



Managing your COPD

A SELF-CARE WORKBOOK FOR PATIENTS



YOUR CONDITION

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Your personal health information

Primary care doctor: _____ Phone: _____

Pulmonologist: _____ Phone: _____

Home care agency: _____ Phone: _____

Pharmacy: _____ Phone: _____

Last flu vaccination: _____ Last COVID-19 vaccination: _____

Pneumonia vaccination: _____ RSV vaccination: _____

Shingles vaccination: _____ Whooping cough vaccination: _____

Allergies: _____

APPOINTMENTS WITH MY CARE TEAM

Date	Who did I see?	What did I see them for?

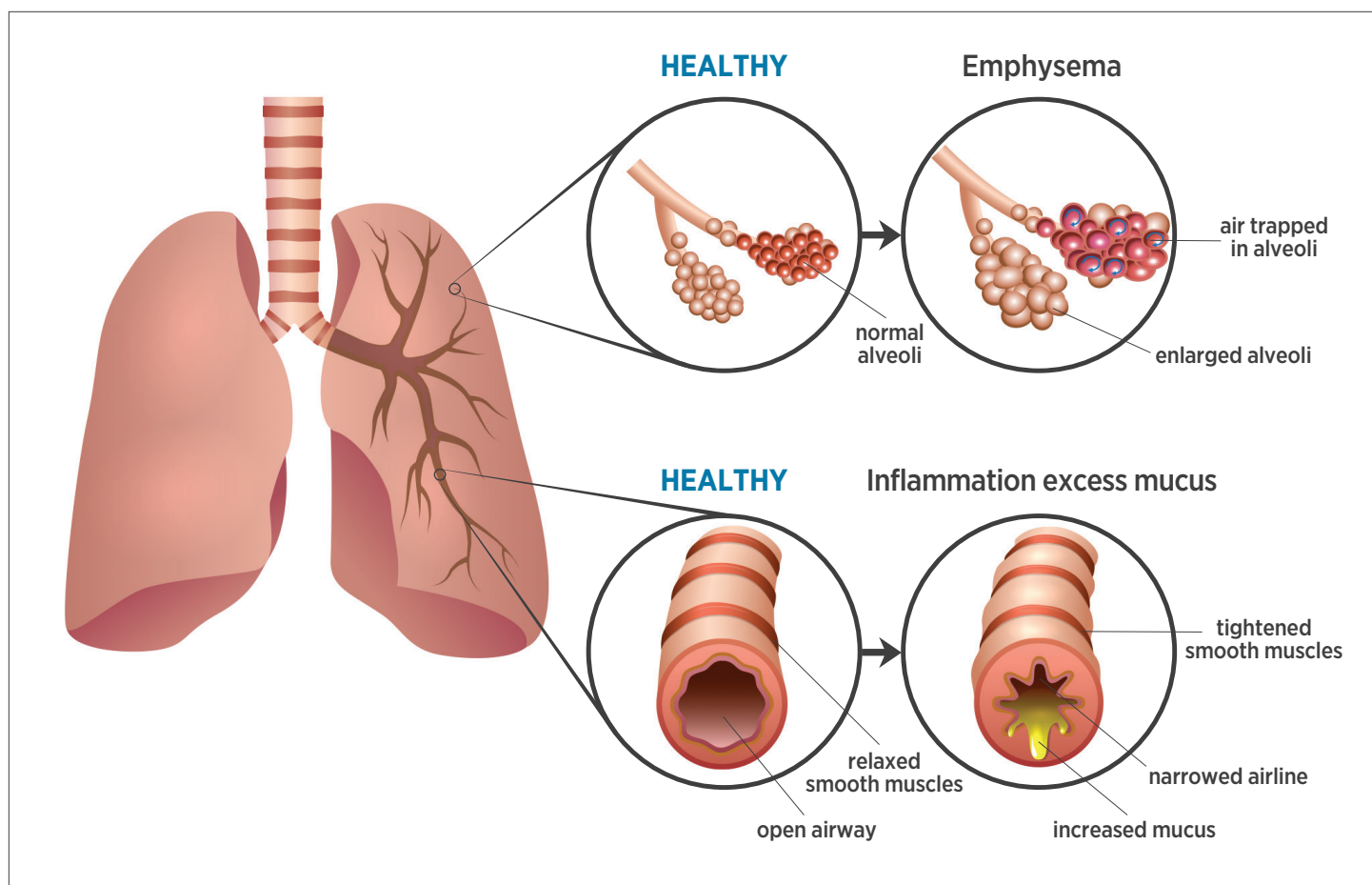
Information about your condition

WHAT IS COPD?

Chronic obstructive pulmonary disease (COPD) is a common lung disease that is both preventable and treatable. It is caused when the airways going to your lungs become narrowed. This causes the lung air sacs to become damaged and overinflated (or full). It makes it harder for you to get fresh air in and stale air out of your lungs. Chronic bronchitis and emphysema are both considered types of COPD.

SYMPTOMS OF COPD

- Coughing more often and coughing up mucus
- Shortness of breath that keeps you from doing things you would like to do



Keeping your COPD under control

HERE ARE SOME THINGS YOU CAN DO TO HELP

1. Understand what it means to have COPD.
2. **STOP SMOKING.** Even when you already have COPD, quitting smoking can help your lungs work better.
3. Take ALL your medicines as ordered by your doctor.
4. Eat well — the right nutrition can help you breathe easier.
5. Exercise and stay active.
6. Use oxygen if ordered by your doctor.
7. Ask your doctor about recommended vaccinations (flu, RSV, pneumonia, COVID-19, shingles, whooping cough).
8. Wash your hands often and stay away from people with colds or flu.
9. Avoid lung irritants (smoke, cold air, aerosols, strong cleaning products, etc.)
10. Keep all doctor appointments.
11. Follow your COPD action plan.

Self-assessment



Your name: _____

Today's date: _____

How is your COPD? Take the COPD Assessment Test™ (CAT)

This questionnaire will help you and your healthcare professional measure the impact COPD (Chronic Obstructive Pulmonary Disease) is having on your wellbeing and daily life. Your answers, and test score, can be used by you and your healthcare professional to help improve the management of your COPD and get the greatest benefit from treatment.

