

HORSE SENSE & OXYGEN

I have severe COPD, Chronic respiratory failure with hypoxia and have been on oxygen 24/7 for 10 years. My prescription is for 3 to 4 LPM. At 4 LPM walking will drop my blood oxygen level into the low 80s and with exertion into the 70s.

YET I STILL PLAY PICKLEBALL AND AM VERY ACTIVE!!!

I visit National and State Parks, museums plus other events that interest me. I am physically and mentally active, which contributes to a higher quality of life and better health. I need 10 LPM to play pickleball and use 5 to 10 LPM when out and about and active.

Why are few using supplemental oxygen out and about enjoying life???

They are not getting the oxygen needed to be active!!!

Horse Sense & Medical Oxygen

In August and September of 2022, I took a 6,000-mile, five-week road trip from North Carolina to the Northwest and back. I spent two weeks with family and the rest of the time camping, and visiting national and state parks, museums, and other places of interest. A great road trip like this would have been impossible for me without Liquid Oxygen(LO).

Four years earlier, I drove from Burns, Oregon, to a wedding in Parkfield, California, a round trip of 1,600 miles. I was in a motel every night, so I could refill my oxygen tanks with a Respironics UltraFill System. I needed to wake up and change out the tanks several times during the night. My blood oxygen level was often in the eighties, and I was tired most of the time.

It seems backward that I struggled on the 2018 trip, and the 2022 trip was great. COPD does not improve with time! But the answer is simple. It is all about getting the oxygen needed to stay active and healthy. I had an Eclipse 5 and a liquid oxygen system in 2022 to supplement the Respironics UltraFill.

Activity Promotion: A Paradigm Shift for Chronic Obstructive Pulmonary Disease Therapeutics

It is notable that the studies of interventions designed to increase activity levels in COPD have not featured long-term follow up. Durability of activity improvement resulting from physical activity interventions has been hard to achieve in older adults (38). Especially in the case of pulmonary rehabilitation, there is reason to question whether short-term increases inactivity levels will persist in most participants unless the pro-gram features a formal long-term component.

Proceedings of the American Thoracic Society, Volume 8, Issue 4 Aug 2011, Pages 333-379

A RESET IS NEEDED FOR THE TREATMENT OF COPD WITH A FOCUS ON QUALITY OF LIFE

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My thoughts are in green. For more information contact (Gerald) Skip Miller at hors.sens1@gmail.com

(Year the research is from) Followed by the research title which is also a link to the research and the research URL for those with a hard copy. Then a short clip from the research to help me make a point.

In the 1990s shortness of breath became more noticeable and my coughing increased. By 2000 I became aware my blood oxygen levels were dropping. (Part of my history and the example)

(1992) [Portable liquid oxygen and exercise ability in severe respiratory disability.](https://thorax.bmj.com/content/47/10/781)

<https://thorax.bmj.com/content/47/10/781>

Liquid oxygen systems are regarded as necessary for mobility in the United States, but patients' attitudes are probably different in the United States and in Britain. A pilot study by Wedzicha and colleagues showed that patients increased their activity and their use of oxygen when provided with a liquid rather than a gaseous supply.

I am sure the same is still true today, for both tanks and now pocs.

(1992) [Comparison of liquid and gaseous oxygen for domiciliary portable use](https://thorax.bmj.com/content/thoraxjnl/47/2/98.full.pdf)

<https://thorax.bmj.com/content/thoraxjnl/47/2/98.full.pdf>

Liquid oxygen might be especially suitable for the patient with chronic respiratory disability who could possibly return to regular employment if an eight hour supply of portable oxygen were conveniently available.

I know what liquid oxygen has done for me since the spring of 2022 and I believe I could have continued working in 2014 given a prescription for 6+ LPM of liquid oxygen. I would not have needed to apply for Social Security Disability Income in!

(2003) [Benefits of Supplemental Oxygen in Exercise Training in Nonhypoxemic Chronic Obstructive Pulmonary Disease Patients \(atsjournals.org\)](https://www.atsjournals.org/doi/epdf/10.1164/rccm.200212-1525OC?role=tab)

<https://www.atsjournals.org/doi/epdf/10.1164/rccm.200212-1525OC?role=tab>

In summary, we have shown in moderate and severe COPD patients who do not experience appreciable desaturation during exercise that providing supplemental oxygen during high-intensity endurance training adds to the benefits of training. Training intensity could be kept at a higher level, and apparently as a result, endurance capacity and breathing pattern improved significantly more in patients using supplemental oxygen. In pulmonary rehabilitation, when starting a high-intensity exercise program, supplemental oxygen may be considered for COPD patients with a moderate or severe degree of airflow obstruction.

Instead of following science, Congress limited payments for supplemental oxygen basically ending access to liquid oxygen. Limiting supplemental oxygen increases health costs, lowers patients quality of life and

accelerates the downward spiral of deconditioning, isolation, lower quality of life, exasperations, and hospitalizations. I believe science supports this and I know my experiences do!

Congress needs to make the appropriate supplemental oxygen available to all who need it, not just to stay alive, but to increase our ability to remain physically and socially active leading to lower healthcare costs while increasing the quality of life! Many organizations agree and have created guidelines for Congress to use.

