

**COPD
SURVIVAL
GUIDE
Tips and Hacks
for
Breathing Easier**

From COPD Survivors around the Globe

A COPD diagnosis is not a death sentence. Your doctor may have told you that you have so many years, or months, or days to live. They are seldom correct with their expiration dates. My name is Dawn. They gave me less than a week to live in January of 2015. They kept moving the expiration date out, then quit giving me an expiration date. Yes, there are things you will not be able to do that you once could. Find a starting place. Then, build a new life.

1. Pursed-Lip Breathing.

First things first: Do you know how to take an effective breath? Your goal is to get oxygen in and CO₂ out. A good exhale is crucial for a good inhale. Breathe from your belly, not your chest. Take a deep breath through your nose, from your belly, purse your lips, and GENTLY blow for twice the length of the inhale. "Smell a flower, flicker a candle flame." This is pursed-lip breathing, and it will help get your breathing under control. It is crucial during an exacerbation.

An exacerbation is a sudden worsening of symptoms brought on by an infection, panic, or environmental conditions.

If you have a temperature, get thee to a hospital. If you cannot get control of your breath, get thee to a hospital.

If an exacerbation is brought on by panic or environmental condition, some of us can get our breath under control using pursed lip breathing. When you cannot breathe, you panic. When you panic, you cannot breathe. They feed off one another. You need to calm down and get your breath under control. If you cannot do that, dial emergency.

If you suffer from panic attacks, talk to your doctor about anti-anxiety medication.

2. Generator: You need it.

Plan ahead. If you depend on an oxygen concentrator to live, a generator is not a luxury item. A small generator, enough to power your oxygen concentrator and a light, is a must.

3. Pulmonary Rehab.

People are often told they do not have enough lung function to benefit from rehab. That is not true. I was diagnosed with 18% lung function. Before rehab, I could not walk across a room. Now I take four large dogs to the dog park two or three times a week. My lung function has increased to 24%.

Pulmonary rehabilitation will not only keep you alive, it will allow you to thrive. If rehab is not available to you, watch the YouTube videos under "COPD exercises." More on rehab later.

4. Move around—safely.

Faster does not mean better. Do not go far, fast, and then be unable to get back home. Use your muscles but go slowly and gently. Rehab is about stretching, strengthening, toning. Weakened muscles result in breathlessness. One of the measures they use to define how damaged you are is "tolerance to exercise". If you increase your tolerance to exercise, you increase your health.

5. Find your people.

Finding people who are going through what you are going through is the best way to get real information. Facebook groups, online groups, a small group at the gym if you are up to it. There are many groups. Find the one that feels authentic to you. If a group is filled with people selling snake oil, it is not the group you want.

6. Portable Nebulizers.

You will be more likely to use your Albuterol if you don't have to haul out a machine. People try various models. Post online and ask for recommendations. Amazon is a great place to read real-life reviews.

7. Non-invasive ventilators.

The Trilogy (made by Philips Respironics) is a lifesaver. Literally. You will need your doctor's approval to get one, and you might have to push for it, but it is worth it. The hockey mask is not necessary. I use the DreamWear headgear. That first deep breath was the most exciting thing that has ever happened to me. They are beneficial to CO2 retainers and to those with low lung function. The high pressure holds your airways open and gives you deeper breaths. It breathes deeply for you all night, or any other time you want it. It has a strap, so it is easy to carry into the living room if you want to enjoy breathing while you watch television. I don't go to sleep any longer wondering if this is the night I will quit breathing. I went without it one night and felt like I had a hangover the next day. I realized that I used to feel like that all the time.

The Life2000 by Hillrom is another miracle. The unit is extremely portable – about the size cell phones were when they first came out. They recommend cleaning the cannula thoroughly once a week. I recommend swabbing the cannula out a couple of times a day with FOAM swabs, the type used to clean computers. 50% white vinegar, 50% water.

[200 Pieces Foam Swab Cleaning Swab Foam Tips Sponge Stick for Inkjet Printer Print Head Camera Optical Lens Optical Equipment \(Black,9.3 cm\): Amazon.com: Industrial & Scientific](#)

You must wear a chin strap to keep your mouth closed. Turning into a wind tunnel can be amusing but not effective.

