Living with COPD

Education for Patients, Families and Caregivers
The content of this booklet has been developed by Qualidigm with funding from the Centers for Medicare & Medicaid Services (CMS). More information, as well as educational videos about COPD, can be found on our website: www.LungTalk.org or by emailing: LungTalk@Qualidigm.org

Special thanks to the various volunteer partners, patients, families and other contributors for their efforts and valuable input in creating this educational booklet, especially the various staff and patients of:

- All About You! Home Care Services
- Day Kimball Hospital
- Genesis HealthCare
- Hartford Hospital
- Hospital for Special Care
- Middlesex Hospital
- New England Home Care
- UCONN Health

And to the team at Qualidigm who spent countless hours creating Lung Talk:

- Tricia DiLella
- Anne Elwell
- Nickie Fazzi Hereford
- Janine Hewitt
- Nancy Kelly
- Alberta Noonan
- Michelle M. Pandolfi
- Dan Qazi
- Anna Rubin

Also, thank you to Elena Gerard for illustrating Lung Talk.

This booklet is dedicated in memory of Robert L. Draper, who lived well with COPD. His valuable feedback contributed to the development of this educational booklet for patients and their families, so they too, could live well with COPD.
Inside this Booklet

This booklet has been written for people diagnosed with COPD and their families and caregivers. It is meant to provide you with key steps and information to keep yourself feeling well with COPD.

Some of the words in this booklet may be new to you. A glossary explaining words can be found at the end of this booklet.

Following the steps and other information in this booklet will keep you feeling well and help you avoid going to the hospital. Being informed about your COPD and planning for your care in partnership with your healthcare team is important to keep you feeling well. When you have questions, be sure to ask your healthcare team about them. Your healthcare team may include:

- Pulmonologist (Lung Doctor)
- Family Doctor
- Physician Assistant (PA)
- Advanced Practice Registered Nurse (APRN/NP)
- Nurse
- Pharmacist
- Respiratory Therapist
- Physical, Occupational or Speech Therapist
- Nurse Aide, Home Health Aide, Medical Assistant
- Social Worker
- Nutritionist
What is COPD?

COPD refers to a group of diseases that affects the lungs, the most common being chronic bronchitis and emphysema.

COPD stands for:
- **Chronic** means *long term*
- **Obstructive** means *blocked*
- **Pulmonary** means *in the lungs*
- **Disease** means *sickness*

COPD is a lung disease that:
- Can be prevented
- Makes it hard to breathe
- You will always have
- Can get worse over time
- Is treatable!
What Happens with COPD?

Your lungs take oxygen from the air you breathe in and send it through your bloodstream to the rest of your body. When you have COPD:

- Air is harder to get in and especially out of your lungs
- Your breathing tubes (airways) are smaller and may be blocked with mucus
- Air can get trapped in the air sacs of your lungs
- Air sacs become damaged and no longer work well
- It’s harder for your air sacs to release oxygen into your bloodstream
- People with COPD often feel like they can’t catch their breath

Here are some of the everyday symptoms you might have with COPD:

- Feel like it’s hard to breathe
- Feel tightness in your chest
- Feel tired
- Hear wheezing or a whistling noise when breathing
- Cough with or without mucus or phlegm (pronounced “flem”)
Can COPD be treated?

YES!

Although COPD is a chronic disease - you will always have it no matter how good you feel – it can be treated so that you can continue to live life.

COPD can be treated by:

- Stopping smoking (smoking cessation)
- Taking medicines, including oxygen
- Going to pulmonary rehabilitation (rehab)

Talk to your healthcare team about the best options for you.

“You know there are other people out there that have the same condition, and you know you’re not going to die.”

- Kim, Living with COPD
What YOU can do!

People with COPD have an important role in keeping themselves feeling good and out of the hospital. You can live well for many years by following these 6 Steps:

1. Stop Smoking
2. Know your Symptoms and Have an Action Plan
3. Take your Medicines
4. Go to all of your Medical Appointments
5. Stay Active and Exercise
6. Follow Tips for Healthy Living

Each of these steps is further explained in this booklet. Keep reading...
Step 1: Stop Smoking

The best thing you can do to keep your COPD from getting worse is to stop smoking (smoking cessation). Remember, it is never too late to stop smoking. If you stop smoking it will improve your quality of life and help you live longer.

- Smoking is the number one cause of COPD
- Smoking harms the body, especially your lungs
- Smoking will make your COPD worse

It may be hard to stop smoking and it may take many tries. That’s okay – just keep trying to stop! Talk to your healthcare team about stopping and how they can help. Help to stop smoking may include:

- Talking to your healthcare team
- Counseling
- Medicines

“For me, who truly felt that I must be so addicted to cigarettes that I could not quit... I did!”