For each item below, place a mark (X) in the box that best describes you currently. Be sure to only select one response for each question.

Example: I am very happy

0	1	2	3	4	5
---	---	---	---	---	---

 I am very sad

		SCORE							
I never cough	<table border="1" style="display: inline-table;"><tr><td>0</td><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td></tr></table>	0	1	2	3	4	5	I cough all the time	<input type="checkbox"/>
0	1	2	3	4	5				
I have no phlegm (mucus) in my chest at all	<table border="1" style="display: inline-table;"><tr><td>0</td><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td></tr></table>	0	1	2	3	4	5	My chest is completely full of phlegm (mucus)	<input type="checkbox"/>
0	1	2	3	4	5				
My chest does not feel tight at all	<table border="1" style="display: inline-table;"><tr><td>0</td><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td></tr></table>	0	1	2	3	4	5	My chest feels very tight	<input type="checkbox"/>
0	1	2	3	4	5				
When I walk up a hill or one flight of stairs I am not breathless	<table border="1" style="display: inline-table;"><tr><td>0</td><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td></tr></table>	0	1	2	3	4	5	When I walk up a hill or one flight of stairs I am very breathless	<input type="checkbox"/>
0	1	2	3	4	5				
I am not limited doing any activities at home	<table border="1" style="display: inline-table;"><tr><td>0</td><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td></tr></table>	0	1	2	3	4	5	I am very limited doing activities at home	<input type="checkbox"/>
0	1	2	3	4	5				
I am confident leaving my home despite my lung condition	<table border="1" style="display: inline-table;"><tr><td>0</td><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td></tr></table>	0	1	2	3	4	5	I am not at all confident leaving my home because of my lung condition	<input type="checkbox"/>
0	1	2	3	4	5				
I sleep soundly	<table border="1" style="display: inline-table;"><tr><td>0</td><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td></tr></table>	0	1	2	3	4	5	I don't sleep soundly because of my lung condition	<input type="checkbox"/>
0	1	2	3	4	5				
I have lots of energy	<table border="1" style="display: inline-table;"><tr><td>0</td><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td></tr></table>	0	1	2	3	4	5	I have no energy at all	<input type="checkbox"/>
0	1	2	3	4	5				

