## PATIENT'S GUIDE TO LUNG CANCER

## #HOPEUNITES



LUNG CANCER CANADA 14.11

# ABOUT THIS GUIDE

This Patient Guide was written and produced in its entirety by Lung Cancer Canada to meet the information needs of patients and caregivers. It is up-to-date and represents current practices in Canada.

This guide is not intended to replace medical information or advice offered by your doctor. Questions or concerns should be addressed with members of your cancer care team.

## ACKNOWLEDGEMENTS

We would like to thank the following people for their involvement in the development of this Patient Guide:

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# #HOPEUNITES

# FOREWORD

Any cancer diagnosis can leave you and your loved ones reeling—there is shock, anxiety, and a sense of helplessness and urgency. The diagnosis has far reaching effects on the patient, their friends, and their family. We hope that this guide will help you navigate your way through this challenging time.

We have both been exactly where you are now and know all too well the myriad of emotions you are experiencing. We have been living with lung cancer for many years—8 years for Anne Marie and 13 years for Roz—and we are here to tell you that there is life after a lung cancer diagnosis!

We were very glad to be asked once again to write the foreword to this guide. The fact that a new version was needed is indicative of the progress being made in the fight against lung cancer. The promising advances in targeted therapies and immunotherapy continue to bring hope to many.

Lung cancer can happen to anyone, whether they smoked or not. Lung cancer does not discriminate by age or gender—the truth is if you have lungs, you can get lung cancer. Lung cancer patients face the added burden of stigma due to its association with smoking. Smoking is not only a major cause of lung cancer, but also a powerful addiction that, over time, causes a variety of other health issues. Irrespective of whether a person smoked or not, all patients with lung cancer deserve the best of care, treatment, support, and compassion.

So, what do you do now? Reading this guide is a great start, and we hope it will answer many of the questions that you must have. What causes lung cancer? What are the types and stages of the disease? How is it diagnosed? What are the treatment options? The information in this guide can help you understand how to become an active participant in caring for yourself or your loved one.

Lung cancer can affect every aspect of your life. Help is available—remember to seek assistance from the appropriate professionals should you need it. Lung Cancer Canada is here for you too.

## Stay strong, keep fighting, and – most importantly – be kind to yourself.

 Anne Marie Cerato, Toronto, Ontario Roz Brodsky, Thornhill, Ontario



# OVERVIEW OF LUNG CANCER

## THE LUNGS

The lungs are a pair of spongy organs in the chest and are separated from each other by the heart. The lungs are divided into lobes<sup>1</sup>. The right lung has an upper, a middle, and a lower lobe; and the left lung only has upper and lower lobes.

When you breathe in, air flows past your nose and larynx (or voice box) and into the trachea (or windpipe). Just before it reaches the lungs, the trachea divides into two smaller airways called the bronchi, one bronchus for each lung. These airways divide further and further into smaller tubes called bronchioles, which end in the alveoli. The alveoli are microscopic air sacs where oxygen from inhaled air enters the blood; and carbon dioxide leaves the blood and is eventually exhaled.

Each lung is enclosed and protected by the pleura—two layers of thin pleural membrane. The pleural space between these two layers contains a small amount of pleural fluid to lubricate the membranes so they can slide easily over each other when you breathe. Below the lungs is the diaphragm, a thin sheet of muscle that helps you breathe.

## TAKE CARE OF YOURSELF

**Be good to your body.** Eat a healthy diet and get enough rest. If you feel unwell, talk to your healthcare team to receive help for your symptoms.

<sup>1</sup> The terms in **green** are defined in the glossary at the end of this guide.

#### LUNG ANATOMY



## LUNG CANCER

Cells are the building blocks that make up the tissues and organs. Normally, before a cell dies, it makes a new cell to take its place. However, sometimes a cell becomes abnormal and makes many copies of itself. These copies pile up and form a tumour, a lump of abnormal cells. They mimic healthy cells in the body to evade the body's natural defences.

Benign tumours, like moles and warts, cannot invade their surrounding tissue or spread to other locations in the body.