- Carolyn, Living with COPD

Remember, if you stop smoking today you can improve your breathing, be more active and live longer.
Step 2: Know Your Symptoms and Have an Action Plan

Knowing your body and how you feel (symptoms) can keep you in control of your own health. If you know what to do when you notice changes in your everyday COPD symptoms, you can stay out of the hospital. It is very important to have a plan for what to do when changes happen, such as when your breathing gets worse.

Check off the symptoms you feel every day and share with your healthcare team:

- Have a hard time breathing and/or feel like you can’t catch your breath
- Feel tightness in your chest
- Feel tired
- Hear wheezing or a whistling noise when you breathe
- Cough with or without mucus or phlegm
When your COPD symptoms get really bad, it is called a **flare-up** or **exacerbation**. A flare-up can happen quickly and get worse fast! Flare-ups are usually caused by **triggers**.

**TRIGGERS** can include:

- Respiratory infections (getting sick)
- Not taking medicines as prescribed
- Not using your inhaler correctly
- Wind, cold, dry or humid air
- Burning fireplace/pit
- Exhaust/gas fumes
- Cleaning products
- Strong perfumes/odors/air fresheners
- Animal dander or fur
- Pollen and cut grass
- Worry or anxiety
- Smoke
- Second-hand smoke
- Air pollution
- Dust

Check the triggers above that make it hard for you to breathe. Once you are aware of your own personal triggers, you can do your best to stay away from them.
The most common reason, or trigger, for a flare-up is a respiratory infection. Do your best to stay away from others who are sick and follow these tips to avoid infections and prevent flare-ups:

- Wash your hands often
- Keep your hands away from your face
- Get a flu shot every year
- Get a pneumonia vaccine

**FLARE-UPs**

Flare-ups will feel different for everyone. Below are common flare-up symptoms you might have.

- Harder to breathe than usual
- Breathing fast
- Wheezing or whistling noise when you breathe becomes worse
- Harder to complete normal daily activities
- More coughing than usual
- Feeling more anxious because you can’t breathe

(continued on the next page)
FLARE- UPS (continued)

- Unable to eat because you can’t breathe
- Feeling like you have no energy, more tired than usual
- Needing to use more pillows to sleep sitting up
- More mucus than usual
- Change in the odor of your mucus
- Change in the color of your mucus to yellow, green, or brown
- New or worsening chest tightness
- Fever
- Confusion or not thinking clearly

Tell your healthcare team right away if you notice any changes in your everyday symptoms (how you feel), or your flare-up symptoms (you have gotten worse). Don’t wait or try to “beat it.” Have a plan to stay well.
HAVE A PLAN

A good way to monitor (watch or observe) how you are feeling is to use the COPD Zones. Green, Yellow and Red “zones” label your symptoms and list a plan for you. It is very important to have a plan in each zone. Having a plan will keep you out of the hospital. Follow the advice from these zones. Don’t wait or try to “beat it” if your symptoms get worse. Ask yourself...

Am I having a:

- **Good Breathing Day**
- **Bad Breathing Day**
- **Emergency Breathing Day**

Tell your healthcare team which “zone” you are in when you call them or see them at an appointment.

Follow the advice from the Zones to Manage COPD on the next page to help you feel better and stay out of the hospital.
# ZONES TO MANAGE COPD

<table>
<thead>
<tr>
<th>Medications</th>
<th>Name of Medication</th>
<th>How much to take</th>
<th>When to take it</th>
</tr>
</thead>
<tbody>
<tr>
<td>Everyday Inhaler</td>
<td></td>
<td></td>
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<tr>
<td>Rescue Inhaler</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Nebulizer</td>
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</table>

<table>
<thead>
<tr>
<th>Green Zone</th>
<th>I am doing well today:</th>
<th>Mucus is clear/white</th>
<th>What to do:</th>
</tr>
</thead>
<tbody>
<tr>
<td>GOOD BREATHING DAY</td>
<td>- Breathing easily – able to do usual activities and exercise</td>
<td>- Mucus is clear/white</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Sleeping well at night</td>
<td>- Mucus is easy to cough up</td>
<td>- Take everyday medicines as ordered</td>
</tr>
<tr>
<td></td>
<td>- Appetite is good</td>
<td>- Able to think clearly</td>
<td>- Continue regular exercise and healthy eating</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Yellow Zone</th>
<th>I feel worse today:</th>
<th>Appetite is not good</th>
<th>What to do:</th>
</tr>
</thead>
<tbody>
<tr>
<td>BAD BREATHING DAY</td>
<td>- Hard to breathe – have less energy</td>
<td>- Appetite is not good</td>
<td></td>
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<td></td>
<td>- Coughing more than usual</td>
<td>- Fever/cold symptoms</td>
<td>- Call doctor or nurse</td>
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<td></td>
<td>- New or more wheezing</td>
<td>- Everyday medicine is not working-using rescue medicines more</td>
<td>- Continue everyday medicines</td>
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<td>- Thicker mucus</td>
<td>- Trouble sleeping-sleeping sitting up or using extra pillows</td>
<td>- Use rescue medicines</td>
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<td></td>
<td>- More mucus than usual</td>
<td></td>
<td>- Start steroids and/or antibiotics if ordered</td>
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<td></td>
<td>- Change in color of mucus</td>
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<thead>
<tr>
<th>Red Zone</th>
<th>I am having a very bad day:</th>
<th>Coughing up blood</th>
<th>What to do:</th>
</tr>
</thead>
<tbody>
<tr>
<td>EMERGENCY BREATHING DAY</td>
<td>- Very hard to breathe even at rest</td>
<td>- Coughing up blood</td>
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<td></td>
<td>- Feel scared because can’t breathe</td>
<td>- Confused, not thinking clearly</td>
<td>- Call 911</td>
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<td></td>
<td>- Fever, shaking, chills</td>
<td>- Not able to sleep because can’t breathe</td>
<td>- Get help – go to emergency department</td>
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<td></td>
<td>- Coughing up a lot of mucus</td>
<td>- Rescue medicines are not working</td>
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<td></td>
<td>- Chest pain or tightness</td>
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**Emergency Contact Name:** ____________________________  **Phone #:** ____________________________
Step 3: Take Your Medicines

