Living Well with COPD™



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Understanding COPD

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This module is also available on the website
www.LivingWellwithCOPD.com

The skills you need to manage your COPD

Chronic obstructive pulmonary disease, or COPD, is a disease that can seriously affect every part of your life. As the disease progresses, it can take a toll on your daily activities. Fortunately, there is a lot that you can do to try and manage these limitations and improve your well-being. This is why we have created this series of workbooks on COPD self-management.

How can this program help me with the self-management of the disease?

This module is part of the Living Well with COPD program. It is an educational program in which you learn skills to help manage your disease and adopt healthy new lifestyle behaviours. The Living Well with COPD program has been tested in several clinical trials and the results were very encouraging. Patients who used these workbooks in collaboration with their healthcare worker, "case manager" or resource person and physician had fewer exacerbations requiring hospitalizations or emergency room visits. Their quality of life has also improved, enabling them to do more of the activities they enjoyed, and better cope with their disease.

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National and international guidelines agree that self-management education is extremely valuable for individuals with COPD. The Living Well with COPD Self-Management Program, which you can adapt to your own situation, was created by medical experts in collaboration with COPD patients.

This is your guide. Use it to write down your questions or concerns. Share it with people close to you so that they can understand what you are going through. Discuss whatever thoughts and feelings you have with your case manager or resource person and your physician.

Good luck with your program!

Dr. Jean Bourbeau
Montreal Chest Institute,
McGill University Health
Centre (MUHC)

Maria Sedeno BEng, MM
Executive Director
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Welcome to “Understanding COPD" of the Living Well with COPD series

Being diagnosed with COPD can be a scary and confusing time. You will have a lot questions and concerns. COPD stands for Chronic Obstructive Pulmonary Disease. It affects your breathing and lungs.

Living well with COPD means understanding what makes COPD happen and how it can impact your life.

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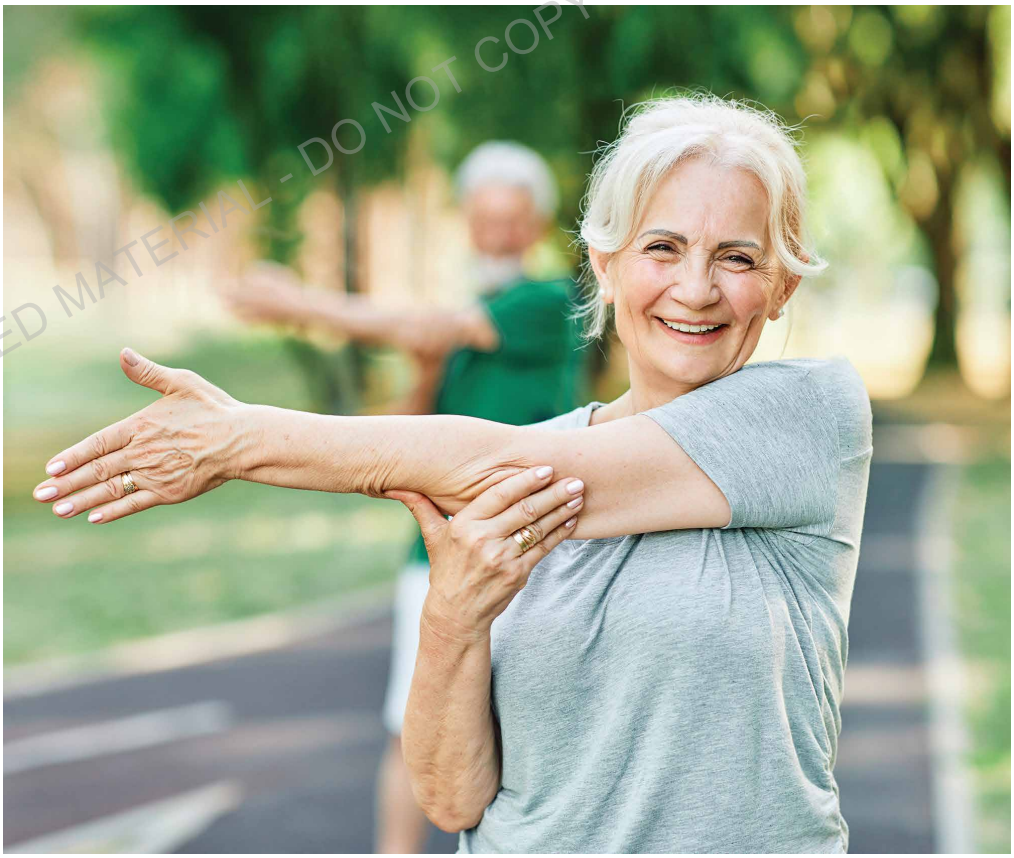
The meaning of being healthy

Living well with COPD is about adopting and maintaining healthy behaviours in your life. This will mean changing your lifestyle. You may have already discussed the need for help with your treating team. Help to quit smoking and to exercise more. Perhaps you are ready for this journey but don't know where to start?