TOTAL SCORE

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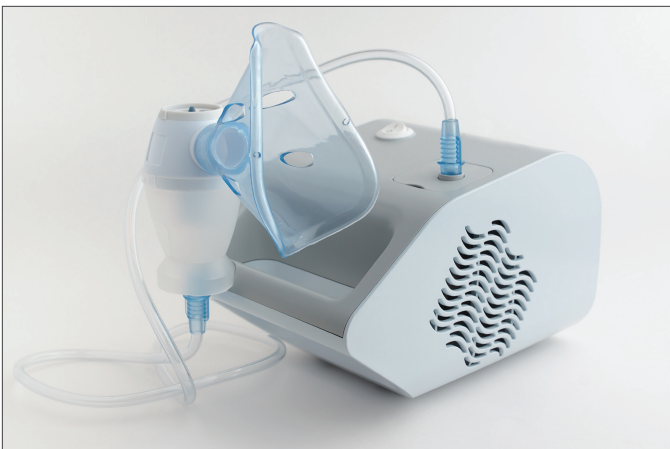
Medicines

Inhalers and nebulizers put medicine directly into your lungs. This is different from pills or shots, which send medicine into your whole body. Here's what else you need to know about using inhalers and nebulizers:

- Inhalers deliver medicine to lungs using fine mists or sprays that must be inhaled.
- Nebulizers change liquid medicine into a fine mist that is inhaled.

Your doctor, nurse, respiratory therapist or pharmacist will work with you to make sure you understand all of your medicines.

NEBULIZER



INHALERS



Types of medicines you may be taking

MEDICATION	PURPOSE	POSSIBLE SIDE EFFECTS AND SPECIAL PRECAUTIONS
<input type="checkbox"/> Inhaled bronchodilator My medication: _____	Relax and open up your lungs, making it easier for you to breathe Can be short acting (effect lasting 4-6 hours) or long acting (effect lasting 12-24 hours)	Nervousness, insomnia, faster heartbeat, increased blood pressure, dry mouth, feeling shaky and unable to sleep
<input type="checkbox"/> Inhaled steroid My medication: _____	Decrease inflammation (swelling) and mucus in the lungs Decrease lung sensitivity to allergens and irritants	Thrush (a mouth infection); rinsing and spitting after each use can prevent this
<input type="checkbox"/> Steroid by mouth or through a vein My medication: _____	Decrease inflammation (swelling) and mucus in the lungs Decrease lung sensitivity to allergens and irritants	Inability to sleep, mood changes, weight gain, high blood pressure, glaucoma, cataracts, osteoporosis Oral steroids should be taken with food or milk
<input type="checkbox"/> Phosphodiesterase (PDE) inhibitor My medication: _____	Can reduce the number of COPD flare-ups (exacerbations)	Diarrhea, nausea, headache, insomnia, back pain, reduced appetite, dizziness
<input type="checkbox"/> Biologic (dupilumab) My medication: _____	Can reduce the number of COPD flare-ups (exacerbations), improve lung function and quality of life	Skin rash, dry/itchy eyes, eye infection, decreased mobility