It is important to take your medicines as your doctor or healthcare team has explained. Taking your medicines as explained will help you stay well and out of the hospital. COPD medicines may be:

- Inhalers
- Nebulizer
- Pills
- Oxygen

INHALERS

People with COPD take “inhaled medicines” (medicines that you breathe in) by using inhalers or nebulizers. There are many kinds of inhalers with different directions, but there are two main types of inhalers:

1. **Everyday Inhalers** that you use every day to keep you breathing better.

2. **Rescue Inhalers** also called quick relief inhalers that you use when you have a flare-up (when you have hard time breathing). You may use these inhalers when you are in the Yellow and Red Zones.
USING YOUR INHALER

It’s very important to use your inhaler the right way, so ask your healthcare team how to use the inhaler ordered for you. Not using inhalers correctly is a leading cause of triggers and hospitalizations.

After you use in your inhaler, every time:
- Rinse your mouth with water
- Spit the water out, do not swallow the water
- Wash your hands

NEBULIZERS

Sometimes you may use an inhaled medicine that is breathed in by using a nebulizer machine. A nebulizer is just another way to get the inhaled medicine into your lungs. Be sure to:
- Clean your nebulizer after using it, every time
- Follow the other care instructions that come with the nebulizer machine

“Inhalers...they can be mysterious. I think sometimes you need to be shown [how to use inhalers] more than once or twice.”
- Elene, Living with COPD
**PILLS**

Sometimes your COPD symptoms may be worse and your doctor will tell you to take pills.

These pills can be:

- Antibiotics that help fight infections
- Steroids like prednisone, to reduce swelling and inflammation to help you breathe better
- Medicines for anxiety or depression

**OXYGEN**

Sometimes people with COPD will need oxygen to breathe better and to feel better. Oxygen is a medicine that requires a prescription, so be sure to use it as your doctor explained.

Using oxygen can make activities easier.

Oxygen goes where you go! Oxygen companies have lightweight tanks that you can carry when you leave home.

“I don’t let using oxygen keep me at home. I always say ‘have oxygen, will travel.’”

- Anne F, Living well with COPD
Follow all safety directions that come with oxygen tanks and machines.

**Oxygen Dos**
- Do know how to use your oxygen machine
- Do keep oxygen tank/machine away from heat and direct sunlight
- Do turn oxygen tank/machine off when not in use
- Do wear your oxygen tubing correctly

**Oxygen Don’ts**
- Don’t smoke near your oxygen machine
- Don’t use oil-based products like petroleum jelly in your nose with your oxygen tubing
- Don’t use oxygen near open flames like a gas stove, fireplace, candles or cigarettes/cigars

It is important to keep a list of all your medicines, including oxygen. Use the forms on the next pages to write down your medicines. Your medicines may change after each medical appointment or when you are in the hospital. It can be confusing, so...

- Keep an up-to-date list of your medicines
- Bring the list to all of your appointments and Emergency Room visits

**People who take their medicines as explained by their healthcare team, live longer, stay well and spend less time in the hospital!**
### My Medicine Chart for Everyday Medicines

<table>
<thead>
<tr>
<th>When do I take this medication? (time of day)</th>
<th>Medicine name (generic and brand names)</th>
<th>How much do I take of this medicine?</th>
<th>How do I take this medicine?</th>
<th>Why am I taking this medicine?</th>
<th>Who is the doctor who gave it to me?</th>
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**Remember your refills!** Always have a week’s worth of medicine available. Please share this list with your healthcare team. Be sure to bring this list to each of your medical appointments.
### My Medicine Chart for my Rescue (Quick Relief) Medicines

<table>
<thead>
<tr>
<th>I take this medicine when I am feeling: (symptoms)</th>
<th>Medicine name (generic and brand names)</th>
<th>How much do I take of this medicine?</th>
<th>How do I take this medicine and how often?</th>
<th>Who is the doctor who gave it to me?</th>
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**Remember your refills!** Always have a week’s worth of medicine available. Please share this list with your healthcare team. Be sure to bring this list to each of your medical appointments.
Step 4: Go to All of Your Medical Appointments

It is important to go to your medical and doctor appointments, even if you are feeling good and especially if you don’t feel good. Your healthcare team is there to keep you feeling good and out of the hospital.