TO CHANGE YOUR LIFESTYLE, YOU MUST FIRST DEFINE HEALTH

Taking charge of your health starts with looking at your needs.

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The meaning of being healthy

Throughout this series "Living Well with COPD" we will discuss multiple strategies for you to live a better and longer life, even when you have COPD.

What does health mean to you?

What do you do to stay healthy?

What healthy leisure activities do you make time for?

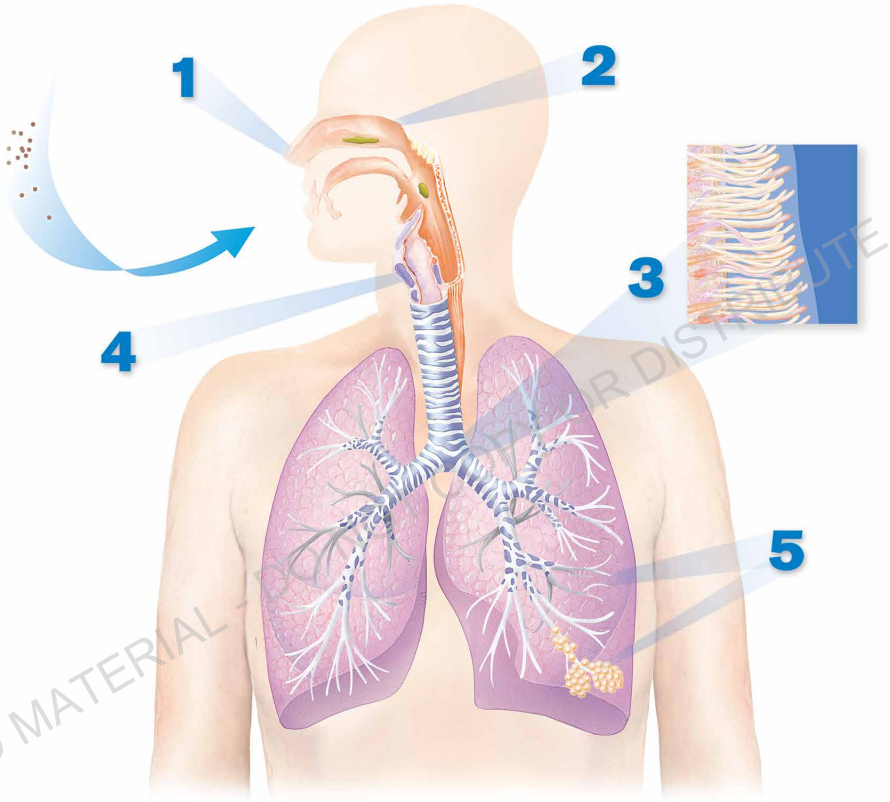
How can friends and family help you?

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Even if you have COPD, you can still be healthy. Knowing as much as you can about your disease and managing it on a daily basis in order to still do thing that you enjoy can help you live better with your COPD.



Normal Lungs



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1. Every time you breathe, air is drawn into your lungs – along with dust and pollutants.
2. Many of these particles are trapped inside your nose and other smaller particles stick on tiny mucous layers in your airways.
3. Mucus or secretions move up to your **trachea** by tiny hairs called **cilia** and then move further up to your throat.
4. Once in your throat, mucus is then swallowed or removed by coughing.
5. This process prevents particles from reaching the lower airways and doing damage to your **bronchi (airways)** and **alveoli (air sacs)**.