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Malignant tumours are cancerous. They continue to grow and invade the surrounding tissue. Sometimes cancer cells break away from the tumour and travel to other organs via blood or lymph vessels. This process is called **metastasis**. Cancer can metastasize to any part of the body; however, cancerous cells from a lung tumour commonly spread to the other lung, lymph nodes, adrenal glands (which are located on top of each kidney), bones, brain, and liver.

Cancers are named after the site in which they first develop — in the case of lung cancer, the **primary tumour** is in the lung. Even when lung cancer spreads to other parts of the body, the diagnosis remains lung cancer; and the cancer that has spread is called a **secondary tumour** or **metastatic lung cancer**. Similarly, if cancer from elsewhere spreads to the lungs, it is not referred to as lung cancer, but as *lung metastases* from the primary site.

#### **CANCER GROWTH AND METASTASIS**



OVERVIEW OF LUNG CANCER

## LYMPH NODES

**Lymph nodes** are small, bean-shaped structures located throughout your body that are part of the lymphatic system. The lymphatic system is a network of organs, vessels, and lymph nodes that helps circulate body fluids, and defends the body against microbes and abnormal cells.

When there is an infection, injury, or cancer in a part of the body, the lymph nodes in that area get bigger. For example, when you have a cold or a sore throat, the lymph nodes in your neck get swollen. If you visited a doctor with these symptoms, they may have felt your neck to check for these enlarged lymph nodes.

Cancer cells from a malignant tumour will sometimes break away and travel through blood or lymph vessels. The cancer cells can lodge themselves in nearby lymph nodes, which normally filter out microbes and abnormal cells. There, they will grow and divide to form a new tumour, which may shed more cancerous cells that can then spread further in the body.

The spread of cancer to the lymph nodes is an important factor in determining the extent or **stage** of that cancer. The number of affected lymph nodes, the amount of cancer in them, and how far they are from the primary tumour are all considered when your doctor creates your treatment plan.

## IF YOU HAVE LUNGS, YOU CAN GET LUNG CANCER

Lung cancer is one of the most commonly diagnosed cancers—approximately 1 in 13 Canadians are expected to be diagnosed during their lifetime. Lung cancer is also the most likely cause of cancer-related death among men (1 in 14 chance) and women (1 in 17 chance).

Responsible for the deaths of approximately 1 in 4 Canadians with cancer, lung cancer is the leading cause of cancer-related death. The disease takes more lives than the next top three cancers (breast, prostate and colorectal) combined.

### **CAUSES OF LUNG CANCER**

During a lifetime, the human body is exposed to many things—including radiation, and certain chemicals and infections—that can damage its cells. This sort of damage increases the likelihood that cells will grow and divide out of control to form a tumour.

The immune system, which gets rid of abnormal cells, becomes less efficient as people grow older. Over the years, little bits of wear and tear that did not cause a problem at first can add up. This is one reason that the odds of getting cancer of any kind increases with age. Some people may also be genetically predisposed, so that their cells are more susceptible to damage.

#### Smoking

The majority of lung cancer cases—about 85%—are directly related to smoking tobacco, particularly cigarettes. Tobacco smoke contains **carcinogens**, which are toxic, cancer-causing chemicals that promote cell damage over time. This is why the risk of lung cancer increases with the number of years and the number of cigarettes a person has smoked. Inhaling smoke also destroys the defence system that keeps harmful substances out of the lungs.

## TAKE CARE OF YOURSELF

**If you currently smoke, stop.** Smoking hurts your body's ability to heal. Your risk of developing complications from your treatment, especially when it includes surgery, is much higher if you continue to smoke.

Your healthcare team can put you in touch with many resources and support systems to help you stop smoking. It is never too late to quit.

Find the resources to help you quit at www.lungcancercanada.ca/Lung-Cancer/Smoking-Cessation.aspx.

#### **Second-Hand Smoke**

Second-hand smoke contains the same harmful chemicals that a smoker breathes in. Exposure to tobacco smoke from other people's cigarettes, pipes, or cigars is a major cause of lung cancer in non-smokers.