MEDICATION	PURPOSE	POSSIBLE SIDE EFFECTS AND SPECIAL PRECAUTIONS
<input type="checkbox"/> Oxygen My dose: <hr/>	<p>Can raise oxygen level if you have low levels in your body</p> <p>Relieves shortness of breath, fatigue and dizziness</p> <p>Can provide more alertness, improved sleep and overall better feeling</p> <p>Can provide ability to do more activities such as traveling, exercising, etc.</p>	<p>Headaches, confusion or increased sleepiness may indicate you are getting too much</p> <p>Dryness and bleeding of the lining of the nose can be caused by oxygen settings of 4 liters per minute or above; a humidifier attached to your oxygen equipment or certain water-soluble lubricants can help prevent or treat dryness</p>
<input type="checkbox"/> Noninvasive ventilation My settings: <hr/>	<p>Some people may experience severe chronic hypercapnia, or higher levels of CO₂ in the blood, and have a history of hospitalization because of acute respiratory failure. In select candidates, noninvasive ventilation, a form of noninvasive positive pressure ventilation (NPPV), may decrease mortality and prevent rehospitalization. NPPV can be used at home and help with the breathing process through a face mask.</p>	<p>Nasal dryness or irritation: Common if a humidifier isn't used</p> <p>Discomfort or pressure sores: Around the nose or face from the mask</p> <p>Air leaks: Can reduce effectiveness and cause noise</p> <p>Bloating: From swallowing air (aerophagia)</p> <p>Eye irritation: From air escaping the mask</p>

Oxygen safety

Oxygen makes fire burn hotter and faster, so it is important that you reduce the chance of fire when using oxygen. Please review the safety guidelines below.

THINGS TO DO

- Display an “oxygen in use” sign at the main entrance to your home.
- Make sure there are working smoke detectors and smoke alarms in your home.
- Clean and replace your oxygen equipment as instructed.
- Set the flow rate for only the number of liters ordered by your doctor.
- Arrange equipment to avoid tripping, especially at night.
- Oxygen can be drying. You may use saline nasal spray or apply water-based lubricant like K-Y® Jelly to the nasal membranes.
- Notify your local fire department and power company that you have oxygen in your home.
- Always be aware of the amount of oxygen left in your tank.
- Oxygen tanks should be stored upright in an oxygen holder. When no holder is available, oxygen tanks must be placed on their side.

THINGS NOT TO DO

- Do not smoke while using oxygen.
- Do not permit smoking in the room with oxygen.
- Do not place oxygen within 10 feet of heat (open flame, candle, gas stove, gas dryer, pilot light, wood-burning stove or direct sunlight).
- Do not place oxygen supply within 10 feet of an electrical appliance or equipment.
- Do not spray aerosols (such as air freshener or hair spray) near oxygen.
- Do not apply petroleum-based jelly like Vaseline® to your nose and lips. Petroleum-based jelly can serve as a fuel if ignited.
- Do not prop or lean oxygen tanks against the wall.
- Do not change the oxygen flow rate without talking to your doctor.
- Do not cover the oxygen concentrator with linens or pillows.
- Do not store oxygen in a closet.

Optimal inhaler technique

Optimal inhaler technique increases medicine effect and can help you better manage COPD.

- Inhaler delivery devices fall into three categories:
 - Metered-dose inhalers (MDI)
 - Soft mist inhalers (SMI)
 - Dry powder inhalers (DPI)
- The optimal inhaler technique differs depending on what inhaler you are using.

METERED-DOSE INHALER WITH CHAMBER



METERED-DOSE INHALER WITHOUT CHAMBER



Mindful breathing tips

If at any point you feel like you are losing your breath or becoming severely short of breath, **PAUSE**



Pause the exercise (or activity).



Adjust your position to a comfortable one that helps your lungs' movement.



Use pursed-lip breathing

with an inhale count of at least two seconds and an exhale count of at least four seconds; closing your eyes can help the relaxation effects.