What is COPD

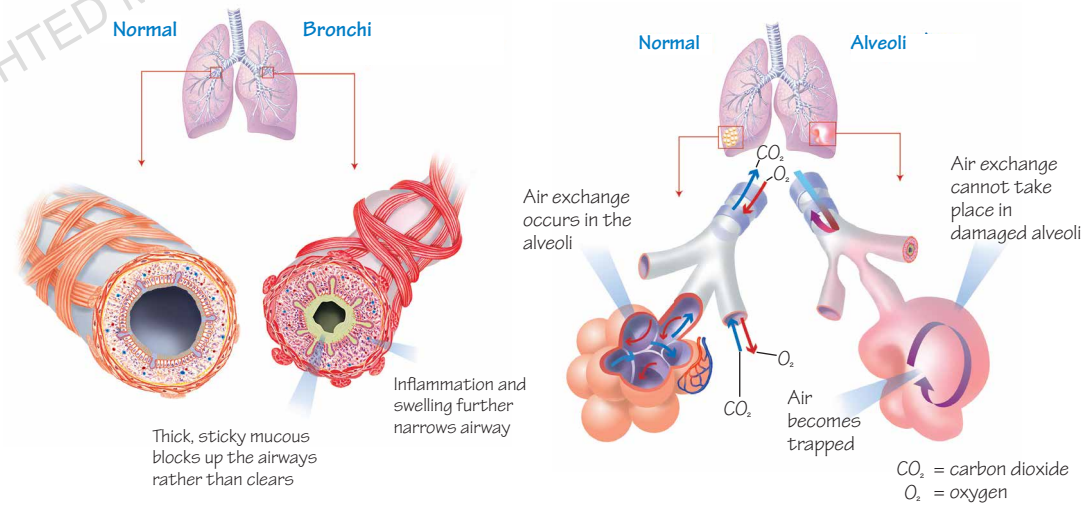
COPD means Chronic Obstructive Pulmonary Disease. COPD causes airways to become "obstructed" or blocked.

How does COPD develop?

When your airways are constantly attacked by pollutants, such as those found in cigarette smoke, they become inflamed, red and swollen.

Your airways become filled with thick, sticky phlegm. You cough to clear your airways. Over time, your airways may become permanently scarred causing blockage or obstruction (or there is limited airflow). Because of airway blockage, your lungs do not fully empty and air becomes trapped in your lungs.

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What is COPD?

Your lungs are filled with different sizes of tubes that eventually branch down to millions of tiny air sacs called alveoli. In these little sacs the body breaths in the oxygen it needs and breaths out the waste gas of carbon dioxide.

In people with COPD, your alveoli become damaged or destroyed, it becomes difficult for the lungs to get the needed oxygen into your body. This damage can also lead to narrowing or blockage of the airways and air being trapped in your lungs.

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Symptoms of COPD

The most common signs and symptoms of COPD are:

- Shortness of breath. When even simple chores like dusting make you short of breath.
- Making lots of phlegm every day. Chronic inflammation in the airways from pollutants can lead to increased phlegm production and coughing.
- Frequent coughing. A persistent and bothersome cough that does not get better.
- Wheezing, especially when you exert yourself like for example when going up the stairs.

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Tell us about your symptoms

What symptoms of COPD bother you even when you are at your best?

When do these symptoms bother you (e.g. some strenuous activities, pollutants, stress)?



Main Cause of COPD

Cigarette smoke is the leading cause of COPD.

- Many people who suffer from COPD are current or former smokers.
- However, 1 in 4 people with COPD have never smoked. There are other elements such as second-hand smoke, occupational exposures, air pollution and many others that can increase your risks of developing COPD.
- A very small number of people with COPD have a genetic condition called alpha-1 antitrypsin deficiency which leads to a much higher risk of COPD if they are exposed to cigarette smoke or other pollutants in the air.

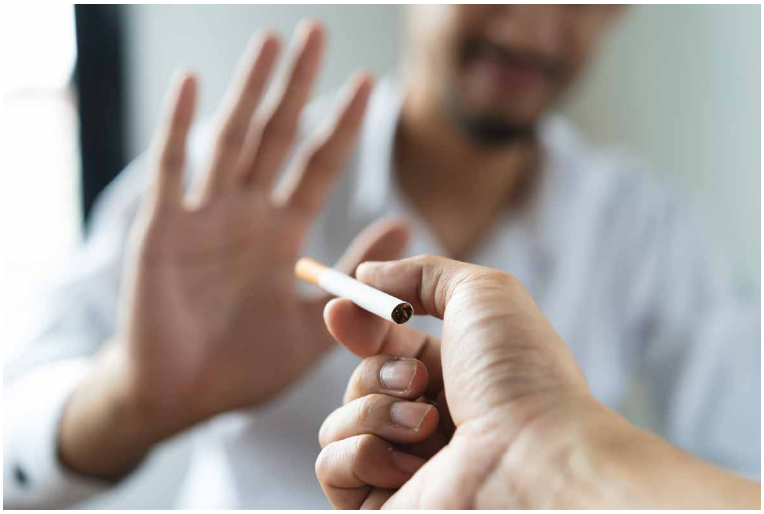
If you would like more information and helpful tools on how to quit smoking, you can refer to the module **"Living Well Smoke Free"** of the Living well with COPD education series.

