



PATIENT AND
CAREGIVER
RESOURCE GUIDE



Advanced Lung Care Program™

*A guide for people living with
advanced lung disease*



NPHI National Partnership
for Healthcare and
Hospice Innovation



Table of Contents

Welcome	3
Understanding Your Lungs & Advanced Lung Disease	8
Symptom Management & Self-Care Tips	10
Medications	17
Diet	24
Advance Care Planning	26





Appendix A: Monitoring Symptoms Chart	27
Appendix B: My Action Plan— What to Do When I Feel	28
Appendix C: Journaling Tool— How I Feel Every Day	29
Appendix D: Tripod Positioning	30
Appendix E: How to Use Your Devices	31
Appendix F: When to Replace Your Inhaler	36
Appendix G: Medications	37
Appendix H: Understanding a Good Diet	38
Acknowledgements	41
Important Notes	42

Dear Patients living with Advanced Lung Disease and their Caregivers,

The National Partnership for Healthcare and Hospice Innovation (NPHI) has developed a special Advanced Lung Care Program to support the home care of patients with advanced lung disease. Our mission is to ensure you and your family are well supported and informed so symptoms can be managed under our care, with you safely at home.

This guide represents the best standards of care for advanced and end-stage lung disease, as defined by the American Lung Association with the collective input of over 90 hospice, palliative, and advanced illness care organizations.

Many patients living with end-stage lung disease frequently visit the doctor's office, emergency room and hospital due to breathing difficulties, fatigue, and other worsening symptoms. These exacerbations could be prevented or managed with hospice and palliative care. With our program, you can expect:

- To receive regular visits by a nurse with specialized training in the evaluation of lung disease, to evaluate and manage your lung disease, and to control the symptoms at home. The nurse will follow the direct orders of your physician or care team.
- To receive patient education specifically designed for you and your family. If you have any questions about the contents of this booklet, please ask your care team.
- To be part of a team overseen by our physician who is board certified in Hospice and Palliative Medicine and who works directly with your primary care physician or care team.
- To have medications ordered by your physician or care team to help control symptoms. Your nurse will review your medications with you and order those medications that are essential for your symptom management.
- To receive additional supportive care in the form of visits provided by a social worker, a nurse assistant, a chaplain, a counselor, and/or another member of your care team, as might be helpful to you.
- The management of your lung disease takes a team effort, and YOU are the KEY member of the team. The rest of your team members depend on you to call your care team if you have any concerns.





We are pleased to share this Advanced Lung Care Guide, which includes valuable information to address your questions and concerns and ensure high-quality advanced lung disease care from the safety and comfort of your home.

Please reach out to us 24/7 to find a care provider in your area at 1-844-GET-NPHI (438-6744) or visit us at www.hospiceinnovations.org.

On behalf of The National Partnership for Healthcare and Hospice Innovation and the American Lung Association, we wish you the best, knowing you have access to the best in advanced lung disease care.

Sincerely,

Tom Koutsoumpas
CEO

National Partnership for Healthcare & Hospice Innovation





Greetings,

We know it can feel overwhelming at times when you have advanced lung disease or are caring for someone who does. That is why we are pleased to be working with the National Partnership for Healthcare and Hospice Innovation (NPHI) to develop and share this guide as a reference to many of your questions and concerns.

The mission of the American Lung Association is to save lives by improving lung health and preventing lung disease through education, advocacy and research. For over 115 years, we have been a driving force to create change that provides for healthy air for all Americans and keeps kids from starting tobacco, while helping those addicted quit for good. All the while, we are supporting individuals diagnosed with advanced lung disease and their loved ones.

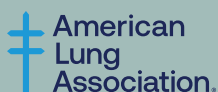
Whether you have COPD, lung cancer, interstitial lung disease or another type of chronic lung disease, there is support available to you on Lung.org or you can call our tollfree Lung HelpLine at 800-LUNG-USA (option 2) to speak with a healthcare professional free of charge.

Yours in Lung Health,

Deb Brown

Chief Mission Officer, American Lung Association

Lung.org
800-LUNG-USA
info@lung.org





Understanding Your Lungs & Advanced Lung Disease

How Your Lungs Work

As you breathe, air (oxygen) travels down through your airways and reaches the air sacs or alveoli in the lungs.

The alveoli are tiny balloon-like air sacs where the exchange of oxygen and carbon dioxide takes place. They are surrounded by blood vessels that take in the oxygen and deliver it through the blood stream to the rest of the body. As the cells in your body use oxygen, a waste gas is produced called carbon dioxide that the blood carries back to the lungs to be expelled as you exhale.

Gas exchange is the process of getting oxygen into your body and expelling carbon dioxide.

What are Chronic Lung Diseases?

There are several categories of chronic lung diseases:

Obstructive Lung Diseases are characterized by shortness of breath when exhaling (air stays in lungs even after breathing out).

- COPD (chronic obstructive pulmonary disease)
- Chronic Bronchitis
- Emphysema
- Asthma
- Cystic Fibrosis
- Bronchiectasis

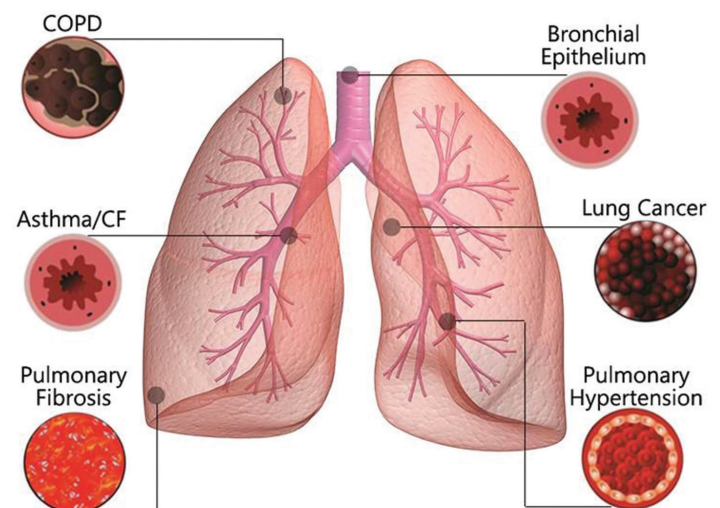
Restrictive (interstitial) Lung Diseases

decrease the amount of air the lungs can hold and make it difficult to inhale (to breathe in).

- Pulmonary Fibrosis
- Sarcoidosis

Other conditions

- Pulmonary Hypertension
- Lung Cancer



Obstructive Lung Disease

If you have been diagnosed with an obstructive lung disease, it is difficult for you to exhale all the air from your lungs, which can leave you feeling breathless. Symptoms include breathing difficulty, coughing, mucus production and wheezing.

COPD (chronic obstructive pulmonary disease) is an obstruction in the airways that makes breathing harder and may affect the process of gas exchange. COPD is an umbrella term for having one or both of the below diseases:

- **Chronic Bronchitis** is an inflammation (or irritation) of the airways (also called bronchial tubes) in the lungs. When the airways are irritated, thick mucus forms in them. The mucus plugs up the airways and makes it hard for air to get into your lungs.
- **Emphysema** is a condition in which the air sacs of the lungs are damaged, rupture, and create bigger air pockets. The air is then trapped in the damaged sacs, and the gas exchange is reduced which makes breathing harder.