Chin straps are a good idea for everyone. Mouth breathing is not an effective way to breathe. The one that has the least bulk, does not produce itching or sweating, is this one:

[Amazon.com: Anti Snore Chin Strap | Anti-Dry Mouth Chin Strap for CPAP Users | Stop Noise | Snoreless Sleeping Solution for Men and Women | Breathing Aid for Snoring : Health & Household](#)

8. Mucus.

To get rid of mucus, a device can help you. My favorite is the Flutter thingy. That is probably not the Latin term. [More](#) about these later. Mucinex can become your new best friend, but you must drink a lot of water if you take Mucinex. You want straight Mucinex, which will say "Mucus Relief", 100% Guaifenesin. You do not want "Multi-Symptom". Multi-Symptom has the same active ingredient as Sudafed, which causes "rebound congestion". Like Afrin, Sudafed is heroin for the nose. You become addicted to it, and your sinuses swell shut when you do not have it. At a certain point, your sinuses will swell shut even while you are using it.

If you need a nasal spray, use something with a corticosteroid, using the technique found below.

Your body produces something like six quartz of mucus a day. In healthy people, it slides down the throat and is dealt with by stomach acids. For people with respiratory or sinus issues, it can fill up the sinuses and stay there, causing everything from breathlessness to sinus infections to migraines. Straight Mucinex and lots of water is a huge help in dealing with uncooperative mucus.

DO NOT USE SUDAFED OR AFRIN FOR MORE THAN THREE DAYS.

Breathing through a warm, wet washcloth will also loosen mucus and keep your sinuses moist. Use pursed lip breathing. Place the washcloth over your nose, inhale, take it away, purse your lips and gently blow.

9. Tubes.

To keep your oxygen tube from tangling and kinking when you unwrap it, toss it in the dryer on hot for one minute. Take it out and immediately unwind it. It will slither around nicely behind you. If you want a great tube that does not tangle and kink, google "violet crush-resistant low-memory oxygen tube." Look at a few. The violet ones are all the same, but prices vary. Put the violet ones in the dryer for three minutes because they are thicker. Unwind it immediately so it does not cool tangled. Try a lingerie dryer bag (made of mesh fabric) for the tube-in-the-dryer trick to keep the hose from tangling in the dryer. Dollar stores have lingerie dryer bags.

NEW: They have come out with a braided, split cable for electric wires. They sell them on Amazon. Put these around your tube, and tangling, kinking, and going back to find out what you are stuck on nine million times a day comes to a halt. MAKE SURE IT IS BRAIDED CABLE. I have tried ribbed plastic and the noise it makes scratching along on the floor makes me insane.

KEEPING YOUR CANNULA ON YOUR FACE WHEN YOU SLEEP

There are a couple of ways to go about this. Some people like headbands:

[Headbands Amazon.com : holder to oxygen tubing sleep](#)

I like surgical tape. Soft paper tape – there are several types for sensitive skin:

[Amazon.com : surgical tape sensitive skin](#)

If you are sensitive to tape on your skin, you can apply a barrier substance:

[Amazon.com : Protective barrier wipes cream film](#)

10. Nasal and Sinus Rinses.

The Sinugator: Nasal rinses sound weird, but they are great if you want to breathe. Doing contortions with the Neti Pot is no longer necessary. You push a button on the Sinugator and it gently shoots water up one nostril and out the other. No, you will not drown. DISTILLED WATER ONLY! Again, prices vary. Walgreens (a U.S. drug store chain) has one for about \$25.00. Walmart charges over \$100 for the same thing.

The newer Sinugator has two speeds, both slower than the old Sinugator. People who are freaked out by nasal rinses may like this. For some, it is not effective; for others, it's essential. [\[DL3\]](#)

The SinuPulse is about \$80. It is more expensive, but that baby WORKS. It has 10 speeds and the reservoir holds 16 ounces of water. The Sinugator and squeeze bottles usually give you a six-ounce rinse, but the HydroPulse just keeps going and going and going. After I use it, I blow an extra 50 points on the peak flow meter. A breath will do you no good if there is nowhere for it to go.