If you would like more information on the genetic determinants of COPD you can refer to our module on **"Alpha-1 Antitrypsin Deficiency (AATD)"** of the Living well with COPD education series.

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Benefits of Quitting Smoking

- Slows the progression of COPD.
- Lowers your risk of death from COPD, heart disease and cancer.
- A healthy lifestyle that includes living smoke free can help you to be more independent, stay employed longer and do more activities that you enjoy.
- Save money that is not spent on tobacco.





How is COPD Diagnosed?

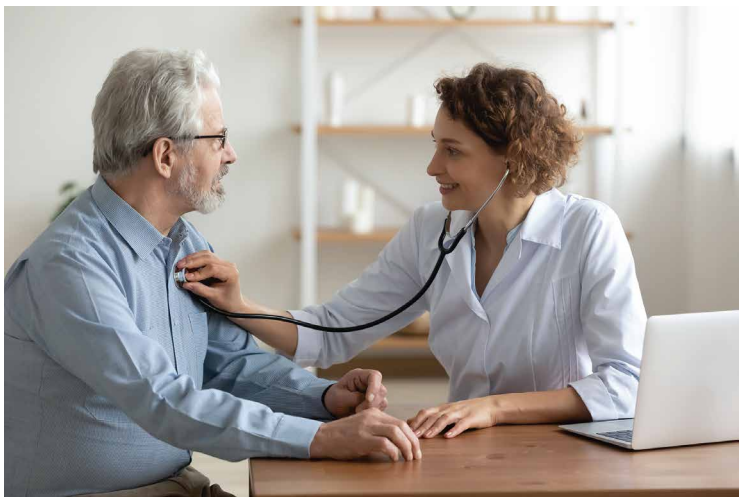
Medical history and physical exam

Your healthcare practitioner will start out by doing a complete medical history and exam. You will be asked many questions regarding your medical history, current medications, symptoms, your smoking history and exposure to different agents in your workplace and environment.

Some questions your doctor might ask:

- Your symptoms
- If you have had any lung attacks (exacerbations)
- What medications do you take and how you take them
- Your environment and occupation
- Your smoking history
- Other medical conditions you have that could also contribute to your symptoms

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You may be referred to a respirologist (lung specialist) who will confirm your diagnosis and decide the best course of treatment for you.



Your doctor may order some tests

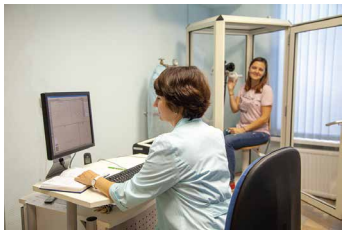
Spirometry



Spirometry is a simple and painless breathing test. It involves blowing as hard and as fast as you can into a mouthpiece connected to a machine. The machine will measure the amount of air you blow out in the first second and the amount of air you blow out in total. These measurements are key in diagnosing COPD.

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Pulmonary Function Tests



Your doctor may order more breathing test to better understand what is happening in your lungs. These breathing tests can measure the volume of air in your lungs and how well your lungs (air sacs) can exchange oxygen and carbon dioxide.

Chest Imaging: X-Ray and CT scan



X-Rays and CT scans take different pictures of your chest and can give your doctor an idea of what is happening in your lungs. They can help rule out other diseases that could be causing similar symptoms.

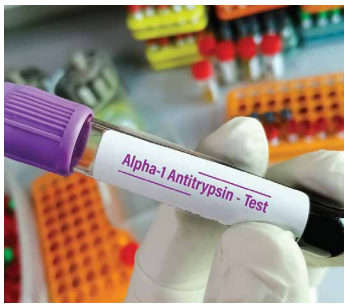


Your doctor may order some tests



Arterial Blood gas analysis

This test takes blood from an artery (usually in your wrist) to measure how well your lungs bring in oxygen and take out carbon dioxide.