Four Pillars for Oxygen Reform @ the National Health Council

<https://nationalhealthcouncil.org/blog/four-pillars-for-oxygen-reform/>

Four Pillars for Oxygen Reform @ the American Lung Association

<https://www.lung.org/getmedia/7f68e05f-29e5-4d46-acfa-cee31c2c62c2/Four-Pillars-for-Supplemental-Oxygen-Reform-7-26-22.pdf>

(2005) [Liquid oxygen, is it the gold standard? \(sagepub.com\)](https://journals.sagepub.com/doi/epdf/10.1191/1479972305cd088ed)

<https://journals.sagepub.com/doi/epdf/10.1191/1479972305cd088ed>

Until recently, the use of liquid oxygen seemed to be the gold standard for LTOT in ambulatory, younger patients who wanted to spend more time out of their homes and move around. When compared with small oxygen cylinders, portable liquid oxygen showed a benefit to patients by improving their compliance with the treatment and the time spent out of home. It also improved their quality of life and was preferred by the patients. Limited French data from the ANTADIR Registry advocate the use of liquid oxygen for selected patients who wish to move around. The main difference for this therapy is the cost. Liquid oxygen therapy is about four times more expensive when compared with concentrators. The capital cost, labor cost and decreasing reimbursement for LTOT have reduced the proportion of patients using liquid oxygen to less than 10% in the USA and prevented the introduction of the system into many parts of the world.

The use of liquid oxygen was reduced because of cost, even though it has been proven time and time again patients are more active using liquid oxygen. Congress lowered what it would pay for liquid oxygen because it was cheaper to use concentrators even though it severely decreased our ability to remain active and greatly increased our downward spiral of deconditioning and increased medical costs. Getting rid of liquid oxygen did not make good use of horse sense.

(2006) [Impacting patient-centred outcomes in COPD: deconditioning](https://err.ersjournals.com/content/errev/15/99/42.full.pdf)

<https://err.ersjournals.com/content/errev/15/99/42.full.pdf>

CONCLUSIONS: The growing understanding of the mechanisms of exercise limitation in chronic obstructive pulmonary disease patients has important implications for management. Pulmonary

rehabilitation is now established as an important component of treatment, but maximizing the effectiveness of such training depends upon effective concomitant treatment. Ideally, patients should be encouraged to maintain activity levels in the follow-up period following participation in a pulmonary rehabilitation programme.

To encourage patients to stay active they need to be prescribed the LPM so they are able to stay active. Not getting patients the needed oxygen takes away motivation and makes it a struggle to stay active. I have been there.

(2014) [Comparison of domiciliary oxygen using liquid oxygen and concentrator in northern Taiwan \(sciencedirectassets.com\)](https://www.sciencedirect.com/science/article/pii/S0929664612002483?via%3Dihub)

<https://www.sciencedirect.com/science/article/pii/S0929664612002483?via%3Dihub>

Conclusion: Patients using liquid oxygen went out of the home more often and demonstrated longer periods of daily oxygen use compared with patients using concentrators. Our findings for pulse rate change suggested that an ambulatory supply of portable liquid oxygen may enhance the domiciliary walking of patients with COPD. We recommend that health care practitioners consider ambulatory liquid oxygen for patients who want to be active and for patients seeking the benefits of physical reconditioning.

According to this study patients using liquid oxygen were more active. Just what the previous study encouraged. Instead, in 2013 the use of liquid oxygen became only available to those who had been grandfathered in even though the case for liquid oxygen has been proven time and time again!

Around 2010 I began carrying an oximeter and using it to help keep my blood oxygen levels out of the 70s and in the mid eighties to low 90s the best I could. In September 2014 I was still working full time in the produce department at a local grocery store and was so tired I didn't know if I could make it another day. I was prescribed 2 LPM of supplemental oxygen. I continued working full time and playing tennis 3 or 4 times per week. In October 2014 I bought an Inogen One G3(with 4 settings) to have oxygen 24-7. On the walk test I took to qualify for a handicapped parking permit I needed 3 LPM to keep my oxygen level in the mid-eighties. The G3 I had bought, at best supplied me with the equivalent of 2.5 LPM, not near what I needed when ambulatory.

At Christmas, when my daughter saw me for the first time after starting 24-7 oxygen therapy, she said, "dad you have color again!"

(2015) [Burden of chronic obstructive pulmonary disease: Healthcare costs and beyond - PMC \(nih.gov\)](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5554331/)

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5554331/>

CONCLUSION: Overall, COPD is associated with significant morbidity, mortality, health-care use and reduced quality of life. With this comes increased health care cost and burden on the health care system. It is a serious public health burden that needs to be addressed in the U.S. and worldwide with the goal to

prevent COPD, reduce costs associated with the disease, and in the end, improve the patient's quality of life.

May SM, Li JT. Burden of chronic obstructive pulmonary disease: healthcare costs and beyond. *Allergy Asthma Proc.* 2015 Jan-Feb;36(1):4-10. doi: 10.2500/aap.2015.36.3812. PMID: 25562549; PMCID: PMC5554331.