#### Radon

Radon, a colourless, odourless radioactive gas, is the leading cause of lung cancer after first- and second-hand cigarette smoke. This gas seeps out of the earth's crust, and can build up in poorly ventilated enclosed spaces and reach unsafe levels. When breathed in, radiation from the gas damages the DNA of cells in the lungs.

If you are concerned about radon, you can purchase a kit or hire a professional to test the radon levels in your home. More information is available at **www.canada.ca/en/health-canada/services/radon/testing-your-home-radon.html.** 

#### Personal History of Cancer or Other Lung Disease

Lung cancer is more common in people who have been previously diagnosed with cancers of the mouth or throat. Damage from previous lung diseases or conditions—for example, chronic obstructive pulmonary disease (COPD, which involves emphysema and chronic bronchitis), pneumonia, and tuberculosis—also increase the risk of lung cancer.

#### **Family History**

Cancer cells contain **mutations** (that is, genetic changes) that make them behave abnormally. Some mutations can be passed down from parent to child. So people who have a family history of lung cancer may be predisposed to developing cancer themselves. This increase could also be the result of shared behaviours (for example, smoking) or a shared environment that exposes them to carcinogens.

#### **Pollutants in the Environment**

Exposure to certain pollutants and chemicals at home, in the workplace, and in the environment can increase the risk of lung cancer. Air pollution from motor vehicles, factories, and power plants contain microscopic particles, nitrogen oxides, diesel exhaust, benzene, and polycyclic aromatic hydrocarbons. Some people are exposed to asbestos, chromium, nickel, silica, and arsenic at their workplace. Other chemicals known to contribute to lung cancer risk include bis(chloromethyl) ether, vinyl chloride, uranium, and coal tar products.

## LUNG CANCER SCREENING

Screening or checking for a disease when there are no symptoms often provides a greater chance of catching the disease early and at a curable stage. Lung cancer screening using low-dose CT (LDCT) scans can prevent as much as 20% of deaths from cancer.

Many provinces have programs or ongoing trials for lung cancer screening. Participants are selected based on various factors, including their risk for lung cancer, age, and history of smoking. These programs may also offer help with quitting smoking.

For those in provinces that do not yet have a screening program, doctors do not recommend self-directed LDCT screening.

## SIGNS AND SYMPTOMS OF LUNG CANCER

Early stages of lung cancer often do not produce any signs or symptoms. As the disease progresses, the signs and symptoms mentioned below may occur; however, they can also be caused by other conditions or diseases.

#### **Common Symptoms**

- Pain in the chest, shoulder, back, or arms
- Recurrent lung infection (pneumonia or bronchitis)
- Worsening or persistent cough that lasts for three or more weeks
- Fatigue
- Shortness of breath
- Coughing up blood
- Hoarseness or changing voice
- Loss of appetite or unexplained weight loss

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#### **Less Common Symptoms**

- Wheezing
- Swelling in the face or neck
- Blood clots
- Weakness or dizziness
- Bone pain or fractures
- Painful lumps (swollen lymph nodes) in the neck or near the collarbone

If you have any of these signs or symptoms, do get them checked by your healthcare provider.

## THE STIGMA OF LUNG CANCER

Although smoking causes most lung cancers, about half of those diagnosed have either never smoked or quit smoking years ago. Even among lifelong never-smokers, lung cancer occurs at high rates and is among the leading causes of cancer-related death. Among East and South Asian women diagnosed with lung cancer, between 60% and 80% have never smoked. Widespread prejudice about smoking adds stigma to the already heavy burden of a lung cancer diagnosis.

The stigma associated with lung cancer can be isolating. It can make you hesitate to tell others about your diagnosis and ask for support.

If you feel this way, it's important to remember that *anyone* with lungs can get lung cancer. No matter what, *no one deserves it*. And you deserve compassion, treatment, and support. Do not let the stigma stop you from fighting your cancer!

# A MULTIDISCIPLINARY

Your treatment team will be made up of many specialized healthcare professionals. They will help you and your family through your cancer diagnosis and treatment. Some of their roles are described below.

Keep an open dialogue with your treatment team. You will find tips and advice on this in Chapter 12. Let them know how you feel physically and emotionally. Ask them any questions that come up. They are here for *you*!