Stabilize your breath by continuing to use pursed-lip breathing until you feel you have gotten your breath back and/or find that your shortness of breath has improved.



Engage slowly back into the exercise (or activity) at comfortable effort and repeat PAUSE as needed. Call your healthcare provider and/or seek medical attention if you continue to be severely short of breath.

Aerobika® PEP device



The Aerobika is an oscillating positive expiratory pressure (OPEP) device that has several benefits for people with lung disease.

OPEP/PEP devices keep your airways open by creating a positive pressure when you breathe in and out of them. The positive pressure moves mucus into your upper airway so you can cough it out. This can help to prevent infections and move mucus out of your lungs.

USING THE AEROBIKA DEVICE

Your clinician will tell you how often you should use the device and the resistance level you should use. Before you use the device, set the resistance (1 is lowest resistance, 5 is hardest resistance). This is set with the black switch on the front of the device (resistance indicator).

CLEANING THE AEROBIKA DEVICE

Clean the device every day and as needed to prevent germs from building up that could cause infections. The mouthpiece is the only part of the Aerobika device that can be washed.

TO USE THE DEVICE:

- Place your lips tightly around the mouthpiece.
- Breathe in and hold your breath for two to three seconds.
- Breathe out for six to nine seconds.
- Repeat these steps for 10 breaths, or as prescribed by your physician.

Disinfect the device mouthpiece once a week. Clean the mouthpiece before you disinfect it. You can use one of these disinfecting methods:

- Soak the mouthpiece in 70% isopropyl alcohol for five minutes. Rinse, drain and dry.
- Soak the mouthpiece in 3% hydrogen peroxide for 30 minutes. Rinse, drain and dry.

If you have any questions, talk with your respiratory therapist or physician.

CLEANING INSTRUCTIONS:

1. Remove the mouthpiece from the device.
2. Soak the mouthpiece in warm, soapy water for several minutes.
3. Rinse and dry.
4. Once the mouthpiece is completely dry, put it back on the device.

Activity

STAYING ACTIVE AND SAFE

Exercise is very important when you have COPD. This may include chair exercises, walking or using a stationary bike.

Exercise will:

- Help with shortness of breath
- Increase your energy
- Make you feel less tired

QUICK TIP

Your COPD symptoms should be under control before starting an exercise program.

A physical therapist can help you begin your exercise program. They will teach you ways to safely exercise, such as pacing yourself and stopping to rest when needed.

QUICK TIP

Your doctor may tell you to use a rescue inhaler before exercising.



Energy conservation tips

WALKING

- Walk at a slow, comfortable pace.
- Have chairs placed throughout your home to allow rest stops.
- Use a rolling cart to transport items.
- Consider using a walking aid (e.g., wheeled walker) .

BATHING

- Use a bath stool or bench during bathing.
- Use a handheld shower head.
- Use long-handled sponges or brushes.
- Consider sponge bathing.
- Use a terry cloth robe to help dry off after bathing.

DRESSING

- Use slip-on shoes that cover the heel, with elastic ties.
- Use dressing aids (sock aid, shoehorn, dressing stick, reacher, etc.).
- Dress seated instead of standing.
- Avoid clothes that are tight, or have many buttons, etc.



GROOMING

- Perform grooming tasks seated.
- Let hair air dry or use hair dryer cap instead of a hair dryer.

TOILETING

- Avoid waiting to use the toilet, which might cause rushing and anxiety.
- Consider using a bedside commode.



Planning your day

Planning ahead and getting organized will help you to feel better and maintain your energy throughout the day.

WHEN POSSIBLE

- Organize “work centers” so all necessary items are together.
- Simplify tasks as much as possible (e.g., prepare light meals).
- Prepare for activities by resting and performing breathing exercises.
- Keep room temperature comfortable.
- Ask for help when you need it.

Is sex safe when I have COPD?