Part of the solution is liquid oxygen. Not getting the oxygen we need to stay active leads to the downward spiral of deconditioning, increased health care costs and lower quality of life.

In January 2015 I had my first pft. (https://hors-sens.com/oxygen/my_thoughts/pft2015/pft2015.html) my FEV1 was 47% of predicted. Findings were indicative of severe obstructive lung disease associated with air trapping and a moderate diffusion impairment. I began the paperwork to apply for SSDI.

(2015) Benefits of physical activity on COPD hospitalization depend on intensity

<https://erj.ersjournals.com/content/erj/46/5/1281.full.pdf>

In conclusion, a greater quantity of low-intensity physical activity reduces the risk of COPD hospitalization. The observation that high-intensity daily-life physical activity does not generate additional protective effects in the most severe COPD patients will require replication.

I know high-intensity physical activity has been good for me. One of the many benefits, I believe, is it improves my ability to clear my lungs of mucus. First, it strengthens my ability to breathe and makes coughs more productive. Second, high-intensity physical activity bring deeper inhaling and more forceful exhales and loosens phlegm making it a good way to quickly get phlegm out.

(2015)Disease Progression and Changes in Physical Activity in Patients with Chronic Obstructive Pulmonary Disease

<https://www.atsjournals.org/doi/epdf/10.1164/rccm.201501-0081OC?role=tab>

Clinical Implications and Conclusions: Recent guidelines advocate regular physical activity for patients with COPD at all severity stages despite the fact that little COPD-specific evidence exists (1). Our data clearly support this recommendation, because a sustained low level of physical activity over time is associated with an accelerated progression of exercise intolerance and muscle depletion. Furthermore, we have demonstrated that physical activity decreases early in the course of the disease, along with a worsening of lung function and health status. Of note, our results were obtained in a cohort that for the current presentation excluded patients who had died during follow-up. For those deceased patients, physical inactivity was already shown to be the strongest predictor of mortality (12). Therefore, the role of physical inactivity in disease progression might even be underestimated in the current analysis.

In January 2015 my pft indicated that I had severe obstructive lung disease associated with air trapping and moderate diffusion impairment. My FEV1 was 47% of expected. Around the 1st of May I applied for

SSDI and was accepted in the first part of August 2015. It only took 3 months for me to get approved for Social Security Disability Income. My last day at work was July 18, 2015.

For the next three years I struggled to stay active and was definitely in the downward spiral this study addresses..

(2016) An Embarrassing Situation

<https://copd.net/living/an-embarrassing-situation>

Incontinence is the medical term for the inability to hold your urine or bowel movements long enough to get to a restroom. When you experience extreme shortness of breath, your body goes into "survival mode". When your oxygen level is dangerously low, the body starts shutting down and conserving oxygen for the most vital organs. In survival mode, oxygen is diverted away from organs like the bladder and bowel (as they are not necessary for survival), to the parts of our bodies that keep us alive: heart, brain, and lungs.

From COPD.net

Once I had liquid oxygen I could stop incontinence in a minute or two if I had a filled T1000 portable liquid oxygen unit with me. All I had to do was crank it to 10 or 15 LPM and in a minute or so I could casually walk to a restroom. Liquid oxygen is needed and at high liter flows.

(2018) [Impact of Previous Physical Activity Levels on Symptomatology, Functionality, and Strength during an Acute Exacerbation in COPD Patients](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6316170/pdf/healthcare-06-00139.pdf)

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6316170/pdf/healthcare-06-00139.pdf>

Conclusions - We conclude that patients with COPD who regularly perform PA have less dyspnea and cough and better functionality, exercise capacity, and strength during an exacerbation.

Couldn't say it better!!!

(2018) [Long-term effects of oxygen-enriched high-flow nasal cannula treatment in COPD patients with chronic hypoxemic respiratory failure](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5909797/pdf/copd-13-1195.pdf)

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5909797/pdf/copd-13-1195.pdf>

Conclusion: This study shows that in COPD with hypoxic failure treated with LTOT, adjunct HFNC therapy reduces exacerbations, admissions and symptoms. In addition, HFNC stabilizes the clinical condition of advanced COPD patients, but does not improve all-cause mortality. In future, HFNC should therefore be

considered a beneficial adjunct to the recommended treatment of COPD patients with chronic hypoxemic respiratory failure.

I doubt if they're talking about a high flow nasal cannula delivering 6 to 15 LPM of supplemental oxygen. But I do know that once I started using higher liters per minute of oxygen I was able to exercise harder and started to reversing the deconditioning that I experienced between 2014 and 2018.

In August of 2018 I got my second pft. After 4 years of not getting the Supplemental oxygen I needed my FEV1 had dropped from 47% to 30% of expected. In 2018 Medicare kicked in and I received a home concentrator and a Respironics UltraFill System with 3,000 psi tanks allowing me to use 6 to 8 LPM for 2 to 3 hours per day. I believe that stopped the downward spiral, at least until covid.