Asthma is characterized by the airways in your lungs becoming inflamed and narrow. When your swollen and sensitive airways are exposed to an 'asthma trigger', you may have an asthma attack, resulting in the muscles surrounding the airway to tighten and spasm making it difficult to breathe.

Cystic Fibrosis is a progressive genetic disease that causes thickened mucus to form in the lungs, blocking the airways, creating lung damage, and making it hard to breathe.

Restrictive or Interstitial Lung Disease

This disease occurs when there is scarring of the lungs causing the lung tissue to be inflexible and stiff. When this occurs, you have difficulty filling up your lungs with air as you inhale.

Pulmonary Fibrosis is a lung disease that occurs when lung tissue becomes damaged and scarred. This can occur because of an underlying autoimmune condition such as lupus or rheumatoid arthritis, an occupational exposure, or for unknown causes in which case it is called idiopathic. This thickened, stiff tissue makes it more difficult for your lungs to work properly. As pulmonary fibrosis worsens, you become progressively shorter of breath.

Sarcoidosis, an autoimmune disease, can affect many organs of the body, most commonly the lungs.

Additional Chronic Lung Diseases

Pulmonary Hypertension is a disease where the walls of the arteries in the lungs become stiff, damaged, and narrow. Blood flow between the lungs and heart becomes more difficult, causing blood pressure to rise in the lungs and requiring the heart to work harder to pump blood throughout your body.

Lung Cancer occurs when cells in the lungs mutate and begin to grow uncontrollably, clustering together to form a tumor and destroying healthy lung tissue.

Common Symptoms of Advanced Lung Disease

- Shortness of breath, especially with activity, or at rest (just sitting)
- Constant or worsening cough
- Changes in mucus production
- Fatigue and/or decrease in alertness or episodes of confusion
- Fever
- Chest pain or tightness
- Loss of appetite and/or unintentional weight loss
- Dizziness
- Edema (swelling in the legs, ankles and occasionally the abdomen, due to a build-up of fluid)
- Poor sleep

Many of the above symptoms can be managed or controlled with medications and self-care techniques in the comfort of your own home.

Symptom Management & Self-Care Tips

Self-Care Techniques to Reduce Symptoms

In advanced lung disease, air does not move easily in and out of lungs. You may have trouble breathing, experience a persistent cough, have excess mucus in your lungs and other related symptoms. Learning ways to decrease symptom burden and clear your lungs may help conserve energy and oxygen. It may also help to prevent lung infections.

Chest pain: Chest pain associated with the increased workload of your heart, as well as the pain associated with low oxygen levels to your heart muscle itself, can be addressed. Descriptions of some of the common medications used to reduce chest pain are included in the “medication” section of this booklet.

Edema (swelling): Edema is a medical term for fluid retention. Swelling or edema can be managed using diuretics or “water pills.” Nutritional support and reduction of salty foods and fluids contribute to the reduction of edema (swelling) in your body. Lower extremity (legs) edema can be relieved by elevating your legs; this will also help your heart not work as hard. Your care team may recommend compression stockings or wraps. Regular physical activity can help reduce swelling.

Anxiety, Restlessness, or Depression: Anxiety, restlessness, and depression are not uncommon for individuals (and caregivers) dealing with the stress of living with advanced lung disease. Take care of yourself by staying as active as possible while modifying activity based on your energy level. Spread activities out throughout the day. Social connection is important so visit friends and connect with others. Practice relaxation techniques and breathing exercises. And speak with your medical provider about your emotional well-being so they can work with you to understand the cause of your feelings and help identify coping strategies.

Sleep Apnea: Managing sleep apnea can help lower blood pressure and reduce stress on the heart and lungs. Sleep apnea may be managed with a PAP (Positive Airway Pressure) device as recommended by your care team. The PAP device works by delivering pressurized air through a mask to support the airway.

Shortness of breath (trouble breathing): A feeling of shortness of breath may be felt with activity, when sitting still, or when lying down, as it takes more effort for air to travel in and out of the lungs. Shortness of breath can be reduced by the following:

- **Positioning**
 - Sitting upright in a tripod position (Appendix D)
 - Elevating your head and shoulders with several pillows
- **Breathing Techniques.** Pursed-lip breathing may reduce shortness of breath. This method of breathing helps to slow down a person's breathing allowing more air into their lungs. Practice this technique when you are not having difficulty breathing.
- **Fan.** Using a fan to blow room temperature or cool air on the face may reduce the feeling of breathlessness.
- **Relaxation Techniques** when practiced may help you relax if you feel short of breath. Practice relaxation techniques daily.
- **Progressive Relaxation Technique:**
 - Sit in a quiet room or lie down
 - Begin pursed-lip breathing
 - Tighten a muscle in your body like your feet or hands and hold the tension while you breathe in
 - Relax the muscle when you breathe out
 - Repeat steps 3 and 4 with another part of your body such as your arms or legs. Start from your feet and work your way up
- **Visualization Technique:**
 - Sit in a quiet room or lie down
 - Picture yourself relaxed in a peaceful setting and use your imagination to fill in specific details
 - Keep those images in your mind
 - Refocus if other images attempt to take over your visualization and concentrate on your breathing

Other Ways to Help Your Symptoms

Breathing Techniques & Exercises

- Pursed-lip breathing may reduce shortness of breath. This method of breathing helps to slow down a person's breathing allowing more air into their lungs. Practice this technique when you are not having difficulty breathing.
- Deep breathing (sometimes called diaphragmatic breathing) is a breathing method that allows more air to flow into your lungs. Practice this exercise 3–4 times per day.
- Controlled coughing
- Positive expiratory pressure (PEP) device (Flutter® valve, AerobikA®, Acapella®)
- Incentive spirometer

Pursed-Lip
Breathing
video from the
American Lung
Association



Improve Air Quality In The Home

Irritants in the home can make it harder to breathe when you have a lung disease.

Irritants include (not limited to):

- Chemical cleaning products
- Tobacco smoke
- Dust
- Paint
- Candles

To improve the air quality in the home, try to:

- Limit exposure to chemicals
- Use an air filtration system and open windows
- Vacuum with a HEPA filter and dust regularly with a wet washcloth or microfiber cloth

Quit Smoking (and do not allow smoking in your home)

Tobacco smoke is irritating and causes inflammation that narrows the airways, making it difficult for air to pass. Smoking may reduce the effectiveness of some inhaler medications. Nicotine causes the airway to contract (narrow), decreasing the amount of oxygen your lungs can receive. Nicotine also constricts (tightens) blood vessels. Constricted blood vessels decrease the amount of oxygen and nutrients your cells receive.

Conserve Energy

Pace yourself! While regular exercise will help maintain or increase your strength and endurance, it is equally important to conserve energy to best manage symptoms.

Managing your Mucus and Coughing

Chronic lung disease can cause your lungs to produce excess mucus, leading to frequent coughing. Over time, mucus becomes thicker and can block the air passages making it very difficult to breathe. Not all coughs are effective in clearing excess mucus from the lungs. Explosive or uncontrolled coughing can cause airways to collapse and spasm, trapping mucus. Chest physical therapy can help move mucus and clear the airway.