Alpha-1 Antitrypsin Deficiency Test

Alpha-1 Antitrypsin Deficiency is a rare genetic disorder that can cause COPD (and liver problems), even in people who have never smoked. It can be diagnosed with a blood test to check your levels of alpha-1 antitrypsin, a protein that protects the organs against harmful substances.

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Things in the environment that can make your symptoms worse

When you have COPD, some factors can cause your symptoms to be worse. When these symptoms get worse and you need to adjust your COPD medication (for example, you need to take prednisone or an antibiotic, or you need to go to the emergency room for your breathing), it is called a COPD exacerbation or "lung attack".

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Most common factors:

Indoor pollutants



Tobacco smoke, household cleaning products, strong odours, dust

Outdoor pollutants



Exhaust fumes, gas fumes, smog

Emotions



Anger, anxiety, stress

Changes in temperature



Extreme heat or cold, wind, humidity

Respiratory Infections

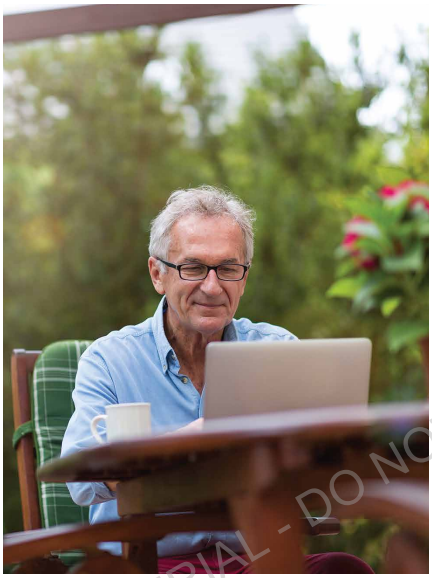


Cold, flu, bronchitis, pneumonia, COVID-19, respiratory syncytial virus (RSV)



Suggestions to reduce or avoid exposure to those factors

Indoor and Outdoor Pollutants



- Quit smoking and avoid second-hand smoke. Talk to your healthcare practitioner and/or resource person about the strategies that can help you and your close ones to quit smoking.
- Avoid strong odours. Work in well-ventilated areas.
- Avoid smog. If the air quality is not good, then try to stay indoors.
- Avoid exhaust and gas fumes.

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Emotions



- If you are stressed and anxious, talk to your friends and family about your feelings.
- Practice breathing and relaxation techniques.



Suggestions to reduce or avoid exposure to those factors

Changes in Temperature

A) When it is cold, dress warmly and cover your nose with a scarf.
B) When it is hot:



- Stay in an air-conditioned environment.
- Drink plenty of water (if there are no medical restrictions).
- Avoid strenuous activities.
- Wear light clothing, preferably in light colours, and a hat.

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Respiratory Infections



- Avoid people who have a respiratory infection such as a cold, the flu, RSV or a COVID-19 infection. Wash your hands if you are in contact with them. Wear a mask in crowded spaces or in large crowds.
- You, and the people you are living with, should get a flu shot every fall. You should stay up to date with your COVID-19 shots as recommended by the current health guidelines. Ask your resource person or doctor about the pneumonia and RSV vaccines available now.



Suggestions to reduce or avoid exposure to those factors

Why people with COPD should get their recommended vaccines



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- Having respiratory problems means that you are more likely to become very sick when you catch a respiratory infections. Vaccines can help prevent infections, complications, hospitalizations and worsening of your COPD.
- Although vaccines can help reduce the risk of getting sick from specific viruses, there are a lot of other viruses that do not have a specific vaccine. So, it is important to take other precautions such as hand washing, masking and avoiding friends/family when they are sick even if you are vaccinated.
- Remember, these vaccines do not cause these conditions or contain any live viruses.