- Be sure to tell your healthcare team which “zone” you are in at each appointment
- Use the zone chart on page 15. You can download a free chart on www.LungTalk.org too

“I never miss my appointments, especially not my pulmonary appointment because that’s the one that keeps me breathing.”

- Eloise, Living with COPD
Step 4: Go to All of Your Medical Appointments (continued)

Ask your healthcare team questions. Do not be afraid to talk to your doctor, nurse or other members of your healthcare team about any concerns you may have.

Always ask someone if you don’t understand something, or if you feel something is “just not right.”

Appointment tips to follow:

- Set up your next appointment before you leave the hospital or other care facility
- Keep all of your scheduled appointments
- Make sure you have a ride to your appointment
- Bring a family member or friend into the appointment with you
- Bring all medicines or an up-to-date medicine list with you
- Bring a list of your most important questions
- Have your family member or friend write down the answers to your questions

COPD is not simple. Your healthcare team needs to see you often to keep you well.
Step 5: Stay Active and Exercise

It may seem silly to think about staying active when you have a hard time breathing. However, staying active helps your lungs work better. Exercising and staying active will keep you feeling well and out of the hospital. Exercise can help you get in (and stay in) shape, which may also help you breathe easier.

**EXERCISE** can include:

- Walking
- Dancing
- Swimming
- Sex
- Bathing and dressing
- Lifting light weights
- Daily activities like cleaning, cooking, and yard work

“Sometimes the weather doesn’t permit me to go outside but I’ll walk in place for 20-30 minutes.”

- Eloise, Living well with COPD

Talk to your healthcare team about what kind of exercise is safe for you. Your doctor might suggest that you attend pulmonary rehab, a specialized program, to learn safe ways of exercising and how to better manage your COPD.
PULMONARY REHAB

Pulmonary rehabilitation, or pulmonary rehab as it is often called, is a program that helps people be active and improve their quality of life. It can include supervised exercise and education about:

- Your lung disease and how to manage it
- Ways to save your energy
- Ways to make breathing easier
- Your medicines
- Oxygen use and safety
- Healthy eating tips
- Emotional support and self-help (could include counseling)

Your doctor can refer you to a comprehensive pulmonary rehab program nearest to you.

“When the doctor recommends pulmonary rehab go right away! Don’t wait like I did.”

- Linda, Living with COPD
PACE YOURSELF TO SAVE ENERGY

Because COPD makes breathing harder, people with COPD use more energy breathing than people without COPD. To help save your energy throughout the day, make work simple. Save your energy so you can continue to enjoy what is important to you.

For example:

- Sit down when brushing your teeth
- Sit down using a shower chair while showering
- Keep everyday items you use at waist level to avoid reaching above your head

“I love to work in the yard and didn’t want to stop because of my COPD. Now, I have four chairs around my yard. I sit down and rest in-between my weeding and flower planting.”

- Bob, Living with COPD
BREATHING TECHNIQUES

There are certain breathing techniques that can help you breathe easier when you have COPD – pursed lip breathing and diaphragmatic breathing. These two breathing techniques (ways of breathing) can be used every day and especially to help you breathe better when you are short of breath (can’t catch your breath), during anxious times or during activities.

Pursed Lip Breathing

To breathe through pursed lips, follow these steps:

1. Relax your neck and shoulder muscles.
2. Breathe in slowly through your nose like you are going to, “smell the roses.”
3. “Purse” your lips like you are going to whistle.
4. Breathe out slowly through your pursed lips like you are gently, “blowing out a candle.” Try to blow out twice as long as it took you to inhale.

With regular practice, this technique will get easier and become part of your everyday breathing. Pursed lip breathing and pacing yourself will help when you exercise and climb stairs. It may also help calm you when you feel anxious.
Diaphragmatic (Belly) Breathing

Breathing with your diaphragm (the dome shaped muscle under your lungs) allows you to use only one muscle instead of many, which means you will use less energy to breathe.

Follow these steps for diaphragmatic breathing:

1. Sit down in a chair or lie down on your back.
2. Breathe in slowly through your nose.
3. As you breathe in, your belly should move out so your chest can fill with air.
4. Breathe out slowly through pursed lips.
5. As you breathe out, you should feel your belly move in.