Chest physical therapy at home

Chest physical therapy (CPT or Chest PT) are airway clearance technique(s), including percussion (clapping), vibration, deep breathing, and coughing, to move the mucus from the lower parts of the lung to the upper part of the lungs to allow you to cough up the mucus.

An effective, or controlled, cough comes from deep within the lungs and has just enough force to loosen and carry mucus through the airways without causing them to narrow and collapse.

Airway Clearance Techniques:

Controlled coughing

1. Sit on a chair or on the edge of your bed, with both feet on the floor. Lean slightly forward. Relax.
2. Fold your arms across your abdomen and breathe in slowly through your nose. (The power of the cough comes from moving air.)
3. To exhale: lean forward, pressing your arms against your abdomen. Cough 2-3 times through a slightly open mouth. Coughs should be short and sharp. The first cough loosens the mucus and moves it through the airways. The second and third cough enable you to cough the mucus up and out.
4. Breathe in again by "sniffing" slowly and gently through your nose. This gentle breath helps prevent mucus from moving back down your airways.
5. Rest.
6. Perform again if needed.



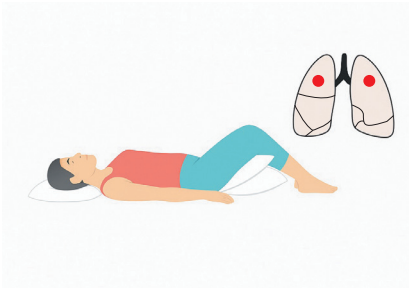
Tips

- Avoid breathing in fast or deeply through your mouth after coughing. Quick breaths can interfere with the movement of mucus up and out of the lungs and can cause uncontrolled coughing.
- Use the controlled coughing technique after you use your breathing medication or any time you feel mucus (congestion) in the airways.

Huff Cough. Huff coughing is a technique that helps move mucus from the lungs by combining breathing techniques with coughing. This helps you cough more effectively without wearing yourself out.

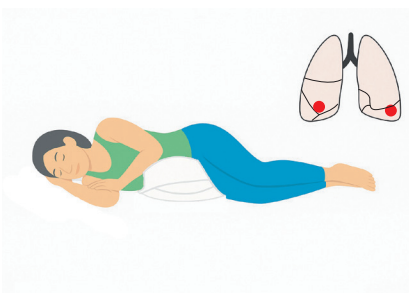
- Sit up.
- Take a breath that is a little deeper than normal.
- Use your stomach muscles to blow air out in three breaths, making a Ha Ha Ha sound. It is like huffing or blowing onto a mirror or window to steam it up.

Postural Drainage Position



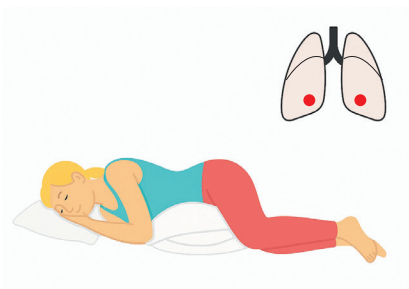
Back

- Chest should be lower than the hips, which can be achieved by lying on a slanted surface or propping hips up about 18 to 20 inches with pillows or a wedge.
- This position is best for draining the bottom front parts of the lungs.



Side

- Place pillows under the hips, chest should be lower than the hips.
- A left lying position will clear congestion from the bottom part of the right lung.
- A right lying position will clear congestion from the bottom part of your left lung.



Stomach

- Lay on a stack of pillows or other object, such as a beanbag, to support the arms and head, chest should be lower than the hips.
- This position is best for clearing mucus in the lower back area of the lungs.

Percussion (clapping/cupping). Chest percussion is a technique which involves clapping on the back (lung area, not below the bottom rib) to loosen thick mucus from the lungs. It allows secretions to drain from the lung segments into larger airways where it can be removed by coughing.

- Best used while the patient is in a postural drainage position (see page 12).



ADAM.

Vibration. Vibration technique involves gentle vibrations (shakes) to the upper chest and back, assisting mucus to move into the larger airways and allowing for a more productive cough.

- Technique is best used when the patient is in a postural drainage position.
- Vibration therapy can be done at home by using a handheld massager.

Mucus Clearing Devices. PEP (Positive Expiratory Pressure) device: A hand-held device called a Flutter® valve or Acapella® (the “pickle”) that creates resistance and vibrations to help loosen and clear mucus from the airways.

Other Self-Care Tips

- **Avoid people who are sick:** Avoiding being exposed to a cold, the flu, or any other respiratory infection is important because they can worsen your existing lung disease.
- **Healthy environment:** Take steps to reduce irritants, such as cigarette or woodstove smoke, or other fumes such as cleaning products, air fresheners and products that emit fragrance in your living area. This will help with breathing.
- **Exercise and activity:** Try to remain as active as possible. Walking for several minutes each day, if able, could help you feel stronger. However, avoid activities that make you more tired than usual or short of breath without first discussing with your medical provider. Rest completely between activities.
- **Sleep:** Getting good rest is important and if you are struggling to do so, try the following:
 - Get regular physical activity, if able
 - Limit or eliminate alcohol intake
 - Avoid caffeine
 - Develop pre-bedtime routine—warm bath, dimming lights, or herbal tea
- **Wear loose clothing:** Avoid tight clothing that restricts the abdomen/diaphragm area.
- **Healthy diet:** Eat a heart-healthy diet that is low in sodium, low in simple carbohydrates, and rich with complex carbohydrates (see Appendix H for tips).
 - Avoid caffeine
 - Eliminate or limit alcohol intake
 - Focus on fresh foods
 - Avoid processed or canned foods, as they are usually high in salt or sodium content
- **Hydration:** Good hydration is important for you to manage your lung disease. Being well hydrated can help thin your mucus making it easier to cough up. If you also have heart disease, you will need to balance your fluid intake to decrease stress to the heart. If your care team has instructed you to limit your fluid intake, please follow the recommendation of your medical provider.

If your mucus is too thick to cough up, contact your medical provider.

- **Fluid Balance:** Monitor your fluid balance by weighing yourself daily. Consistency is key – weigh at the same time, with the same scale, with the same amount of clothing daily for the most accurate measure. An increase in weight may signal fluid build-up.
- **Symptom Tracking:** Keep a notebook (or use the chart in Appendix C) to record your weight and any symptoms so you can report them to your medical provider. A weight gain of 2 pounds overnight (24 hours) or 5 pounds in one week (7 days) should be reported to your care team.

Medication Management

Medications: Take your medication as prescribed by your care team. Do not make changes to your medication without speaking with your care team. Your team nurse can help with your medication management and will review it with you at each visit.

Short-Acting Bronchodilators: These medications work to relax and open the airways. They increase the movement of cilia to help clear the mucus. They also reduce/prevent wheezing. These medications should only be used as directed in the case of respiratory crisis to help stop attacks and are commonly known as rescue medication.

Working Together to Manage Your Symptoms

The support of your family and loved ones is especially important. They are a part of your life and are affected by your condition too. Including your family in your decisions and lifestyle changes will help to foster support and understanding. Share the information you read. Invite family members to talk with your care team. Let them know what they can do to help you. The team social worker can help you and your family with important decisions regarding your care.

