. O'Donohue WJ Jr: Long Term Oxygen Therapy; Scientific Basis and Clinical Application. M Decker, NY, 1995, 391 p.

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