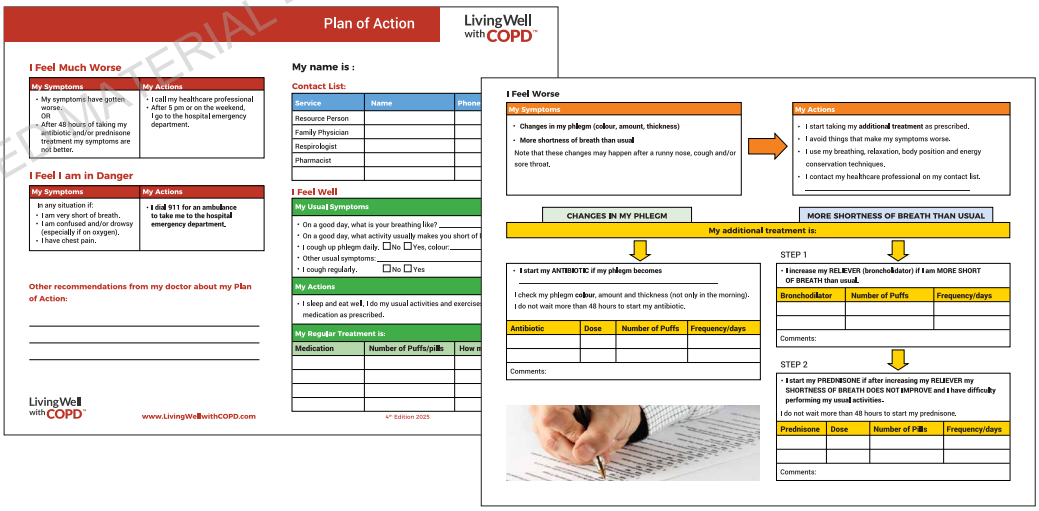
Suggestions to reduce or avoid exposure to those factors

Discuss with your healthcare practitioner or resource person about the use of an action plan to better prevent and manage your respiratory symptoms earlier.

Why people with COPD should get their recommended vaccines

- You can get these vaccines in community centres, in health centres, your local pharmacy and from your family doctor. Some vaccines are only available at certain times of the year (e.g. fall). Some vaccines are not covered by the province and you may have to pay out of pocket.
- You may have some pain and discomfort in the arm where you get the shot, a slight fever or aching muscles. These side effects are minor and do not last long.

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Your doctor has said that you have COPD

What worries you most about having COPD?

Describe the kinds of support you have to help you manage living with COPD (friends, family, other people living with COPD).

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It might also be helpful for you to meet other people with COPD You could discuss how they manage their disease. Please see the resource section on page 25.

Talk to your doctor or your resource person about wanting to meet other patients or contact some COPD patient associations in your region.



Adjusting to a COPD diagnosis

A diagnosis of COPD can change the way you see yourself. You may feel trapped, of no use to your family and friends. You may feel hopeless. These are common reactions.

We are going to look at the concerns often felt by people who are diagnosed with copd:

- You can discuss them with your doctor or resource person.
- Support groups are also a resource for gaining understanding of how to deal with the disease.
- You can also develop a plan for improving the situation such as trying to get additional information, cultivating a positive attitude or asking for help.

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Adjusting to a diagnosis of COPD

Emotional Consequences (perception of the disease progression and awareness of death, feeling of dependency, loss of self-esteem...)
My concerns:
My plan:

Family-Related and Social Consequences (loss of job, limited leisure activities and mobility, isolation...)
My concerns:
My plan:

Disease-Related Consequences (symptoms, costs, etc....)
My concerns:
My plan:

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Don't forget to be proactive!

Don't keep your concerns and fears to yourself. Discuss your feelings with your doctor, your resource person, your family and friends.



You have COPD: What happens next?

When diagnosed with COPD, what you do now matters.

Reducing your symptoms and future risk of lung attacks (exacerbations) will determine how your COPD progresses over time.

What do you need to do to better manage your COPD and live well?

1. Quit smoking if you are a current smoker.
2. Take your medications (inhalers) correctly and as prescribed by your doctor.
3. Keep up to date with your vaccine recommendations.
4. Avoid exposure to factors that can make your symptoms worse.
5. Stay active and exercise.
6. Have a written action plan and know when to use it.
7. Manage any other health problems you may have along with COPD.
8. Take part in a pulmonary rehabilitation program.

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Your doctor may refer you to other professionals (respiratory educator, pharmacist, social worker, etc.) to help you explore ways to cope with your COPD.
They can help you to:

- Voice your concerns about your COPD and your medication and ensure you can take them as prescribed.
- Develop and integrate your Action Plan.
- Check your inhaler technique so you become an expert at it.
- Give you strategies so you can better cope with your COPD on a daily basis.
- Address any other challenges: depression, stress, anxiety, social factors.





Let us hear the story of Ruth

I was diagnosed with COPD 4 years ago after seeing my GP and several specialists including a respirologist for a heart murmur. At that time, I was prescribed a puffer and rescue medication. I found the first the puffer I tried did not make much difference in treating my shortness of breath. I am on a different puffer right now that is 3 medications in one and I only have to take it once a day. I notice a difference with this puffer. I feel more stable and more in control of my symptoms now.