How Your Family Members Can Help

- Set realistic goals and plans
- Participate in your healthcare decisions
- Keep track of your medications and appointments
- Adapt favorite family recipes to your diet
- Assist with activities of daily living and physical activities
- Ask questions. It is important for you and your family to understand your condition

Call Your Care Team If You...

Begin to have an increase in shortness of breath or develop chest pain
Notice an increase in mucus production
Notice that your mucus has changed color or thickness
Develop a fever
Notice decreasing alertness, particularly with activities previously tolerated
Experience increased fatigue
Notice that you have gained weight. Patient weight range:_____
Notice that you have an increased swelling (edema) in your feet, ankles, legs, or abdomen
Wake at night with shortness of breath and/or anxiety, which is not relieved by sitting up for several minutes
Notice a reduction in appetite or a tendency to nausea
Experience any unpleasant side effects after you take your medication
Have unusual feelings or problems
Have not had a regular bowel movement in three days or if you have a dry, hard stool that is painful or difficult to pass



Medications

Taking medication every day is necessary to manage most advanced lung diseases and many people will take more than one medication. It is essential to take your medications as they are prescribed by your care team to help control your symptoms. Never stop taking your medications or change your dose unless instructed by your nurse, physician, or medical provider. It is also important to note that with disease progression, your medical provider may modify your medications.



Common medications include:

ACE (Angiotensin Converting Enzyme) Inhibitors Examples include benazepril (Lotensin), captopril (Capoten), enalapril (Vasotec), lisinopril (Zestril or Prinivil) and fosinopril (Monopril) Your Prescribed Medication Name:	This medication works to increase the flow of blood, lower blood pressure and reduce the amount of work the heart must do. You may experience a dry cough, dizziness, constipation, or a dry mouth. Your care team can easily change your prescription or offer other medications to manage blood pressure. Let your care team know if any of these symptoms occur. To minimize light-headedness, always rise slowly from a sitting or lying position and dangle feet before standing; avoid sudden changes in position. Take your medication one hour before meals and only as directed.
ARBs (Angiotensin Receptor Blockers) Examples include: losartan (Cozaar), candesartan (Atacand), and valsartan (Diovan) Your Prescribed Medication Name:	This medication works very similarly to the ACE Inhibitors but avoids some of the side effects. As with the ACE Inhibitors, you may experience light-headedness if you rise quickly from a sitting or lying position. To reduce this, rise slowly from a lying position and dangle feet before standing; avoid sudden changes in position.
Anticholinergics Examples: ipratropium + albuterol (Atrovent, Combivent), SABA, ipratropium (Spiriva) Your Prescribed Medication Name:	These medications protect the airways from spasms called bronchospasms, which can cause the airway to become narrower (tight) and can make it difficult to breathe and may increase coughing and/or wheezing. These medications are sometimes used as bronchodilators. They help relax and dilate (open) the airways in the lungs making it easier to breathe. They also reduce the amount of inflammation and mucus produced, again making it easier to breathe.

Corticosteroids Oral – prednisone, dexamethasone Inhaled – fluticasone (Flovent), budesonide (Pulmicort), mometasone (Asmanex) Your Prescribed Medication Name:	These medications reduce inflammation and swelling in the airways. They also reduce mucus production and decrease the sensitivity of airways to irritants and allergens. It is especially important for you to thoroughly rinse your mouth after inhaled steroid use to avoid throat irritation and mouth infection.
Diuretics Examples include furosemide (Lasix), bumetanide (Bumex or Burinex), torsemide (Demadex), and metolazone (Zaroxolyn) Your Prescribed Medication Name:	This medication is commonly called a “water pill.” It helps rid the body of excess water, making it easier to breathe. Sometimes a diuretic causes people to lose potassium. Your medical provider or care team may recommend that you eat foods that are high in potassium such as bananas, tomatoes, and strawberries. It is recommended to take your diuretic in the mornings on an empty stomach for better absorption. It is better to take your last dose no later than 3pm to reduce and prevent having to disrupt sleep at night to urinate, unless directed differently by your physician or care team. Signs of too much potassium loss include: • Muscle pain or cramps (especially legs) • Muscle weakness • Dry mouth • Increased thirst • Mental status changes • Heartbeats that skip • Nausea or vomiting • Weak pulse • Excessive fatigue

Inhaled Combination Medications Beta 2 agonist + inhaled corticosteroid Salmeterol + fluticasone (Advair) formoterol + budesonide (Symbicort) Your Prescribed Medication Name:	These medications combine the effects of several types of medications that include pairing two bronchodilators together or even adding an inhaled corticosteroid to bronchodilators. These can be delivered by hand-held devices such as meter dosed inhalers, dry powder inhalers, soft mist inhalers or nebulizers. Modification may be necessary depending on your ability to effectively administer the medication.
Long-acting beta-2 agonist (LABA) Examples: arformoterol, Salmeterol, Serevent, formoterol Your Prescribed Medication Name:	These bronchodilators are medications that relax and open the airways. They take effect slowly and the relief lasts longer than short-acting beta-2 agonists. These medications increase the movement of cilia to help clear mucus. They also help prevent exercise-induced wheezing.
Mineralocorticoid Receptor Antagonists (MRAs) Example: spironolactone (CaroSpir or Aldactone) Your Prescribed Medication Name:	This medication is given to help rid the body of excess water, making it easier to breathe. It is usually taken at the same time as other diuretics.
Opioids Example: morphine sulfate (Roxanol) <i>** If you have an abnormal renal (kidney) function, your medical provider may prescribe another opioid to help with pain symptoms. Example: hydromorphone (Dilaudid) **</i> Your Prescribed Medication Name:	This medication may be included as part of your symptom management medications to help control pain. It may also be given to treat and help control your shortness of breath. Some side effects of Morphine may include nausea, indigestion, anxiety, drowsiness, or itching. Tell your care team if you experience any of these side effects.

Saline Nebulizers Your Prescribed Medication Name:	Saline hypertonic nebulizers help clear out mucus and help to relieve breathlessness. They also help you cough up mucus in your lungs.
Short-acting beta-2 agonist (SABA) Examples: albuterol, levalbuterol, metaproterenol, terbutaline Your Prescribed Medication Name:	These bronchodilators are medications that work to relax and open the airways quickly. They increase the movement of cilia to help clear the mucus. They also reduce/prevent wheezing. They may be prescribed to prevent exercise-induced asthma and decrease the need for rescue inhalers. These medications should only be used as directed in the case of respiratory crisis to help stop attacks and are commonly known as rescue medications. If using, please contact your medical provider.
Short-acting muscarinic antagonist (SAMA) Examples: atrovent, ipratropium Your Prescribed Medication Name:	This combination medication improves lung function and reduces symptoms of dyspnea by opening up the medium and large airways in the lungs.
Selective phosphor diesterase-4 enzyme (PDE) inhibitor Examples: roflumilast (Daliresp) Your Prescribed Medication Name:	This medication reduces the number of flare-ups or worsening symptoms (breathlessness, cough, excess mucus) due to bronchitis form of COPD; it helps in bronchodilation and reduces inflammation.