(2019) [Urinary Incontinence in Chronic Obstructive Pulmonary Disease:](https://pubmed.ncbi.nlm.nih.gov/31201688/)

<https://pubmed.ncbi.nlm.nih.gov/31201688/>

Evidence suggests that the prevalence of UI is higher in subjects with chronic obstructive pulmonary disease (COPD) than in age-matched controls in both sexes. UI is classified as stress, urge, and mixed, and has a considerable impact on quality of life. However, the prevalence of UI in individuals with COPD is mostly unexplored in clinical research and often underestimated in clinical practice.

Battaglia S, Benfante A, Principe S, Basile L, Scichilone N. Urinary Incontinence in Chronic Obstructive Pulmonary Disease: A Common Co-morbidity or a Typical Adverse Effect?

Drugs Aging. 2019 Sep;36(9):799-806. doi: 10.1007/s40266-019-00687-4. PMID: 31201688.

This problem needs addressed. I am lucky, I had some problems with incontinence but only one time did I have a puddle at my feet in public. No motivation to stay active when this happens.

(2020) [Exercise and Chronic Obstructive Pulmonary Disease](https://pubmed.ncbi.nlm.nih.gov/32342470/)

<https://pubmed.ncbi.nlm.nih.gov/32342470/>

Systemic effects of COPD lead to cardiovascular co-morbidities, muscle wasting and osteoporosis that, in turn, lead to inactivity and physical deconditioning. This evolution has a direct influence on the health-related quality of life (HRQoL) of patients suffering from this respiratory disease. Pharmacological therapy leads to improvement in shortness of breath, but it has a limited effect on the physical deconditioning. Pulmonary rehabilitation relieves dyspnoea and fatigue, improves emotional function and enhances the sense of control that individuals have over their condition. These improvements are moderately substantial and clinically significant. Rehabilitation serves as an essential component of the management of COPD and is beneficial in improving health-related quality of life and exercise capacity.

*The down ward slide of deconditioning can be devastating. **Pulmonary rehabilitation is essential for the above reasons!!!** Pulmonary rehabilitation would also be a good place to check the LPM patients need for various activities and for the patient to experience what higher LPM can do for them! Nothing was more motivating for me to stay active than experiencing the benefits of higher LPM flows!*

(2020) [Is Structured Exercise Performed with Supplemental Oxygen a Promising Method of Personalized Medicine in the Therapy of Chronic Diseases? - PMC \(nih.gov\)](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7564446/)

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7564446/>

5. Conclusions - Exercise medicine as a part of personalized therapy provides a huge potential for diseased populations and, thus, innovative methods for various chronic conditions are warranted. The use of supplemental oxygen during exercise might at least theoretically bear the potential for an effective therapeutic approach to counteract chronic disease-induced inflammation and tissue hypoxia for literally all chronic diseases, while concomitantly increasing patient adherence and therapy compliance. However, as shown by this systematic review, so far the majority of studies assessing the effects of chronic exercise with supplemental oxygen were carried out in COPD patients, while we found only one study that was performed with CAD patients and currently no evidence exists for other chronic diseases. Our findings also indicate very scarce data concerning safety and feasibility of exercise with supplemental oxygen and this data is limited to COPD and CAD. Moreover, the interpretation of that data is somewhat hindered by incomprehensive reporting. Interestingly, even though it appears that supplemental oxygen is a common therapeutic method to support exercise interventions in COPD patients, our findings support previous reviews by clearly indicating that there is currently no evidence superior effects in terms of physical fitness, functional capacity or patient-reported well-being. While it is likely that this may be related to heterogeneous study designs and/or technical aspects of oxygen delivery (i.e., low flow rates and oxygen delivered through nasal cannula), there seems to be a gap between findings obtained from acute study designs and long-term interventions. Thus, future studies should aim at identifying dose-response relationships of supplemental oxygen delivered and further assess whether this type of training may be a beneficial part of a personalized medicine approach for other types of chronic diseases.

Freitag N, Doma K, Neunhaeuserer D, Cheng S, Bloch W, Schumann M. Is Structured Exercise Performed with Supplemental Oxygen a Promising Method of Personalized Medicine in the Therapy of Chronic Diseases? *J Pers Med.* 2020 Sep 19;10(3):135. doi: 10.3390/jpm10030135. PMID: 32961816; PMCID: PMC7564446.

In 2020 I bought a liquid oxygen reservoir and a T1000 portable unit and immediately recognized the benefits of liquid oxygen. In 2014 I had asked a respiratory therapist and my doctor about liquid oxygen, they both told me it was no longer available. Through the years many people have told me medical liquid oxygen is not available. It took me six years to prove them wrong and another four years learning how it should be used. In North Carolina it took me over six months to find a steady supply of liquid oxygen. Just goes to show how hard it is for someone like me to get liquid oxygen. If I were to lose my source of liquid oxygen I don't know if I would want to go on.

(2020) [Oxygen therapy and inpatient mortality in COPD exacerbation \(bmj.com\)](https://emj.bmj.com/content/emmermed/38/3/170.full.pdf)

<https://emj.bmj.com/content/emmermed/38/3/170.full.pdf>

One-year mortality: Mortality at 1-year post discharge in those treated with supplemental oxygen in patients who received supplemental oxygen on admission and survived to discharge, the risk of death at

1-year was 28%. The 12-month mortality rates, excluding inpatient deaths, were: 87% or less=32%, 88%–92%=31%, 93%–96%=23% and 97%–100%=28% (including inpatient deaths these figures were 43%, 37%, 32% and 40%) (figure 3). The 93%–96% group had a significantly lower risk of death than the 88%–92% group, and overall (online supplemental table 5 includes further information relating to 1-year mortality).