KEEP YOUR EQUIPMENT CLEAN. THIS IS CRUCIAL FOR AVOIDING INFECTIONS.

Nasal rinse machines come with little packets of powder to mix into the distilled water, but you can make your own. For every 8 ounces of water, add ½ teaspoon of baking soda and ½ teaspoon of non-iodized salt.

Cold water is unpleasant, so for 8 ounces, I microwave it for 30 seconds. For 16 oz, I microwave a coffee cup full of distilled water for one minute, pour it into the reservoir, then add room-temperature distilled water to the reservoir.

11. The humidifier on your O2 concentrator.

For two years, I did not know that oxygen concentrators have add-on humidifiers. That was two years of waking up every morning with a bloody pillow. Again, DISTILLED WATER ONLY. When your nasal passages get dried out, they swell, making it hard to breathe. If you need more moisture, there is an inexpensive gel called Ayr at most drug stores. I like Carmex, but DON'T USE PETROLEUM PRODUCTS if you smoke, lean over to blow out a candle, or have any other open flame around your head. Catching your nose on fire would suck. Petroleum products can also break down the rubber nose piece on the DreamWear, which is headgear used with CPAP machines, and nasal cannulas. A humidifier will keep your sinuses moist, which makes it easier to breathe. Moisture is also crucial to lung health. I have one on my O2 concentrator, and one on my Trilogy.

12. Humidifiers in general.

Clean your humidifiers once a week with 50% white vinegar and 50% water. If you use a CPAP or Trilogy, clean the nose piece or mask daily with a little Dawn dishwashing liquid.

13. DreamWear headgear.

The DreamWear is a little piece of rubber that rests under your nose. You need a chin strap to keep your mouth closed. Occasionally I relax enough before falling asleep that bubbles start popping out of my mouth. I feel like a goldfish. I slap a piece of water-proof medical paper tape over my mouth. It peels off easily and painlessly.

If you have a Trilogy non-invasive ventilator and you are having a hard time with the mask, the DreamWear headgear is wonderful.

14. Cleaning supplies.

Stay away from cleaning chemicals, especially bleach. Use white vinegar instead when practical but bear in mind that white vinegar does not kill viruses. Rubbing alcohol kills viruses.

15. Air purifiers.

Keep the air in your home clean. Invest in good filters for central heat and air. Put a small air cleaner where you spend most of your time. Do not open windows on bad air days or during storms. In the U.S., most of us can check the air quality by typing AQI (air quality index) and your zip code into a search engine.

Fine particulate matter, AKA dust, is your enemy. Make it go away.

No fires, unless you have a fireplace insert that will not let smoke escape.

If you really miss fires, they have inexpensive electric fireplaces now, and they are quite realistic. Unless you like blue flames. I do.

16. Bladder control.

If you suddenly find yourself standing in a puddle of urine, your body has decided that your saturation is too low to keep everything going and has taken your bladder off the list of essential organs. No, you do not get a vote. Most insurance, including Medi/Medi, will pay for incontinence products with a doctor's prescription. If this is news to your doctor, have him/her call Byram Healthcare at (877) 902-9726. My general practitioner set this up for me. Apparently, most pulmonary doctors are unaware that this is a common symptom of COPD. If this is happening to you and your pulmonologist does not know this is a symptom, please educate them.

17. Pace yourself.

Keep two pulse oximeters, one for home and one to keep with you. If your saturation drops, lean against something or sit down. If people want to know if you are okay, do not waste your breath talking. Give

them a thumbs up. If it helps, get a walking stick. I have seen some cool ones. Walking sticks with feathers, Tibetan walking sticks. Rock your equipment.

When exercising, ALWAYS have a chair with you.

If you need extra help going out, get a walker. Some walkers have a built-in seat. Search term: "walker with built-in seat."

Some people find rolling walkers helpful. Search term: "rolling walker."