Diet

How does your diet relate to breathing?

The process of changing food to fuel in the body is called metabolism. Oxygen and food are the raw materials of the process, and energy and carbon dioxide are the finished products. Carbon dioxide is a waste product that we exhale.

The right mix of nutrients in your diet can help you breathe easier. Metabolism of carbohydrates produces the most carbon dioxide for the amount of oxygen used; metabolism of fat produces the least. For some people with COPD, eating a diet with fewer carbohydrates and more fat helps them breathe easier.

Listed below are dietary suggestions that may help you optimize your food and help you breathe easier.

- Choose **complex** carbohydrates, such as whole-grain bread and pasta, fresh fruits, and vegetables (see Appendix H)
 - To lose weight: opt for fresh fruits and veggies over bread and pasta for most of your complex carbohydrates
 - To gain weight: Eat a variety of whole-grain carbohydrates and fresh fruits and vegetables
- **Limit simple carbohydrates**, including table sugar, candy, cake, and regular soft drinks (see Appendix H)
- **Limit foods that cause gas or bloating** such as carbonated drinks and spicy foods, as they can affect diaphragmatic movement
- **Eat frequent, smaller meals** to help reduce the uncomfortable “full feeling” that comes with eating more at one sitting
- **Eat 20 to 30 grams of fiber** each day, from items such as bread, pasta, nuts, seeds, fruits, and vegetables
- Eat a **good source of protein** at least twice a day to help maintain strong respiratory muscles. Good choices include milk, eggs, cheese, meat, fish, poultry, nuts, and dried beans or peas.
 - To lose weight: Choose low-fat sources of protein such as lean meats and low-fat dairy products
 - To gain weight: Choose protein with a higher fat content, such as whole milk, whole milk cheese, and full-fat yogurt
- As a side effect of medications, you may need to **replace potassium** in your body. Foods high in potassium include bananas, melons, sweet potatoes, white potatoes, prunes, oranges (or juice), some fish, low-fat yogurt, low-fat milk, low-sodium tomato juice and tomato sauce,

lentils, and kidney beans. Make sure your medical provider or care team wants you to keep your potassium high enough. Some people need to avoid potassium.

- **Check your weight** – you should speak to your care team if you continue to lose or gain weight while following the recommended diet. There are health complications that can result from being underweight or overweight. A well-nourished body is better able to recover from infections. When people with severe chronic lung disease get an infection, it can become serious quickly and may result in hospitalization. If illness does occur, a well-nourished body can respond better to treatment.
- **Vitamins and Minerals** – many people find taking a general-purpose multivitamin helpful. Often, people with severe chronic lung disease take steroids. Long-term use of steroids may increase your need for calcium. If considering using calcium supplements, look for one that includes vitamin D.
- **Sodium** – too much sodium may cause edema (swelling) that may increase blood pressure. If edema or high blood pressure are health problems for you, talk with your care team about how much sodium you should be eating each day.
 - Avoid adding salt when cooking or shaking salt on your food.
 - Season with herbs, spices, herbed vinegar, and fruit juices.
 - Before using a salt substitute, ask your care team.
 - Limit eating out and eating processed or canned foods.
 - If you use canned foods with added salt, rinse in a colander under running water to remove some of the salt.
 - Some over-the-counter drugs contain a lot of sodium. If you are taking any over-the-counter drugs, review this with your care team to see if the drug is OK for you.
- **Fluids** – Drinking plenty of water is important not only to keep you hydrated, but also to help keep mucus thin for easier removal. Talk with your care team about your level of water intake.
 - A good goal for many people is 6 to 8 glasses (8 fluid ounces each) daily. Note, if you have heart disease, you may need to limit your fluid intake. A typical fluid restriction would be 1200–1500ml (5 to 6 ¼ cups) of total fluid per day. If this applies to you, please discuss with your care team.
 - Do not try to drink your fluid all at once; spread it out over the entire day. Some people find it helpful to fill a water pitcher every morning with all the water they are supposed to drink in one day, then refill their glass from that pitcher and keep track of their progress during the course of the day. Remember, any healthy caffeine-free fluid counts toward your fluid goal, and most foods contribute a substantial amount of fluid as well.

Making a few dietary changes can make you feel more comfortable and may affect your breathing. Your body uses food as fuel for all its activities. The right mix of nutrients in your diet can help you breathe easier. No single food will supply all the nutrients you need – a healthy diet has lots of variety. You and your care team will work out a meal plan just for you.

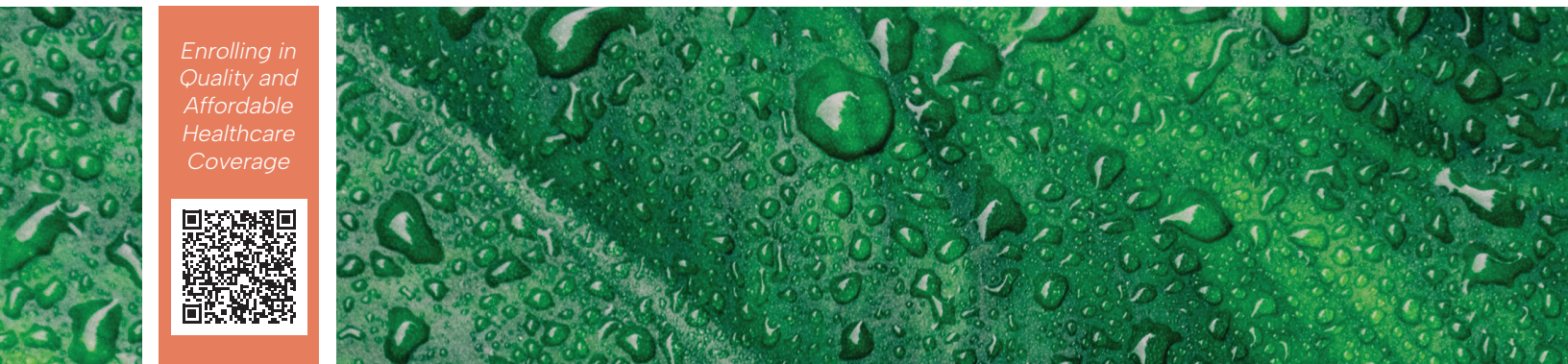
Advance Care Planning

Sharing what matters most with loved ones helps families, medical providers, and communities alike understand your values. That knowledge—and the exercise of talking to one another about deeply personal desires and eliminating the need for family to guess what your wishes might be—can bring comfort and peace of mind in times of stress. There are important topics that must be explored regarding your health care wishes, hopes, and fears with each other. It is a big step and not easy, however, it is necessary and will give those you love the guiding principles required to confidently make decisions for you if needed, ensuring that your healthcare journey takes the course that you establish and lead. Advance Care Planning allows you to have your voice heard when you are not able to physically speak for yourself.

Your healthcare team will talk to you more about this and help guide the discussion with you and those you choose to participate in this discussion—this person is often called your health care surrogate or proxy.