Your diaphragm moves up and down during this technique - it moves up in step 3 and down in step 5. With regular practice, this technique will get easier and become part of your everyday breathing.
Rescue Positions to Make Breathing Easier

There are sitting and standing positions that may make it easier to breathe when you have COPD. These two “rescue” positions allow your belly to drop making more room for your lungs to expand. Rescue positions can help when you are having a hard time breathing.

**Sitting Position**
Follow these steps when sitting down:

1. Place both feet on the ground
2. Lean your chest forward a bit
3. Rest your arms on a table
4. Open your legs and let your belly fall forward
5. Rest your head on your arms
6. Breathe through your nose and out through pursed lips to slow down your breathing

**Standing Position**
Follow these steps when standing:

1. Rest your elbows on a wall, a piece of furniture or on the kitchen sink
2. Lean forward and put your weight on your arms
3. Let your belly fall forward
4. Breathe through your nose and out through pursed lips to slow down your breathing
Step 6: Follow Tips for Healthy Living

Healthy living is about doing the things that will keep you feeling good. The following are tips to help you protect yourself, feel good and stay out of the hospital.

STOP SMOKING

The best thing you can do for your COPD symptoms is to stop smoking which includes:

- Cigarettes (tobacco and marijuana)
- Cigars
- E-cigarettes
- Other inhaled toxins

Talk to your healthcare team about quitting and ways they can help. Smoking is the number one cause of COPD. See Step 1 for more information and watch the video “Talking about Your Smoking and COPD.”

EAT RIGHT

Eating right is especially important for people with COPD. Eating healthy foods gives your body the right type of energy. The right foods will make your stomach less full and give your lungs more room to move when you breathe.

- Eat smaller meals more often throughout the day
- Avoid dairy products that can increase mucus or phlegm
- Avoid foods that produce gas
- Stay at a healthy weight to give your lungs room to move
TALK ABOUT YOUR FEELINGS

COPD can cause anxiety in some people. Anxiety is a feeling of worry or nervousness. When you start feeling this way – breathing can be more difficult. Breathing techniques can help lessen the feelings of anxiety.

- See Step 5 for more information about breathing techniques

COPD symptoms can make some people sad or depressed. Don’t let COPD stop you from doing the things that make you happy. Many people with COPD are able to continue with activities and hobbies that they enjoyed before having COPD.

Talk to your healthcare team if you have been feeling sad, depressed or anxious. It is common to feel this way, and they can help!
TRY YOUR BEST NOT TO GET SICK

Remember, infections are the main cause for COPD flare-ups, so stay away from adults and children who are sick (they can get you sick).

- Wash your hands often. It’s the best way to avoid getting sick.
- Keep your hands away from your face.
- Sneeze and cough into your elbow.
- Get the flu shot every year. This helps to prevent the flu.
- Get the pneumonia shot (vaccine). This helps to prevent pneumonia.

Following these health living tips, will help you stay well and out of the hospital.
Make These 6 Steps A Permanent Part of Your Life!

1. Stop Smoking
2. Know your Symptoms and Have an Action Plan
3. Take your Medicines
4. Go to all of your Medical Appointments
5. Stay Active and Exercise
6. Follow Tips for Healthy Living

“My job is to keep myself healthy and out of the hospital.”
- Robert, Living with COPD

You and your healthcare team are partners! Be sure to talk to them about how you are feeling, any changes in your health and about any questions you might have. Following these 6 Steps and anything else you and your healthcare team decide, will help you stay well and out of the hospital.
Healthcare Planning for Your Future

Who will speak for you, if you can’t speak for yourself?

- 90% of Americans have heard of a living will\(^1\)
- 71% of Americans have thought about their end-of-life preferences\(^1\)
- Only 29% of Americans have a living will\(^1\)

Without a plan, your healthcare team won’t know your wishes, and your family may not know what to do.

Healthcare planning for your future, also known as “Advance Care Planning,” is about conversations and decisions. It is for people of all ages. Advance care planning lets your family and healthcare team know what your choices and wishes are. It allows you to remain in control of your care should you become very sick. Plans for your future healthcare are documented on papers called Advance Directives.

\(^1\) [www.nhdd.org](http://www.nhdd.org)
ADVANCE DIRECTIVES

Advance directives are legal papers that tell others what you want for your medical care when you can’t speak for yourself. Advance directives are used **only** if you can’t speak for yourself.