Yes. Just like exercise, planning ahead can help you feel your best. Start by scheduling sex for the time of day that you have the most energy. If prescribed, use your rescue inhaler 15-30 minutes before sex. It also helps to cough and clear the mucus from your lungs before sex. These tips may also help:

- If you use oxygen during exercise, use it during sex.
- Try positions that require less effort. Lying on your back or side may be easier.
- Use your “pursed lip” and “belly breathing” exercises during sex.

Be sure to take a break during sex if you get out of breath or feel too tired.

WHAT IF I DON'T HAVE ENOUGH ENERGY FOR SEX?

If you are too tired for sex, talk with your partner about other ways to stay close. For example, kissing, holding hands and giving or receiving back rubs can keep you connected.

Nutrition

It is important to eat a healthy diet. If you are underweight and do not eat enough, you will have less energy. If you are overweight, it will be harder to be active and you may have more shortness of breath. Your nurse or a dietitian can help you review your diet, understand food labels and give you lists of healthy foods. Fruits and vegetables, and protein-rich foods such as meat, fish, eggs and milk are good for you.

There are certain things you can do to make it easier for you to eat when you have COPD.






CHECK OFF THE THINGS YOU THINK YOU CAN DO



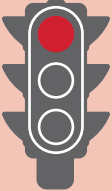
- ☐ Eat a balanced diet with enough calories.
- ☐ Ask your doctor or nurse before taking supplements.
- ☐ Drink enough fluids — this helps keep your mucus loose.
- ☐ Eat smaller meals more often.
- ☐ Avoid foods that give you gas — they make your stomach fuller. This may increase shortness of breath.
- ☐ Include fiber in your diet to decrease constipation.
- ☐ Eat slowly and talk less while you eat.
- ☐ Sit in a chair that allows for good posture while you eat.
- ☐ Avoid activity or exercise for one hour after eating.

Action plan

HOW DO I FEEL TODAY?

	 GREEN ZONE You are in control.	 YELLOW ZONE Take action today. Call doctor: <hr/> Follow “what I should do” on next page.	 RED ZONE Take action now. Call 911 or go to the nearest emergency room. Follow “what I should do” on next page.
How is my breathing?	My breathing is ok. My oxygen saturation is normal.	It's harder to breathe than usual. My oxygen saturation is lower than normal. I have more wheezing than normal.	My breathing is bad, even at rest. My oxygen saturation remains low. I have constant wheezing.
How is my cough?	My cough and mucus are normal.	I have more coughing, and/or mucus than usual. I see a change in mucus color.	I'm coughing up blood.
Is my medicine working?	My COPD medicines are working.	I need to use my COPD rescue medicine more often than normal.	My COPD medicines are not working.
How are my appetite and sleep?	My appetite and sleep are normal.	I'm not eating or sleeping well.	I'm not eating or sleeping at all.
How is my energy?	I am able to do my usual activities.	I have less energy than normal.	I have no energy.
Other		I have a fever.	I feel confused or drowsy.

WHAT I SHOULD DO

 GREEN ZONE	 YELLOW ZONE	 RED ZONE
<p>Continue my usual routines.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Use my rescue inhaler or nebulizer medicine as directed. <input type="checkbox"/> Use my oxygen. <input type="checkbox"/> Use pursed lip breathing and belly breathing when I am short of breath. This will help me stay calm and catch my breath. <input type="checkbox"/> Rest and avoid heavy activity. <input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____ 	<ul style="list-style-type: none"> <input type="checkbox"/> Use my rescue inhaler or nebulizer medicine as directed. <input type="checkbox"/> Use my oxygen. <input type="checkbox"/> Use pursed lip breathing and belly breathing when I am short of breath. This will help me stay calm and catch my breath. <input type="checkbox"/> Rest and avoid heavy activity. <input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____

Main Line Health resources

Your doctor may recommend other Main Line Health programs to help you manage your COPD.