How to Pay for My Advanced Lung Care Treatments

*Enrolling in
Quality and
Affordable
Healthcare
Coverage*



Appendix A: Monitoring Symptoms

Green Zone indicates you have no new symptoms	
My symptom(s) are under control: • Usual activity and exercise level are tolerated • Cough unchanged • Usual amounts of phlegm/mucus • Sleeping well at night • Appetite is good	Actions to follow: • Take daily medications • Use oxygen as prescribed (if you use oxygen) • Continue usual activity and exercise • Continue recommended diet plan • Watch for changes: phlegm/mucus color and texture; cough; weight • At all times avoid cigarette smoke and inhaled irritants
Yellow Zone indicates a change in symptoms. Monitor changes and follow action plan	
My symptom(s) are worsening: • Feeling more short of breath than usual • Increased or thicker phlegm/mucus • Change in color of phlegm/mucus • Using quick relief inhaler/nebulizer more often than usual • More anxiety/nervousness than usual • More fatigue/less energy for my daily activities than usual • More swelling of ankles/lower extremity than usual • More coughing than usual • Symptoms like having a “chest cold” • Poor sleep and any symptoms that cause you to wake up • Less appetite than usual • Medication is helping less than usual	Actions to follow: • Use pursed-lip breathing • Keep temperature cool in the house • Continue medications as prescribed • Use quick relief inhaler or nebulizer as prescribed • Use oxygen as prescribed • Get plenty of rest and conserve energy • Call your care team if you gain 2 pounds in 24 hours or 5 pounds in 7 days • Call your care team if you have any worsening of your symptoms Phone number:
Red Zone indicates symptoms require immediate evaluation by your care team	
My symptom(s) are NOT under control: • Severe shortness of breath, even at rest • Not able to do any activity because of difficulty breathing • Not able to sleep/lay down because of difficulty breathing • Feeling confused or very drowsy • Chest pains • Coughing up blood	Actions to follow: Call your care team immediately for an evaluation, 24 hours a day, 7 days a week Phone number:

Appendix B: My Action Plan— What to Do When I Feel...

Please refer to this guide created for you by your care team to help you when you experience any of the following symptoms:

Symptom	Treatment	Desired Goal
Anxiety	- Breathing techniques (pursed-lip breathing) - Use of a fan - Medication as prescribed by your physician	Decreased anxiety and feeling of shortness of breath
Cough	- PEP (Positive Expiratory Pressure) devices to help with removing mucus from lung and airway walls (Aerobika®) - Medication as prescribed by your physician	Increased mucus production or cough suppression depending on your diagnosis
Decreased Energy	- Pace yourself - Conserve energy by spreading activities out during the day - Plan activities on days and times when you have more energy or feel better	Maintaining your strength and endurance
Increased Mucus	- Fluids to thin mucus - PEP devices - Medication as prescribed by your physician	Thin, mobilize, or clear mucus depending on your diagnosis
Shortness Of Breath	- Use of fan - Breathing techniques - Body positioning - Supplemental oxygen as prescribed - Medication as prescribed by your physician	Decrease work of breathing

Appendix C: Journaling - How I Feel Every Day

It is important to keep a record of how you are feeling every day to share with your care team. The following chart can be used for record keeping.

Week of..... New or worsening Symptoms? Call your Nurse anytime – 24/7

Date	Weight (lbs) Goal weight _____	Blood pressure	Heart rate (pulse)	Temperature	Shortness of breath Circle level of distress 0 (none) 5 (severe) 10 (the worst)	Rescue inhaler use of nebulizer treatment	Change in:			Anxiety (new or worse)	Have there been any changes from yesterday? (Eating, sleeping, restlessness, activity, etc.)
							Sputum (Mucus) Color/Consistency	Cough or Wheezing	Pain Where?		
/	Have you gained 2 lbs overnight or 5 lbs in 5 days? If so, call your nurse				0 1 2 3 4 5 6 7 8 9 10			Yes / No			
/											
/					0 1 2 3 4 5 6 7 8 9 10			Yes / No			
/					0 1 2 3 4 5 6 7 8 9 10			Yes / No			
/					0 1 2 3 4 5 6 7 8 9 10			Yes / No			
/					0 1 2 3 4 5 6 7 8 9 10			Yes / No			
/					0 1 2 3 4 5 6 7 8 9 10			Yes / No			

Did you take all medications as directed, if not, what medication was held and why?

Date	/	/	/	/	/	/
Took all meds	Yes / No	Yes / No	Yes / No	Yes / No	Yes / No	Yes / No
Did not take						
Reason						

0	1	2	3	4	5	6	7	8	9	10
Nothing at all					Severe (heavy)			Very severe		
Very slight					Severe (heavy)			Very severe		
					Very severe			Very, very severe		

Anxiety Level	0	1	2	3	4	5	6	7	8	9
	"Life is good. Nothing to stress about. I can handle anything life throws my way."	"Just a little hiccup. Nothing I can't handle."	"Oh c'mon... where the heck are they? This is NOT a good time!"	"Where did that scratch come from?"	"What am I going to tell them?"	"What the hell am I going to do?"	"This is all too much to handle!"	"I can't take anymore."	"Could anything else freak you out?"	"Silently rocking back and forth"
	How average people start their day.	Akin to misplacing your sunglasses or the remote.	Similar to misplacing your keys when you're running late for work.	Imagine finding a scratch or small ding on your new car.	Imagine being the cause of a scratch or ding on your parents' new car.	Imagine totalling your car, messing up your big presentation at work or failing your final exams at school.	Imagine losing your job, failing the big test AND totalling your car all the same day.	Imagine having all of that happen, then coming home to discover your basement flooded and your family pet died.	Imagine adding to that your identity was stolen, your bank account closed AND your spouse left, taking the kids.	Imagine not being able to take anything else and just wrapping in a blanket and shutting down completely.

Appendix D: Tripod Positioning

- First, make sure you are in a safe location.
- Sit in a comfortable position.
- Lean forward, using your arms and elbows as support.
- Try to achieve an angle of about 45 degrees as you lean forward.
- You can rely on your arms or use a table top or pillow to help you hold this position.
- Take slow and steady breaths.



Appendix E: How to Use Your Devices

Using Your Inhaler

One of the methods to deliver lung medications is an inhaler. Some of the lung medications that you may be prescribed by your care team come in a fine mist, a powder or a spray and are often taken by using an inhaler.

Your care team may recommend that you use a spacer to help deliver more of the medication into your lungs.

How To Use Your Metered-Dose Inhaler:

1. Shake the inhaler (3–4 times).
2. Remove the cap or cover.
3. Breathe out.
4. Put the inhaler in your mouth between your teeth and close your lips around it tightly. (Alternatively, your care team may recommend holding the inhaler 1–2 inches from your open mouth. Please follow your care team's recommendation).
5. Spray one (1) puff by pressing down on the inhaler and start to breathe in slowly, between 5–10 seconds if possible. Then breathe out slowly.
6. Repeat step 5 after 30 seconds if a second puff is prescribed or needed.

How To Use Your Metered-Dose Inhaler With A Spacer/Chamber:

1. Remove the cover for both the inhaler and the spacer/chamber. Shake the inhaler (3–4 times) and attach it to the spacer/chamber.
2. Breathe out.
3. Put the spacer/chamber between your teeth and close your lips tightly around it. Position your chin up.
4. Spray one (1) puff by pressing down on the inhaler and breathe in as deep and slowly as possible (5–10 seconds).
5. Repeat step 4 after 30 seconds if a second puff is prescribed or needed.
 - If you feel your inhaler does not work as well as it used to, please let your care team know. This could indicate that your inhaler is no longer an effective treatment.
 - Please remember to rinse your mouth out after using your inhaler or nebulizer to prevent mouth infections.