18. Avoiding germs.

Try to stay out of hospitals, out of crowds, out of gatherings of small children (otherwise known as germ machines). Getting sick can kill you. If you need to sit in an ER, keep a rubbing alcohol spritzer with you, or anti-bacterial wipes containing alcohol, and sanitize your hands every time you touch something.

Spray your chair before you sit in it. You may look paranoid, but you get to live. Most pharmacies have hand sanitizer stationed every couple of feet because they know. Use it and use it again after using the pen to sign for your prescription. Again, you may look paranoid, but you will not catch whatever the last person handling that pen had. Be aware that many people cough in their sleeves. Then they want to hug you. Aim your little bottle of rubbing alcohol at them.

18. Cannulas.

After wearing a whole lot of cannulas that felt like plastic was eating my face, I found a great one, with small, soft tubing that comes down over the cheeks. Google Westmed REF 0556.

19. Conserve Energy.

Exercise to stay toned and limber and get your blood moving, but conserve energy where you can. Instead of wandering around shopping, most Walmart grocery stores have a service now where you can order and pay on a computer and have everything delivered to your car the next day. Free, and the prices are reasonable. Amazon is starting to offer this grocery service also. I get almost everything on Amazon. With Prime, their prices are competitive.

20. Humor.

Instead of getting furious at your tube, make fun of it. If it will be funny later, it can be funny now. Most things can be funny, even if they are painful. I have found that if I can laugh at it, I have it beat. Or, you can be furious with your tube.

21. Back-up tanks.

Carry a back-up tank and keep an extra cannula in the car. I had one that got a hole poked in it and had no idea why my O2 saturation was dropping like a stone.

22. Kinks and swivel connectors.

If your saturation keeps dropping and you cannot figure out why, check your hose to make sure it isn't kinked. It may be time for a new hose. Check the air filter in the back of your concentrator. If it has been over 6 months, ask your O2 company to come out and clean it or change it. Make sure the lid on your humidifier is on correctly. That tube also needs to be changed occasionally. I spent a week with my saturation plummeting and did all this. It turned that the swivel connector between my cannula and my 50' hose had stopped swiveling. Kind of like the O-ring that brought down the Challenger. KEEP EXTRA

CONNECTORS.

Theoretically, swivel connectors help keep the tube from tangling. Sometimes they fall apart. They also have a shelf-life. My O2 company said the shelf-life "should" be 6 months. Should-be-6-months, for me, turned out to be 2 months. I change them monthly now. They are 6 cents apiece. While you are trying to figure out why you are not getting oxygen, use your portable.

Rigid connectors do not present this problem, and they hold the tubes together better.

23. Keeping your cannula.

If you have dogs or busy little children, keep a death grip on your cannula to keep it from being yanked off your face. I have a 96-pound dog who considers it his sacred duty to follow directly behind me and stand on my tube. (See? If you can laugh, you win.) I kept finding myself walking off with my cannula disconnected from the 50' tube that Burt was standing on. I fixed this by using sticky medical tape to keep my tubes together.

When I discovered rigid connectors, I did not need the tape.

24. Prednisone.

One of the common side-effects of Prednisone is bruised skin, and skin that splits if you look at it funny. Skin lotion for diabetics helps. Walmart has a generic brand (Equate). Lately, I have developed spots. Eczema crème helps fade the spots. Other random side effects of Prednisone include wanting to rip people's heads off or eat the refrigerator. Ask people around you to be patient with you. The side effects are different for everyone. If your inner werewolf is released, try to control it, but do not beat yourself up if you end up snarling occasionally.

25. Steroid inhalers.

If you use an inhaler containing a corticosteroid, rinse your mouth AND gargle afterwards. You do not want thrush in your throat. That can result in a feeding tube. If you want to be thorough, rinse and gargle with warm salt water. Thrush hates salt.

26. Find a Standing Place

This is your new life. Find one thing you enjoy doing and do it as often as you can. If you like to travel and you cannot, consider getting an Oculus Go. You can meet up with your grandkids in virtual reality and be the cool grandparent, the one kids WANT to spend time with. Then find another thing.

27. It is not just you—showers are hard. Try using a shower chair. Keep a terrycloth robe outside the shower, and just put it on, rather than standing there drying yourself. Sit down for a bit if you need to. I wash my hair in the sink and take a million sponge baths. My roommate is threatening a washcloth intervention.