MAIN LINE HEALTH HOMECARE & HOSPICE

Our home health nurses and therapists have advanced training to help you manage your COPD. Our team will focus on your goals of care and create a plan that keeps you healthy. We also offer:

- Tips on using your medicine safely
- Help with getting the most from your medicine
- Help with using oxygen safely in your home
- Customized pulmonary rehab program
- Tips that help you avoid hospital trips

Our home health team sees patients in Delaware, Chester, Montgomery and Philadelphia counties. If you live in other areas, we can help find a home care agency in your neighborhood.

To learn more about Main Line Health HomeCare & Hospice services, call **484.580.1601** or visit mainlinehealth.org/homecare.

NUTRITIONAL COUNSELING

Registered dietitians work with you and your doctor to create nutrition plans based on your health condition and lifestyle. To learn more about nutritional counseling programs at Main Line Health, call **1.866.CALL.MLH (1.866.225.5654)**.



OUTPATIENT PULMONARY REHABILITATION

After home care is done, you may qualify for additional therapy called outpatient pulmonary rehabilitation. This program includes exercise and education that help improve quality of life and prevent unnecessary trips to the hospital.

To learn more about pulmonary rehabilitation programs at Main Line Health, call:

Lankenau Medical Center

100 East Lancaster Avenue
Wynnewood, PA 19096
484.476.2104

Bryn Mawr Hospital

130 South Bryn Mawr Avenue
Bryn Mawr, PA 19010
484.337.3343

Paoli Hospital

255 West Lancaster Avenue
Paoli, PA 19301
484.565.1620

PULMONARY DIAGNOSTIC AND WELLNESS CENTERS

At the Pulmonary Diagnostic and Wellness Centers, we provide comprehensive care for patients with respiratory disorders and chronic lung disease. These teams perform routine pulmonary function tests (PFTs), walking tests (to determine the need for supplemental oxygen and how much), high altitude testing, cardiopulmonary exercise testing and more.

To learn more about the centers, call:

Lankenau Medical Center

100 East Lancaster Avenue
Wynnewood, PA 19096
484.476.2104

Bryn Mawr Hospital

130 South Bryn Mawr Avenue
Bryn Mawr, PA 19010
484.337.3343

Paoli Hospital

255 West Lancaster Avenue
Paoli, PA 19301
484.565.1620

SMOKEFREE PROGRAM

SmokeFree is a free, state-approved program consisting of six sessions designed to help smokers quit. The program addresses the physical and psychological habit of smoking.

To register for any SmokeFree class, call
484.227.FREE (484.227.3733).

Additional resources

National programs are also available.

AIRNOW

Air quality can be an irritant to your lungs. We advise that you check the air quality in your area and plan your days accordingly.

airnow.gov

AMERICAN LUNG ASSOCIATION

The American Lung Association HelpLine has registered nurses, respiratory therapists and certified tobacco treatment specialists who can help. You can speak directly with an expert who can answer questions about your lung disease or about quitting smoking. This compassionate counseling is free, and there is no limit to the number or length of calls.

1.800.LUNGUSA (1.800.586.4872)

lung.org

BETTER BREATHERS CLUB

The American Lung Association Better Breathers Club is a welcoming support group for patients and caregivers affected by chronic lung diseases such as COPD, pulmonary fibrosis and lung cancer.

1.800.LUNGUSA (1.800.586.4872)

COPD FOUNDATION/COPD360SOCIAL

Join the largest free online network of patients, caregivers and supporters of those affected by COPD.

1.866.316.COPD (2673) | copdfoundation.org

COPD360social.org

PA FREE QUITLINE

This is a free program that provides coaching over the phone to help you quit smoking.

1.800.QUIT.NOW (1.800.784.8669)



mainlinehealth.org | 1.866.CALL.MLH

Membership within Main Line Health medical staff does not constitute an employment or agency relationship.