An advance directive has two parts:

1. a living will
2. a durable power of attorney for health care

<table>
<thead>
<tr>
<th>Living Will</th>
<th>Durable Power of Attorney for Health Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is a legal paper(s)/document</td>
<td>Is a legal paper(s)/document</td>
</tr>
<tr>
<td>Is used when you can’t speak for yourself</td>
<td>Is used when you can’t speak for yourself</td>
</tr>
<tr>
<td>Tells your doctors what care you want if you are dying or permanently unconscious and cannot make decisions about emergency treatment</td>
<td>Names someone to make medical decisions for you only when you cannot speak for yourself. The person you name is called a healthcare proxy</td>
</tr>
<tr>
<td>Is for health care choices only</td>
<td>A proxy can be chosen in addition to or instead of a living will</td>
</tr>
<tr>
<td>Is created while you are alive and able to speak for yourself</td>
<td>Is created while you are alive and able to speak for yourself</td>
</tr>
</tbody>
</table>
When choosing a **DURABLE POWER OF ATTORNEY FOR HEALTHCARE**, choose someone you trust to follow your wishes. This person might be a:

- Family Member
- Close friend
- Priest
- Minister
- Rabbi
- Lawyer

**DOCUMENTING EMERGENCY CARE CHOICES**

You have choices about how you want to be treated when there is no longer a cure for your condition or when you are dying. You can make those decisions now while you are alive and well. You can document these decisions in your living will. These decisions are about doctors using emergency treatments to keep you breathing and your heart beating:

- cardiopulmonary resuscitation (CPR)
- ventilator use (breathing through a tube)
- artificial nutrition (tube feeding) or artificial hydration (intravenous fluids)

The following table helps explain each of the above - what it is, when it is used and why it is used.
## EMERGENCY TREATMENTS

<table>
<thead>
<tr>
<th>CPR (cardiopulmonary resuscitation)</th>
<th>Ventilator Use</th>
<th>Artificial Nutrition (tube feeding) or Artificial Hydration (intravenous fluids)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Used after your heart stops.</td>
<td>Used when you can’t breathe on your own. Machines do the breathing for you.</td>
<td>Used if you can’t eat or drink.</td>
</tr>
<tr>
<td>Doctors/nurses push hard on your chest again and again.</td>
<td>A tube connected to a ventilator machine, is put down your throat and pushes air into your lungs. Medicines keep you sleeping, while the tube is in your throat.</td>
<td>Tube feeding: A tube placed up your nose and down your throat, is used to feed you. If using for a long time, surgery is needed to put the tube into your stomach, instead. Intravenous fluids: A tube is placed in your vein to give you fluids.</td>
</tr>
<tr>
<td>Doctors/nurses blow air through your mouth into your lungs.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CPR may re-start your heart, and these actions may also break your ribs or collapse a lung. Doctors/nurses may also use medicines or electric shocks to help re-start your heart.</td>
<td>After a few days, if you can’t breathe without the ventilator machine, doctors may put a tube into your throat through a hole in your neck instead. You can stay awake then, but can’t talk without special help.</td>
<td>The use of tubes for feeding or fluids can be uncomfortable if near death.</td>
</tr>
</tbody>
</table>
DO NOT RESUSCITATE
ALLOW NATURAL DEATH

Do Not Resuscitate (DNR), also referred to as Allow Natural Death (AND), is another way to tell your doctors and healthcare team what your wishes and choices are for treatment when there is no longer a cure for your condition or when you are dying.

DNR and AND promotes comfort and dignity. It means supporting you in your choice to die when nature determines it is your time.

It means that no emergency treatments will be used if your heart stops or you stop breathing.

Other choices you may have to make are included on the next page:

“Just like taxes, we know what’s going to come. Planning takes a lot of stress away. I [also] think it’s very important to relieve your family of that burden. These are decisions that you should make. Just because you have a living will or you make these directives, doesn’t mean that you are going to die tomorrow.”

- Carolyn, Living with COPD
**Hospitalization**

Your time in the hospital may increase and occur often during the last months of life.

**Comfort Care**

Comfort care includes treating symptoms that make you uncomfortable and providing support— for example: managing shortness of breath, limiting medical testing, providing spiritual and emotional counseling, and giving medication for pain, anxiety, nausea, or constipation.

**Comfort care includes...**

<table>
<thead>
<tr>
<th><strong>Palliative Care</strong></th>
<th><strong>Hospice Care</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Focuses on improving quality of life for both the patient and the family</td>
<td>Relieves suffering and also focuses on improving quality of life for both the patient and the family</td>
</tr>
<tr>
<td>It is appropriate at any age and at any stage in a serious illness</td>
<td>It is appropriate at any age and is provided during the patient’s final days, weeks or months</td>
</tr>
<tr>
<td>Care is provided by the entire healthcare team</td>
<td>Care is provided by the entire healthcare team</td>
</tr>
<tr>
<td>Can be received in many care settings; including your own home</td>
<td>Can be received in many care settings; including your own home</td>
</tr>
<tr>
<td>Can be provided along with curative treatment</td>
<td>After death, the hospice team continues to offer support to your family</td>
</tr>
</tbody>
</table>
Making decisions, having the conversations and planning for your future (advance care planning) is an important step in letting your healthcare team and family know your wishes. Many choices are available to you and your family. These choices will keep you in control of your life. Planning now rather than later will make difficult decisions easier for you and your family.