28. Confusion.

If you find yourself unusually sleepy or confused, talk to your doctor about the possibility that you are retaining CO₂. CO₂ levels can rise from too much oxygen as well as too little.

If you are extremely sleepy and confused, a visit to the Emergency Room is called for. As well as making you sleepy and confused, excess CO₂ can also make you dead.

29. Medicare.

If you are on Medicare and are having problems with your health care, Medicare has patient advocates: <https://www.medicareadvocacy.org/>

30. Singing.

If you are alone in the car, singing along with the radio at the top of your lungs is a great way to exercise your chest muscles. If you are not alone in the car, sing aloud to amuse (or annoy) your passengers.

Blowing up balloons and playing the harmonica are also good ways to exercise your chest muscles, but not while you are driving.

31. Spare parts to keep on hand.

If you use tanks, keep spare O-rings because when the rubber wears down, the oxygen leaks.

Keep spare tanks ready to use.

Keep extra batteries (charged).

Keep extra swivel connectors if you use swivel rather than straight.

Keep extra tubing. If you wait to order tubing until your tube has a hole, you waited too long. Plan ahead, remember?

Keep an extra jug or two of distilled water.

Always have an extra cannula with you if you use a portable.

32. A nasal spray's effectiveness lies in how you use it.

If you need a nasal spray, use something with a corticosteroid, like Flonase, or a prescription spray. Lean forward, spray it up towards the front of your nose. Do not sniff hard. Keep your head leaned forward for a minute, letting it sit there. Your sinuses run under your eyes and into your forehead. I rotate my head from side to side and even turn my head upside down so the nasal spray can drain into my sinuses.

33. Essential Oil Diffusers. No, no, and no. You do not want a nice shiny coat of oil in your lungs. Some scents have been found to be beneficial to COPD patients. Eucalyptus is one. I find vanilla calming. You can get a wax warmer on Amazon for around \$20. Soy wax burns cleanly. **MAKE SURE YOU ARE BUYING 100% SOY WAX.** I add a capful of vanilla and the room smells great. I do not know offhand where to get eucalyptus that is not in oil form, but I'm sure it's out there. Fresh, crushed eucalyptus leaves, boiled and strained, would work.

34. Candles.

Burn unscented beeswax or soy candles only. Most candle wax is made of paraffin, a petroleum waste product that creates highly toxic benzene and toluene when it is burned. This can be problematic even for those in good health. Beeswax and soy candles burn pure, but when scent is added by a manufacturer, they can also release toxic chemicals.

35. Track Your Readings

It is a good idea to track your readings. Your oxygen saturation, your heart rate, your peak flow measurement if you have a peak flow. A pulse oximeter, available at any drug store, will give you your saturation and heart rate. A peak flow is available on Amazon. Take them first thing in the morning; keep a journal. If they are off, take your temperature. If you are getting sick, the early warning signs may keep you from getting sicker.

36. Coughing

If you are having non-productive coughing spasms, some of our group members have reported that pineapple juice is helpful. There is also prescription cough medicine available. Fresh pineapple also contains anti-inflammatory compounds.

37. If you need a "down day," take one.

Some days, the best you can do is breathe in and out. That is okay.

Clearing Your Airway

Mucus makes it harder to breathe because it worsens wheezing, coughing, and shortness of breath. Use airway clearance devices to get rid of excess mucus, make breathing easier, and prevent lung infections. You can use these devices with your other treatments, including medications.

Incentive spirometers encourage you to exhale as much as possible, which prevents mucus buildup in your lungs. These help you take slow, deep breaths so the tiny air sacs in your lungs can stay inflated. Here are three kinds:

Intrapulmonary Percussive Ventilation (IPV) devices deliver small bursts of air into your lungs through a mouthpiece. The bursts of air vibrate your chest and loosen mucus deep in your airways. You can continue to inhale and exhale as you normally would while you are using an IPV device.

Image from percussionaire.com.