How to use Your Inhaler with a Spacer/Holding Chamber



1. Check dose counter. Remove cap. Prime if it has never been used before, dropped or not used within 2 weeks. Shake the inhaler for at least 10 seconds.



2. Put together. Insert inhaler into spacer (technique will vary with type of spacer; refer to manufacturer instructions).



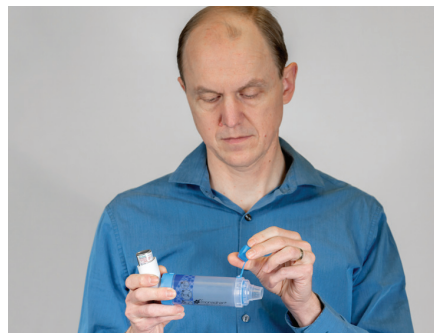
3. Breathe out. Tilt your head back slightly and breathe out away from the inhaler until lungs are completely empty. Put the mouthpiece into your mouth between your teeth and close your lips around it. Do not block opening with your tongue.



4. Press down once on the inhaler canister.



5. Breathe in deeply and slowly through your mouth.



6. Hold your breath as you count slowly to 10, if you can.



7. Wait and repeat, as prescribed. Wait 2 minutes between puffs, and repeat, as prescribed.

For more COPD videos, handouts, tutorials and resources, visit [Lung.org/COPD](https://www.lung.org/COPD).

You can also connect with a respiratory therapist for one-on-one, free support at the American Lung Association's Lung HelpLine at **1-800-LUNGUSA**.

Developed by the American Lung Association, August 2022.



Using Your Nebulizer

Your care team may prescribe medications that are delivered with a nebulizer machine that vaporizes the liquid medication for your lungs into a fine mist. Nebulizers deliver medications very quickly and directly to the lungs and require little effort to use because the mist flows continuously.

Using a plastic mouthpiece or mask, you will breathe in the medication for 10 to 15 minutes or until the mist stops.

How To Use Your Nebulizer or Compressor Machine:

1. Wash your hands before and after the procedure.
2. Unscrew the medical cup from the medication bowl of the machine and add the medication as prescribed. Screw the top back on.
3. Place the compressor on a steady surface and at least 12 inches away from any object that could block the flow of air into the compressor (i.e., a wall).
4. Turn the compressor on and put the mouthpiece in your mouth or bring mask to your mouth and nose. If possible, sit in an upright position.
5. Treatment should last about 10–15 minutes, breathing normally, or until the mist stops.
6. Clean the nebulizer mouthpiece or mask and medication bowl after each treatment by removing the T-piece and mouthpiece and disassembling the medication chamber. Use warm, soapy water, rinse the parts under hot water and then air dry. If used for more than one week, clean with a solution of equal parts vinegar and water.
7. Please remember to rinse your mouth out after using your inhaler or nebulizer to prevent mouth infections.

Oxygen Therapy

You may be prescribed supplemental oxygen if your test results show you have too little oxygen in your blood.

Oxygen Safety Do's and Don'ts

DO:

- Keep oxygen unit (concentrator and/or tank) in an open area at least 5 feet away from any source that may start a fire. Examples: matches, candles, cigarettes (smoking), gas stove (burners), radiators, space heaters, furnaces, fireplaces, or any open heat source.
- Turn off the oxygen concentrator when not in use.
- Keep the oxygen unit in a clear space away from direct sunlight.
- Clean the filters on a weekly basis with warm water (or as directed by the oxygen supply company).
- Put up "No Smoking" or "Oxygen in use" signs in your home for visitors to see.
- Protect the oxygen tubing from kinks and damage from furniture, door jambs, and pets.
- Portable oxygen tanks should be transported in the back seat or trunk of the car.

DO NOT:

- Smoke or allow others to smoke in your home, as it could start a fire.
- Use petroleum-based products (such as Vaseline, A&D ointment, or vapor rubs) while using your oxygen. Mixing these with oxygen may cause burns. Instead use water-based products (such as K-Y Jelly).
- Use aerosol sprays such as air fresheners and hair spray. These sprays are very flammable.
- Use oxygen while cooking on a gas stove.
- Plug your oxygen concentrator into an overcrowded outlet or extension cord.
- Leave the tubing in your bed or under furniture cushions. Do not lay objects on tubing or run it under carpeting. If you accidentally leave the unit on while you are not using it, the oxygen will leak into these items. A spark or flame could cause a fire.

Humidifier Therapy

Using Your Humidifier Bottle:

- It is recommended to use a humidifier bottle for liter flow of 2 liters/minute or more. Do not change your liter flow without consulting your care team.
- If nasal dryness occurs, use a nasal saline spray or a water-based lubricant, such as K-Y Jelly. Do not use oil-based ointments like Vaseline to lubricate, as they are flammable.

Care And Cleaning Of The Humidifier Bottle:

- ONLY use distilled water in the humidifier bottle. Do not fill it past the maximum fill line. Check water level often. If you're prescribed higher oxygen flows, you may need to keep a lower water level in the bottle to prevent water from entering the oxygen tubing.
- Daily, remove the humidifier cup from the concentrator and discard any remaining water.
- Use back-up oxygen while cleaning and filling the humidifier bottle.
- Weekly, disinfect the humidifier bottle by soaking in warm soapy water for a minimum of 20 minutes, then rinse using an equal parts vinegar/water solution and let it air dry.

How To Install Your Humidifier Bottle:

- Using distilled water, fill the humidifier bottle halfway. Do not fill over the maximum line.
- Attach the humidifier adapter to the top of the humidifier lid. Do not cross-thread the lid, as this will cause a loss of oxygen.
- Place the bottle into the concentrator tray.
- Connect the humidifier adapter onto concentrator nozzle.
- Connect cannula and/or tubing onto humidifier bottle nozzle.

Appendix F: When to Replace Your Inhaler

When you get a new inhaler, check how many puffs it contains. Track how many puffs you use daily. If you use your inhaler daily, divide the total number of puffs in your inhaler by the number you take daily to determine how many days your inhaler will last. Or, if you use your inhaler only occasionally, use this chart by crossing off a number each time you use a puff.