The above information has been adapted from the National Institute on Aging website http://www.nia.nih.gov/health/publication/advance-care-planning

**ADVANCE CARE PLANNING RESOURCES**

The following websites have further information and resources for you and your family when discussing your advance care plans:

**National Health Care Decisions Day:** A website about the importance of advance care planning

- [www.nhdd.org](http://www.nhdd.org) (USA)
- [www.AdvanceCarePlanning.ca](http://www.AdvanceCarePlanning.ca) (CANADA)

**Medical/Physician Orders for Life Sustaining Treatment:** Approaches to end-of-life planning that focus on patients’ wishes for care they receive

- [https://www.compassionandsupport.org/index.php/for_patients_families/molst](https://www.compassionandsupport.org/index.php/for_patients_families/molst) (MOLST)

**Five Wishes Document:** A legal living will form in 42 states and available in 26 languages

- [www.agingwithdignity.org/5wishes](http://www.agingwithdignity.org/5wishes)

**National Institute on Aging:** Federal website dedicated to aging research and resources


**Listing of Various Advance Care Planning Websites:**

- [www.LungTalk.org](http://www.LungTalk.org)
HELP Lines

Questions about Lung Health?
Get FREE information from Registered Nurses and Respiratory Therapists on the American Lung Association's HelpLine and Tobacco QuitLine.
Call 1-800-LUNGUSA (1-800-586-4872)

COPD Information Line
Call the COPD Foundation to speak to a specially trained COPD patient or caregiver and ask your questions about coping with your disease.
Call 1-866-316-COPD (1-866-316-2673)

COPD Resources
Visit www.lungtalk.org for a variety of resources about COPD.
Free videos and information on how to stay well with COPD are available at www.LungTalk.org

**Lung Talk: Living with COPD** are videos created for people living with COPD, their families and caregivers. A lung doctor and other members of the healthcare team explain how you can feel and live well with COPD, including tips on how to stay out of the hospital.

To watch the free videos, go to our website: www.LungTalk.org The videos will play like a movie on your computer.

A video on how to stay well with heart failure is available at www.HeartTalk.org

**Heart Talk: How to Live with Heart Failure** is a video created for patients living with heart failure, their families and caregivers. A heart doctor explains how you can feel and live well with heart failure, including tips on how to stay healthy and how to stay out of the hospital.

An educational booklet is also available for free on the website. Use it to follow along and take notes, as you watch the video. To watch the video, go to the website: www.HeartTalk.org and scroll down to Series 3. The video will play like a movie on your computer.
Glossary

A

Air sacs: Small sacks located at the end of your airway branches. They fill with air and look like bunches of grapes. There are 600 million air sacs in your lungs.

Advance Care Planning: Having discussions and making decisions about the care you would want to receive if you were unable to speak for yourself.

Advance Directives: Legal papers that tell others what you want for your medical care when you can’t speak for yourself.

Antibiotic: A medicine used to treat or prevent bacterial infections. Antibiotics do not work on viral infections.

Anxiety or Anxious: A feeling of worry or nervousness.

Artificial Hydration: Fluids given through a tube in your vein, when you cannot drink enough on your own to survive.

Artificial Nutrition: Nutrients (special liquid food) given through a tube placed directly in the stomach (sometimes through your nose) or intestine, when you cannot eat enough on your own to survive. Also called tube feeding.

B

Bloodstream: The flow of blood through the heart and body.

Bronchitis: A type of lung infection.

C

Cardiopulmonary Resuscitation (CPR): An emergency lifesaving procedure that is used after your heart stops. Doctors or nurses push hard on your chest again and again and blow into your mouth to force air into your lungs.

Caregiver: Someone who helps take care of you when you can’t do everything for yourself. A caregiver could physically take care of you and/or help you by organizing your medical appointments, medicines, treatments, etc. A caregiver might be a family member, a significant other, a friend, or a hired aide.
**Chronic:** “Long term.” If you have a chronic condition, it means you will always have it. It won’t go away even if you feel good.

**Constipation:** When you generally have three or fewer bowel movements a week. Bowel movements may be hard and dry, and may be painful with excessive straining.

**Counseling:** Offering or giving support and advice.

**Curative treatment:** Medicine or other types of care that is meant to heal a disease.

**D**

**Depression:** Feeling sad or hopeless for more than a couple weeks.

**Diaphragm:** The dome shaped muscle under the lungs. The most important muscle for breathing

**Disease:** When a part or parts of your body don’t work right. Disease can be caused by bacteria, viruses, chemicals, genetics, etc.

**Durable Power of Attorney for Health Care:** Legal paper that tells others who you want to speak or act on your behalf and has the right to make medical decisions for you if you can’t speak for yourself.

**E**

**Emphysema:** A disease that makes breathing harder because there is damage to the small airways and/or the air sacs in the lungs.