Echevarria C, Steer J, Wason J, et al Oxygen therapy and inpatient mortality in COPD exacerbation *Emergency Medicine Journal* 2021;38:170-177.

“Individuals with COPD should keep their blood oxygen levels between 88% and 92%,” is a dangerous *Myth!!!*

Keeping blood oxygen levels between 88% -92% is valid during medical emergency situations or when a medical professional prescribes it!

If I was experiencing a moderately severe exasperation or medical condition where I was struggling with blood oxygen levels I would do my best to keep my blood oxygen levels between 88% and 92% until a medical professional okayed going back to my normal levels.

When playing pickleball at 10 LPM I prefer my blood oxygen levels are above 80% but do not panic if I drop into the seventies. But want to see the blood oxygen level climb quickly with a short break or even if I just slow down a little. When I get up from watching TV and walk to the bathroom using 3 LPM my blood oxygen level may drop below 88%, but only briefly. Using higher LPM flows allows me to do more and stay above 88% and my heart stays slower and steadier.

Playing pickleball and other exertion that causes me to breath harder makes it easier to get phlegm out even when I am not breathing hard. It also strengthens my ability to inhale and exhale more forcibly. In January 2015 when I first got a peak flow meter I could blow the indicator from 250 to 350. Today, on a good day I am able to max it out, 800 +. When my breathing seems to be getting worse I use the peak flow meter to check where I am. I know I would not be able to max the peak flow meter out if I had kept my blood oxygen level above 88%!

I have heard many consumers say if you drop below a 88% blood oxygen level brain cells are dying. I believe scaring others with COPD or yourself to keep your blood oxygen level above 88% is bad and sad.

PEOPLE WITH COPD NEED EDUCATION ON BLOOD OXYGEN LEVELS! It will help make better decisions, stay healthier and live with a higher quality of life.

During my last pft test the respiratory therapist(?) giving the test did not want me to go below a blood oxygen level of 88%. She asked if I wanted to go to an alternative to the normal test so she would not have to stop the test if I went below 88%. I told her it did not matter if I went to the mid or low 80s. She told me the cardiologists running the clinic giving the test did not want anyone going below 88%. Maybe cardiologist need some education about COPD and blood oxygen levels as well a respiratory therapists and people with COPD.

(2021) [Effects of high-flow nasal cannula with oxygen on self-paced exercise performance in COPD](#)

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8701785/pdf/medi-100-e28032.pdf>

5. Conclusion - Application of HFNC with additional oxygen support improved the self-paced exercise performance by increasing walking distance and arterial oxygen saturation with unaltered PtcCO₂ during the 6MWT in COPD patients. A lower energy cost was also observed in those performing HFNC-aided walking. Therefore, these findings suggest that the use of HFNC makes it feasible and safe to perform physical activity in patients with COPD. However, the application of HFNC in pulmonary rehabilitation warrants further research with long-term follow-up to determine the effects of regular exercise training with HFNC.

Chao KY, Liu WL, Nassef Y, Tseng CW, Wang JS. Effects of high-flow nasal cannula with oxygen on self-paced exercise performance in COPD: A randomized cross-over trial. *Medicine (Baltimore)*. 2021 Dec 23;100(51):e28032. doi: 10.1097/MD.00000000000028032. PMID: 34941043; PMCID: PMC8701785.

More evidence we need highly portable ambulatory supplemental oxygen. Liquid oxygen fits the ticket.

(2021) [Frontiers | Effect of High-Flow Oxygen on Exercise Performance in COPD Patients. Randomized Trial \(frontiersin.org\)](#)

<https://www.frontiersin.org/articles/10.3389/fmed.2020.595450/full>

In conclusion, our study showed an improvement in cycling endurance time by HFOT in patients with stable, mildly hypoxemic, moderate to severe COPD. HFOT was associated with a lower breath rate at isotime, a higher arterial oxygen saturation and less dyspnea and it was well-tolerated. These results are applicable for many COPD patients seen in daily practice and indicate that patients may benefit from HFOT during exercise training.

Another study supporting higher LPM flows.

(2023) *From Respiratory Care* March 2023, 68 (3) 408-412; DOI:

<https://doi.org/10.4187/respcare.10278>

Exertional dyspnea occurs in 80% of individuals with COPD. As COPD's most common symptom, exertional dyspnea contributes to a downward spiral of deconditioning, social isolation, and inactivity. <https://rc.rcjournal.com/content/68/3/408>

I still get short air of but if my blood oxygen levels are okay with me I can control the SOB with pursed lip breathing. I use an oximeter to slow me down when blood oxygen get lower than I like and if my heart rate gets around 140 and it doesn't drop fairly quickly when I stop, I take a break.

Liquid oxygen has helped me reverse the downward spiral. In December 2023 I had my third pft and my FEV₁ was 45% of expected, up from 30% of expected in 2018. I believe that shows I have reversed the spiral of deconditioning, social isolation, and inactivity with the help of liquid oxygen.