Oral High-Frequency Oscillation (OHFO) Devices deliver low-volume, high-frequency sound to your lungs through a mouthpiece to help clear carbon dioxide and sputum from your lungs. You can inhale and exhale as usual while using an OHFO.

Image from sciencedirect.com.

Positive Expiratory Pressure (PEP) device is a face mask or a mouthpiece while inhaling and exhaling as you normally would. It provides mild air pressure as you exhale. This allows more air into the small airways in your lungs, creating pressure to gently dislodge excess sputum and push it toward the larger airways, making it easier to cough up.

Flutter Mucus Clearance System gently vibrates your large and small airways to loosen mucus and accelerate airflow to stimulate mucus clearance. After blowing through the device several times, you can usually cough out the accumulated mucus, but if you have severe airway obstruction, you may not be able to cough hard enough to allow a Flutter device to work properly.

Image from researchgate.net

The High-Frequency Chest Wall Oscillator (HFCWO) is an inflatable vest that uses air pressure to gently vibrate your chest. This action increases airflow to the smaller passages and helps clear mucus away. You can use the vest for five minutes at a time and then cough and huff to clear the loosened mucus. Examples of the HFCWO device include the Vest Airway Clearance System and the Medpulse Respiratory Vest System.

Image from <https://www.noinsurancemedicalsupplies.com>

The Lung Flute is a hand-held device that generates low-frequency sound waves in the airways as you vigorously exhale through a reeded mouthpiece (similar to blowing into a clarinet). The sound waves travel down into the lower airways to stimulate mucus clearance. For best results, perform a set of two blows into the mouthpiece and repeat up to 20 times.

Image from astonixlife.com

Choosing a Device

Choosing the right air clearance device is ultimately individual. Each device works differently. You may need time to get used to the one you select. Do not hesitate to ask your doctor or respiratory therapist for advice. You may also benefit from speaking with people who have used these devices to hear about their experiences. (www.verywellhealth.com)

MORE ABOUT REHAB

Moving around safely is the single most important thing you can do to stay healthy.

Ask your doctor if pulmonary rehabilitation is available. If you can find a respiratory therapist or a physiotherapist, you have struck gold.

Balance is hugely important. Any good doctor will tell you that the secret to good health is “Don’t fall.” Healthy people go down and break a hip and end up with pneumonia. We cannot afford to break things. Following are links to Rachel Garrod’s page and exercise videos. I asked Rachel, a physiotherapist, the exercises she considered the most important. She said chair stands because they enable you to move around. If the chair stands are too difficult, you can stack books on the seat of the chair to raise the seat to make it easier. Simply sit on the chair, cross your arms, and stand up. Shoulder sweeps (slowly pull your arms and shoulders back, like rowing a boat), because they allow your lungs to expand. Squeeze your shoulder blades together, hold for a moment. It feels good.

Put a balance exercise in there. I go down at the dog park all the time, but I practice balance twice a week and I fall right. Although I really need to work on not falling. Prednisone weakens your bones.

All three of these exercises are in the videos at the end of this booklet.

You can incorporate rehab into your life just by doing things, pushing yourself a little. I do not do things that I know are going to tank my saturation, but I walk the track at the dog park, get out there and work in the garden, and wrestle around with my dogs. Another member of our online group lays her own tile. The more you move, the more you will want to move. When I am exhausted, I exercise. Five minutes into stretching and toning, the exhaustion lifts.

If you need to exercise sitting down, sit down. If it HURTS, STOP.

Rachel Garrod has a plethora of free stuff on her page, as well as an option to pay 45 American dollars or 45 euros for a one-on-one Messenger or Skype session. Rachel has free videos of everything she does, and she has been helping COPD patients for years because she is passionate about healthcare. The same material is available to those who cannot afford to work with Rachel one-on-one; it may take a little effort to apply it to your life.

Rachel Garrod's page (make sure and scroll through – there is a LOT of stuff in there):

<https://www.facebook.com/rachelgarrodphysio/>

Try COPD Exercises with Dogs (my dogs do synchronized everything with me). Search term: "COPD Exercises with Dogs" on YouTube.

[COPD Exercises with Dogs - YouTube](#)