**End-of-Life:** The final stage of life’s journey.

**Exacerbation:** A sudden worsening of your COPD symptoms. Also called a flare-up.

**Exhale:** To breathe out.

**F**

**Flare-up:** A sudden worsening of your COPD symptoms. Also called an exacerbation.

**H**

**Healthcare Proxy:** A person named in your Advance Directives, who you have choosen, to make medical decisions for you only when you cannot speak for yourself.
**Hospice Care:** Care that is provided by a team and is generally given during the last six months of life and during the end stages of an illness or disease. The goal of care is to help people who are dying have peace, comfort and dignity.

**Infection:** Your body’s reaction to harmful bacteria or viruses. Infections may cause **inflammation**, fever or sickness.

**Inflammation:** Swelling, redness, tenderness, and/or high temperatures in a part of the body that is trying to fight bacteria, viruses, or other things that don’t belong in your body, like smoke.

**Inhale:** To breathe in.

**Inhaler:** A handheld device used to bring medicine into your lungs when you breathe in.

**Inhaled medicines:** Medicines in the form of a powder or mist that you breathe into your lungs.

**Intravenous fluids:** A tube is placed in your vein to give you fluids. It is the fastest way to get liquids throughout the body.

**Living Will:** A legal paper you make when you are alive, that tells others what you want for medical care when you can no longer speak for yourself.

**Manage:** To be in charge. To take care of and make decisions about.

**Medical Appointment:** A time to meet with your doctor or another member of your healthcare team.

**Mucus:** May also be called **phlegm (flem);** A slimy material that can be coughed or sneezed up; the color can range from clear to yellow, green, and even brownish-red.

**Nausea:** Feeling of sickness; feeling like you want to vomit or “throw-up.”
Nebulizer: A machine that makes medicine into the form of a mist, so you can breathe it into your lungs.

O

Obstructive: Means blocked. With COPD, your airways are blocked making it hard to breathe “out” easily.

Occupational Therapist: A person whose job is to help you relearn or how to do everyday tasks better. Daily tasks include cooking, cleaning and bathing.

Oxygen: A gas that you can’t see or smell, but is necessary to live. It is a medicine that you inhale through nasal tubes or a mask.

P

Palliative Care: Care that is provided for comfort and can be provided for many years. It can be provided along with curative treatment.

Partnership: Working together.

Permanent or Permanently: Forever.

Phlegm (flem): May also be called mucus. A slimy material that can be coughed or sneezed up; the color can range from clear to yellow, green, and even brownish-red.

Physical therapist: A person whose job is to help you improve your body movements and prevent or manage disability.

Physician: A doctor.

Pneumonia (noo-mohn-yuh): A type of lung infection.

Pollution: A harmful or poisonous substance found in the environment.

Progressive: A disease that develops gradually, over time.

Provider: A person who gives you medical or health services. A provider can be any member of your healthcare team.

Pulmonary (PULL-mun-ary): Having to do with the lungs.

Pulmonologist: A doctor with special training in treating and caring for lung conditions and diseases.
Pulmonary Rehabilitation or Pulmonary Rehab: A program that helps improve the well-being of people with lung damage or lung disease.

Pursed lips: When your lips are “puckered” like you are going to blow out a candle or give a kiss.

R

Rescue breathing: A type of breathing involving special body positions to make it easier for you to breathe.

Respiratory: The act of breathing in and breathing out.

Respiratory Therapist: A person whose job is to care for people who have trouble breathing; specialized in both cardiac (heart) and pulmonary (lung) care.

S

Shortness of breath: Difficulty breathing; a feeling like you can’t catch your breath; can be described as “hard to breathe”; your medical team may call it dyspnea.

Smoking Cessation: To stop smoking. Cessation means “to stop.”

Speech Therapist: A person whose job is to help people who can’t make speech sounds or can’t make them clearly; treat a variety of speech, voice and language problems.

Steroid: Medicine that can be in pill or inhaled form to help bring down inflammation.

Symptoms: Signs your body shows when something may be wrong or things aren’t normal for example, a fever.

T

Terminal: Having an illness that cannot be cured and that will soon lead to death.

Trigger: Cause an event or situation to happen. For example, an infection can be “triggered” by a virus.

Tube Feeding: A method to give nutrients (special liquid food) through a tube placed directly in your stomach (sometimes through your nose) or intestine, when you cannot eat enough to survive. Also called artificial nutrition.
U

**Unconscious:** You can’t respond to your surroundings; not aware of what’s going on (can’t talk, walk or do anything).

V

**Vaccine:** An injection given to protect you against a disease or infection.

**Ventilator:** A machine used to do your breathing for you, when you can’t do it on your own.

W

**Wheezing:** A noise that might be heard when you breathe. It can sound squeaky or like a whistling noise.

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This material was prepared in collaboration with Qualidigm, the Medicare Quality Improvement Organization for Connecticut, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy. Pub #CT-508100-201417.

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