(2024) [GLOBAL INITIATIVE FOR CHRONIC OBSTRUCTIVE LUNG DISEASE](https://goldcopd.org/wp-content/uploads/2024/02/GOLD-2024_v1.2-11Jan24_WMIV.pdf)

https://goldcopd.org/wp-content/uploads/2024/02/GOLD-2024_v1.2-11Jan24_WMIV.pdf

Oxygen therapy (page 60) – The long-term administration of oxygen (> 15 hours per day) to patients with chronic respiratory failure has been shown to increase survival in patients with severe resting hypoxemia. Long-term oxygen therapy does not lengthen time to death or first hospitalization or provide sustained benefit for any of the measured outcomes in patients with stable COPD and resting or exercise-induced moderate arterial oxygen desaturation. Breathlessness may be relieved in COPD patients who are either mildly hypoxemic, or non-hypoxemic but do not otherwise qualify for home oxygen therapy, when oxygen is given during exercise training; however, studies have shown no improvement of breathlessness in daily life and no benefit on health related quality of life . There are contradictory studies although the majority do not demonstrate changes.

Oxygen therapy pages 60-61

Ventilatory support bottom of page 61-62

TWO PAGES OUT OF 138 PAGES GIVEN TO OXYGEN THERAPY!!! A 136 pages were given to treatments that make the Respiratory Care Industries BOATLOADS OF MONEY!!!

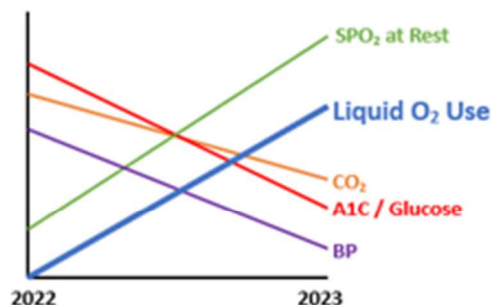
Supplemental oxygen is prescribed at a minimal level, it was enough to keep me alive, but my conditioning and health was on a downward spiral while using a POC for ambulatory oxygen (an Inogen One G3). When I started using the Respironics Self-fill system with 3,000 psi tanks and was able to use more oxygen for about 3 hours a day when ambulatory, I believe, the downward slide was stabilized and conditioning began slowly improving. Staying active was still a struggle. Then I bought the equipment needed to use liquid oxygen, found a steady source that I could afford and began learning how to take advantage of it, my quality of life quickly improved. And My Health as well.

The following shows the health benefits I realized after using liquid oxygen for one year. From September 2022 to September 2023.

- **A1C in 2020, 7.0%; in 2021, 8.0 %; in 2022 9.5% and after a year + with a steady supply of Liquid Oxygen 6.3%.**
- **In 2022 my CO₂ blood level was 30. In 2023 it was 27.**
- **In May 2022, at rest and relaxed, my blood pressure was 145-130 / 90 – 80, In November 2023, 125 – 115 / 75 – 60.**
- **My rest SpO₂ in June 2022 was in the high 80s to low 90s and in November 2023 from the low 90s to mid-90s. My SpO₂ playing pickleball in July 2022 was 70s to low 90s and in November 2023 low 80s to mid-90s.**
- **Since 2018 I have been using about 3 LPM of supplemental oxygen at home, and still am, but the LPM I use while active has increased dramatically. Before June 2022 I would use 800 to 1,500 liters of oxygen per day while active, with the maximum amount available being a little over 2,000 liters per day, allowing me only 2 -3 hours of activity a day. After June 2022, with a steady supply of liquid oxygen, my average daily use jumped to 1,500 to 3,000 liters per day while active and increased to over 3,000 liters per day now, in November 2023. The amount of time I am active has more than doubled from 2-3 hours per day to 5 to 7 hours since finding a reliable source of liquid oxygen in June 2022**
- **In May 2022 I was close to 300 lbs. and in November 2023 am closer to 245 lbs.**

- In February of 2019, I bought a size 8 pair of Justin Ropers boots, the same size I wore in the 1990s but because of the swelling in my feet and lower legs I couldn't come close to getting them on.
- In March of 2023, the swelling had almost disappeared and I am now comfortably wearing the boots.

None of this would have happened without liquid oxygen.



All of my health benefits are made possible by liquid oxygen.

Liquid oxygen has helped me *stop and reverse* the downward spiral of deconditioning so common in respiratory illnesses. Liquid oxygen allows me to play a decent game of pickleball, take trips, visit museums, and stay active in many ways. But only when I am willing to put out the effort to take advantage of it.

OXYGEN THERAPY DESERVES FAR MORE THAN TWO PAGES

"I give liquid oxygen the credit for my improvements since 2021. Liquid oxygen is what allows me to get the oxygen needed to play pickleball, travel and camp out, spend a day at the park, go shopping and so much more. Liquid allows me to be many times more active than the best POC would (luggable POCs came closer). The Resopironics Ultra-Fill system and 3,000 psi tanks allowed me to be more active than POCs. Liquid oxygen immediately allowed me to be more active but the improvements take time and increased activity. With a POC and 3,000 psi tanks it was a struggle to stay active. With liquid oxygen activity is enjoyable.