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My rescue medication has been my lifesaver. If I go into a crisis, where I really can't catch my breath, the rescue medication is what is going to get me through it. I have rescue medication in probably every room in my house and in my purse. So, if I go into crisis, it's usually within arm's reach. My advice to anyone who is diagnosed with COPD is to get a prescription for rescue medication and do not hesitate to take it if you need it. Another thing that helps me take my medication is a chamber. It really helps if you have trouble taking your puffer and are not sure if you are getting medication into your lungs. In the respirology clinic I was taught to use my puffer by a nurse. To be honest the nurse took 5 minutes to show me, and I do not think it was enough. You should find someone who can take the time to demonstrate the proper technique, especially if you have questions, like maybe your pharmacist. I learnt a lot about how to take my puffers properly in the pulmonary rehab program I attended.

Medications are a very important part of helping to treat and manage my symptoms of COPD. Don't think that just because you woke up feeling good today you will not need your medication. You never know what can trigger your symptoms throughout the day like humidity or cold air. I think it is important to work with your doctor and find the right combinations of medications that will work for you.



Setting Goals and Planning Ahead

You have learned new skills to better understand and manage your COPD. It is important to establish a plan by writing down your objectives (the small steps are as important as the big ones!) and the time to achieve them.

My goals to better cope with COPD for the next month:

1.
2.
3.

How confident are you that you can follow your plan to better manage your COPD for the next month?

1	2	3	4	5	6	7	8	9	10
not at all confident									very confident

My goals to better cope with COPD for the next ___ months:

1.
2.
3.

How confident are you that you can follow your plan to better manage your COPD for the next ____ months?

1	2	3	4	5	6	7	8	9	10
not at all confident									very confident

Notes:

Patient's Signature

Date: _____

Healthcare Professional's Signature

Date: _____

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The Integration and Maintenance of Your Program

Take the time to review your objectives and your plan…

Which objectives have you been able to attain?

How did you manage to attain these objectives? What strategies have worked for you?

Are there any objectives you have not yet attained? Which ones?

What could help you attain your objectives?

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Notes:



Helpful Resources

Living Well with COPD
https://www.livingwellwithcopd.com/en/home.html
Living Well with COPD is an internationally renown self-management education program developed to help you achieve better control and improve your quality of life.

https://www.chroniclungdiseases.com
A trusted source for understanding and managing your lung disease. Taking control of your disease starts with the right information.

COPD Canada
http://www.copdcanada.info
COPD Canada is a non-profit patient advocacy association dedicated to providing educational materials to individuals in Canada who are affected by COPD.

Canadian Thoracic Society (CTS)
http://cts-sct.ca/
CTS is Canada's national inter-professional specialty society for respirology bringing together over 1,000 members representing specialists, physicians, researchers and healthcare professionals from a variety of disciplines working in respiratory health.

The Global Initiative for Chronic Obstructive Lung Disease (GOLD)
http://www.goldcopd.com/
GOLD works with healthcare professionals and public health officials around the world to raise awareness of COPD and to improve prevention and treatment of this lung disease.

Canadian Lung Association (CLA)
http://www.lung.ca
The Canadian Lung Association is the leading organization in Canada working to promote lung health and prevent and manage lung disease.

Alpha-1 Canada
http://alpha1canada.ca/
Alpha-1 Canada's mission is to advocate for Canadians affected and to increase awareness and testing for this genetic disease.

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Acknowledgements

Living Well with COPD was developed in coordination with health professional educators on COPD and patients with COPD.

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Sponsors

The power to manage a chronic disease successfully is in your hands. The Living Well with COPD program has been used around the world for the past 20 years. It has been translated to 14 languages, and its effectiveness has been attested in over 40 publications in peer-reviewed medical journals. Developed in collaboration with groups of health professionals, educators in COPD and COPD patients.

"This program has demonstrated a very positive impact on patient's health, as well as an important decrease in the frequency of hospitalizations and emergency room visits."

J. Bourbeau, respirologist
McGill University Health Centre

"A trend to increase the autonomy of the patient in the management of its own medical situation… I saw an invitation to get involved… We are moving towards an extremely important shift in the relationship between the patient and the doctor."

H. Tremblay, expert patient

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