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70
71	72	73	74	75	76	77	78	79	80
81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200

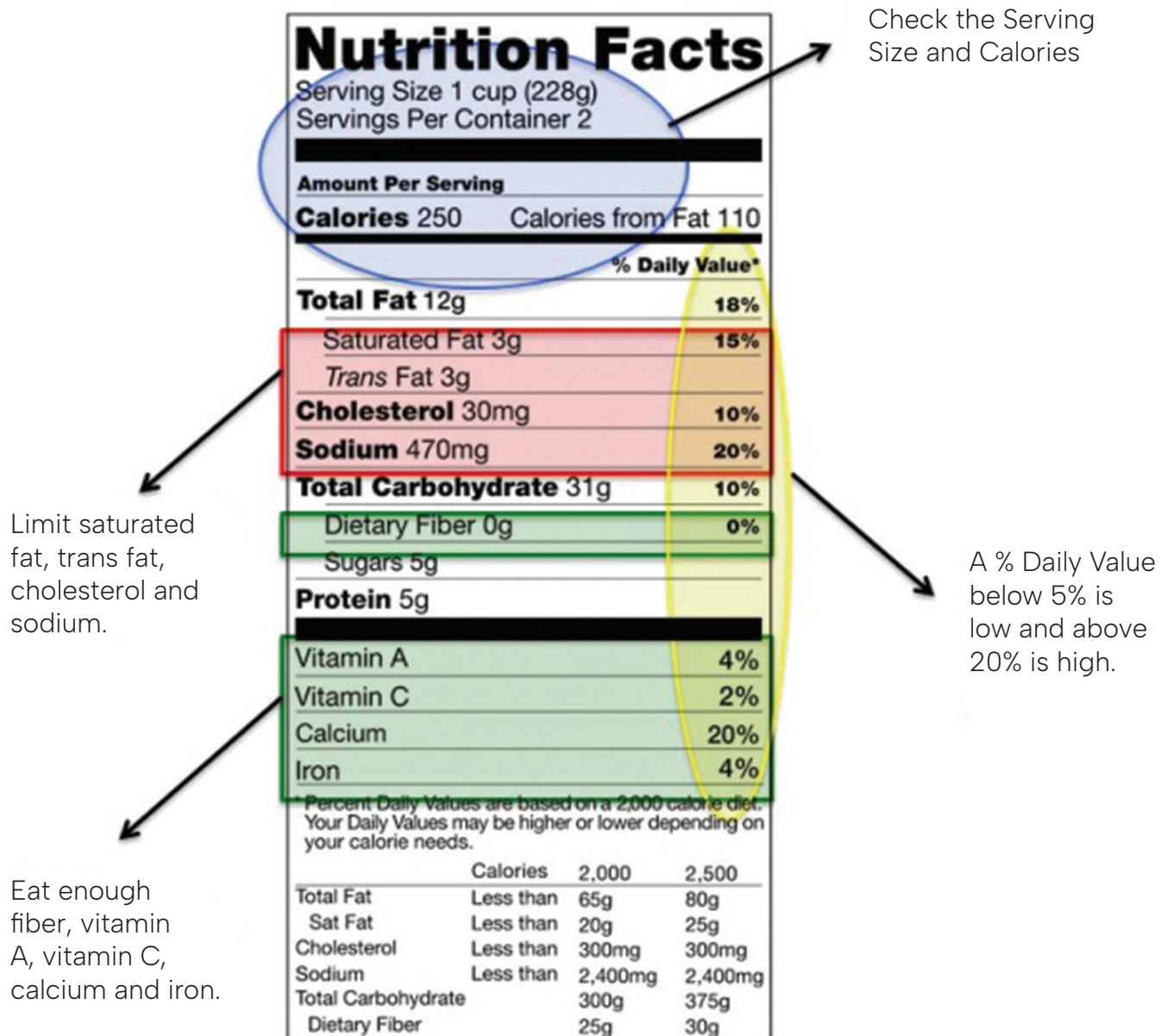


Appendix H: Understanding a Good Diet

It is recommended to eat a diet low in sodium (salt), added sugars, saturated and trans fats. However, always follow your care team's instructions.

Know How to Read Your Food Labels

Sample label for Macaroni & Cheese



What Do These Labels Really Mean?

Sodium free or salt free means less than 5mg per serving

Very low sodium means 35mg or less per serving

Low sodium means 140mg or less per serving

Unsalted or no salt added means no salt is added to the product during processing. (The product may still contain sodium, please read the labels)

Reduced sodium or less sodium means at least 25% less sodium than the standard version. (Please read the label – it may still be too much sodium for you)

Light in sodium means 50% less sodium than the standard version. (Again, please read the label – the sodium content may still be too much for you)

The foods listed below are usually complex carbohydrates (“good carbs”):		The foods listed below are usually simple carbohydrates (“bad carbs”):
• Quinoa • Oatmeal • Popcorn • Black beans • Chickpeas • Edamame • Apples • Bananas • Carrots • Sweet potatoes • Green leafy vegetables	• Brown rice • Skim milk • Multi-grain bread • Yogurt, low-fat • Soy milk • Grapefruit • Prunes • Pears • Strawberries • Oranges • Yams • Potatoes	• Candy • Sugary drinks including soda • Syrups • Table sugar • Fruit juice concentrate • Baked goods made with white flour • Most packaged cereals • Bread made with white flour • Pasta made with white flour

The foods listed below are usually low in sodium:	The foods listed below are usually high in sodium and should be avoided or used sparingly:
• Most fresh fruits and vegetables (1 serving, 0–20mg of sodium) • Breads: white, whole grain (1 serving, 120–140mg of sodium) • Cereals: cooked; granola, puffed rice, puffed wheat, shredded wheat, oatmeal • Crackers: graham, low salt, melba toast • Pasta: macaroni, noodles, spaghetti, rice (20mg to 140mg of sodium) • Unsalted butter, margarine, oil • Yellow mustard, spices, herbs, sugar, syrup • Cheese: cream cheese, Monterey Jack, mozzarella, ricotta • Cream: half & half, sour, whipping • Vanilla ice cream, sherbet, yogurt • Milk (please read labels) • Non-dairy creamer • Frozen fruits and vegetables without sauces • Canned vegetables: low sodium or rinsed • Meats, fish, and poultry, unprocessed (75mg to 120mg of sodium per serving) • Eggs (1 egg, boiled, 60mg) • Unsalted peanut butter, 2 tablespoons (10mg) • Tuna: low sodium or canned that you rinse • Snacks: Nuts, 1oz, mixed, unsalted; unsalted popcorn, 1 cup (0 to 65mg of sodium)	• Canned soups and dry soup mixes (½ to 1 cup, 890mg to 915mg of sodium) • Canned meats and fish • Ham, 3.5oz; bacon, 2 slices; and sausage (290mg to 1500mg of sodium) • Processed meats, such as deli items and hot dogs (290mg to 1500mg of sodium) • Salted butter and margarine • Salted peanut butter, 2 tablespoons (150mg sodium) • Salted snack foods, such as nuts, pretzels, and chips • Foods soaked in brine like pickles, olives, feta cheese, and sauerkraut • Prepackaged frozen dinners over 400mg per serving • Condiments, especially soy sauce (1 tablespoon 1230mg of sodium) • Others include salad dressings, sauces, dips, ketchup, and Dijon mustard • Any seasonings that taste salty, including bouillon cubes, meat tenderizer, seasoned salts, tamari, and Worcestershire sauce • Canned vegetables and frozen vegetables that have seasoning packs included for flavoring • Seasoning mixes (tacos, chili, rice, gravies, etc.) • Fast food (hamburger 475mg to 1000mg of sodium) • Salt (1 teaspoon, 2400mg of sodium) • Ramen noodle soup (1 package, 830mg to 1300mg of sodium)

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Important Notes

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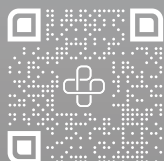
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