My Thoughts

In 2014 I asked my doctor and a respiratory therapist about liquid oxygen. They told me, "It isn't available." I also asked the respiratory therapist if an Inogen One G3 would provide me with the oxygen I needed when active. She wouldn't answer the question even though she knew it wouldn't. At times it makes me mad that she didn't say, "No it won't." But what was she supposed to tell me, "**No it won't, you need liquid oxygen but can't have it.**" Medical liquid oxygen was available in many welding supply stores in the Northwest U.S. but none would help me get it. Extremely frustrating to know it was available and not able to get it.

I didn't see any reason to see a pulmonologist, they couldn't get me liquid oxygen. Neither could I see where those that had a pulmonologist were doing any better than I was and few were as active. I didn't want to be told what to do unless I saw a good reason.

I got to where I am today with limited help from professionals.

A good oxygen delivery system is the one that delivers the oxygen you need allowing a higher quality of life while keeping blood oxygen levels at an acceptable level. At rest I use 3 LPM and for most chores around the house 3-5 LPM. Out and about, shopping, visiting a museum, attending an event, etc.... I use 5-8 LPM. More physical activities like exercising or playing pickleball I use 6-10 LPM.

Getting the oxygen I need does not end being short of breath but does allow me to be more active. It took me close to eight years to get the oxygen delivery system I now have. For the first three and half years I had a home concentrator and an Inogen One G3 that didn't come close to getting me the oxygen I needed. In 2018 I asked for and got an Eclipse 5 and a home concentrator from my DME provider. It gave me a taste of getting the oxygen I needed, but it was too heavy. I changed my DME provider to get a Respironics Ultra-Fill system. I could get the oxygen I needed to play 2 hours of tennis, then needed to spend the rest of the day filling my tanks. Two and a half years later I bought an Eclipse 5, a liquid oxygen reservoir and two portable Companion 1000Ts and had the ability to get the oxygen I needed, but it took another two years to learn how to use and take advantage of the supplemental oxygen and see the health benefits.

How do I know I am getting the oxygen I need? I am far more active now, my blood oxygen levels are up, my heart rate is lower and I have the energy to do more. My blood pressure is lower than it has been for over twenty years. The same is true for the swelling in my feet and lower legs, which has disappeared. All my meds other than oxygen have stayed the same, only the LPM of oxygen has increased.

I still have severe emphysema but am far more active than I was five years ago with a higher quality of life. The medical professionals may have helped keep me alive but the higher quality of life is all me. My struggle and effort to stay active and doing what everyone told me couldn't be done, get medical liquid oxygen, was all me.

My advice to others with COPD

Use an oximeter to measure your blood oxygen levels doing different tasks, then write down the setting or LPM and blood oxygen level for different tasks. If you are dropping into the eighties or seventies call

your doctor to discuss raising your prescription. I believe pulmonologists should ask their patients to do the same. It would give them a better understanding of a patient's oxygen needs.

I know getting the oxygen I need is not going to allow me to do what I did 20 years ago! Getting the needed oxygen allows me to what I am able to do at the time and keep my blood oxygen levels and heart rate at a level that is acceptable to me. I continue to improve my conditioning and lose weight. I don't if I will be more active while playing pickleball six months from now, but believe I will be and that motivates me.

I believe being able to do more of what you want to will motivate most people with COPD. Research on using higher flows of oxygen, how it helps reconditioning and makes it easier to be active needs done. Then use that information to help others do what I have done. Maybe they could do in a year or two what it has taken me 10 years to do.

If I had been given liquid oxygen in 2014 and been told to use 5+ LPM when active I would be far more active than I am now! My Health would be better and I would have a better quality of life!!!

I believe people with COPD will have better lives. But it will take action.

My Four Pillars for a Reset of the Treatment for COPD

- Oxygen prescriptions need to be based on oximeter readings from all activities to ensure the needed oxygen is being delivered to remain active and healthy.
- POC settings need changed so they are equivalent to LPM .
- Education on realistic blood oxygen levels for a wide range of activities is needed.
- More respiratory therapy and education on how to stay active and increase quality of life is needed.

A RESET IS NEEDED FOR THE TREATMENT OF COPD WITH A FOCUS ON QUALITY OF LIFE

My website URL - <https://hors-sens.com/oxygen/oxygen.html>

Activity Promotion: A Paradigm Shift for Chronic Obstructive Pulmonary Disease Therapeutics

Proceedings of the American Thoracic Society, Volume 8, Issue 4 Aug 2011, Pages 333-379

Activity Promotion: A Paradigm Shift for Chronic Obstructive Pulmonary Disease Therapeutics

It is notable that the studies of interventions designed to increase activity levels in COPD have not featured long-term follow up. Durability of activity improvement resulting from physical activity interventions has been hard to achieve in older adults (38). Especially in the case of pulmonary rehabilitation, there is reason to question whether short-term increases in activity levels will persist in most participants unless the program features a formal long-term component.

If activity promotion is to be a major goal for patients with COPD, a major rethinking of our therapeutic strategies will be required. Pulmonary rehabilitation seems like a good place to start: behavior modification has always been at least an informal part of such programs. Activity promotion might be seen as a coprimary goal along with exercise capacity enhancement. Scientifically based strategies for activity promotion might be incorporated, much as they are for exercise capacity enhancement. It seems entirely plausible that the exercise tolerance enhancing potential of bronchodilators or of ambulatory oxygen therapy will not translate into increased activity in everyday life in the majority of patients with COPD. In particular, it might be considered that, if a goal of ambulatory long-term oxygen therapy is to promote activity, it might be considered worthwhile only if delivered in conjunction with an activity enhancement intervention. Whether pulmonary rehabilitation programs could be adapted to this purpose requires investigation.

Medical Professionals, Researchers & RTs

Where are the studies of interventions designed to increase activity levels in COPD with long-term follow up?

Research shows that deconditioning leads to a downward spiral for people with COPD. I believe my experience shows that the downward spiral can be stopped and reversed, leading to better health and a higher quality of life. Long term studies are needed.

Medicare will pay for a Life2000® Ventilation System and I qualify for it. One was brought to my house, titrated for me and I was able to give it a quick trial. I was able to push myself hard while using it and it

performed as well as Liquid oxygen. No surprise, I tested one while in a respiratory rehabilitation program in 2018. I wanted one then but Medicare would not cover the cost and I could not afford it.

“The Life 2000 ventilator is designed to provide portable breathing support for people with respiratory diseases. This lightweight, portable device enables patients to maintain an active lifestyle and engage in activities they care about without being limited by their respiratory condition.”

The research supporting these claims may also support the use of liquid oxygen and may be used to convince Congress and Medicare to start paying a reasonable price for liquid oxygen. I would think there is also research that would support my experience of becoming far more active and increased health when getting the oxygen I need.

Medical Professionals, Researchers & RTs I hope I have motivated a few of you to start the needed research. I also hope you are actively supporting the Four Pillars for Oxygen Reform

<https://www.lung.org/getmedia/7f68e05f-29e5-4d46-acfa-cee31c2c62c2/Four-Pillars-for-Supplemental-Oxygen-Reform-7-26-22.pdf>

Four Pillars for Oxygen Reform

1. Ensure supplemental oxygen is patient-centric
 - Change “home oxygen” to “supplemental oxygen” to ensure people requiring oxygen can live full lives outside their primary residence
 - Create a patients' bill of rights to ensure care is focused on patient needs
2. Ensure access to liquid oxygen for patients for whom it is medically necessary
3. Create a statutory service element to provide adequate reimbursement for respiratory therapists to ensure patients have access to their expertise
4. To ensure predictable and adequate reimbursement and to protect against fraud and abuse, establish national standardized documentation requirements that rely upon a template rather than prescriber medical records to support claims for supplemental oxygen suppliers.

TO ALL ORGANIZATIONS WHO SUPPORT THE FOUR PILLARS FOR OXYGEN REFORM; Stop giving lip service to Oxygen Reform. Congress doesn't care about us with respiratory problems, they want to save money. Show Congress how Oxygen Reform will help them save taxpayers money while increasing the health and quality of life for people with serious respiratory illnesses.

Start Prescribing liquid oxygen for those that need it!!!

Write a Prescription for it & let Medicare tell us we can't have it

**A RESET IS NEEDED FOR THE TREATMENT OF
COPD WITH A FOCUS ON QUALITY OF LIFE**

Congress, Medicare & Medicaid

Over the last twenty years your actions have taken liquid oxygen from people with respiratory problems who need it to stay active and healthier with fewer exasperations and hospitalizations. You did it to save the taxpayers money. You didn't! You increased health costs by causing more exasperations, hospitalizations, and other health problems. You are willing to pay to keep us alive. The Medical Professions knows that and have followed the money. They do an excellent job of keeping us alive. It doesn't seem like you are willing to provide us with a healthier and higher quality of life even if it would be a cheaper option.

Medicare will provide me with a Portable Oxygen Concentrator (POC) that does not keep me active and will barely cover my needs while driving. The same is true for many others. When POCs don't supply the needed oxygen health care cost go up. POC manufactures are following the money and are able to do it because POCs are not well regulated by the FDA. Read [A Message To U.S. Congress Members](https://hors-sens.com/oxygen/needed_changes/congress_fda.pdf) at https://hors-sens.com/oxygen/needed_changes/congress_fda.pdf . The FDA needs to regulate POCs so their settings are equivalent to LPM.

I hope you work with the supporters of **THE FOUR PILLARS FOR OXYGEN REFORM**. Increase our quality of life and save money.

<https://www.lung.org/getmedia/7f68e05f-29e5-4d46-acfa-cee31c2c62c2/Four-Pillars-for-Supplemental-Oxygen-Reform-7-26-22.pdf>

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Getting the needed oxygen to individuals who need it is only the start. Unless they know how and are willing to put out the effort to take advantage of it they may not benefit from liquid oxygen. Programs will need to be set up but will help all with COPD stop the downward spiral of exasperations, hospitalizations and other health problem. A win for all.

**A RESET IS NEEDED FOR THE TREATMENT OF COPD WITH A
FOCUS ON QUALITY OF LIFE**

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For more information.