**Anesthesiologist** — A specialist in anesthetics, drugs that prevent pain and cause temporary unconsciousness during surgical operations.

**Chemotherapy nurse** — A nurse who specializes in administering chemotherapy and other treatments, and manages their side effects.

**Clinical psychologist** — A specialist in mental health. They can help you and your family understand and cope with feelings and emotions that arise during your cancer diagnosis and treatment. They can provide guidance on how to manage pain, anxiety, stress, depression, and many other problems.

**Clinical trial nurse** or **Research nurse** — Provides nursing care in clinical trials.

**Community care nurse** — A nurse who can visit you at home to care for you and help you with daily activities.

**Family doctor** — A general practitioner who provides primary care. They may have referred you to an oncologist or suggested tests that led to your cancer diagnosis.

**Medical oncologist** — A specialist in cancer diagnosis and treatment. They will oversee your cancer treatment and may become your de facto primary caregiver during your cancer treatment.

**Nurse navigator** — Provides information and support, and guides you through aspects of your diagnosis and treatment, like finding financial resources to pay for certain treatment-related costs.

**Palliative care specialist** — A doctor who helps relieve uncomfortable symptoms of cancer and side effects of treatment, such as pain and fatigue, in order to improve your quality of life.

# TREATMENT TEAM

**Pathologist** — A doctor who analyzes tissue samples to diagnose diseases and evaluate important features. The information they provide helps guide treatment of the disease.

**Pharmacist** — A healthcare professional who can guide you on the proper use of medications and managing their side effects, and ensure that your medications will not interact in a harmful way.

**Physiotherapist** — Helps you with rehabilitation after treatment. They can teach you exercises to rebuild and maintain your strength, endurance, and mobility.

**Pulmonologist** or **Respirologist** — Specializes in diagnosing diseases of the lung, usually with a bronchoscope or by taking a sample of fluid from the chest cavity. They also perform procedures to relieve shortness of breath—for example, by placing tubes to drain fluid that has collected in the chest.

**Radiation oncologist** — Specializes in cancer treatment with radiation therapy, and diagnoses cancer with imaging tests like x-rays and CT scans.

**Radiologist** — Specializes in diagnosing diseases with imaging techniques like ultrasound, x-rays, and CT scans. They can assist in surgical operations by guiding surgical tools with imaging techniques.

**Registered dietitian** — A licensed professional who can help you meet your nutritional needs and develop a specific nutrition plan for you.

**Social worker** — A licensed professional who assists you regarding supportive counselling and community resources.

**Surgeon** — Specializes in treatment and diagnosis of diseases with surgical operations. A thoracic surgeon specializes in diseases of the chest, especially the lungs, heart, trachea (windpipe), and esophagus (gullet).

**You** — Although the healthcare providers mentioned above are experts in their field, *you* are the expert on how you feel and know what is important to you. Never hesitate to ask your healthcare team questions. You can also ask them to provide copies of your medical records.



# DIAGNOSIS AND STAGING

If you have any signs and symptoms of lung cancer, your doctor will suggest some tests to learn more about these issues and find their cause. You may have already had an x-ray done and been referred to a lung specialist. Or, doctors may have found an abnormal spot or nodule in your lung because you were identified as having a high risk for lung cancer and are part of a screening program.

Your doctor will explain to you which tests you will undergo and why they are needed. It is normal to feel frustrated during the process or worried about what the tests might reveal. But it is important not to assume the worst. Your doctor is simply trying to determine the reason for your symptoms or rule out certain causes.

## EARLY DIAGNOSIS: NOT A TYPICAL LUNG CANCER CANDIDATE

Almost seven years ago, a CT scan unexpectedly revealed a tiny shadow in my right lung. I was an active fifty-year-old, had quit smoking over twenty years earlier, and had no lung cancer symptoms. So my doctors suggested regular scans to watch for any changes. Two years later, I received the call saying that my shadow had grown. I learned later that it was stage IIIA (locally advanced) adenocarcinoma.

After the initial shock, I worked very hard to stay calm and positive. I reached out to others who had the disease through social media and found that I was not alone. Talking to others gave me strength. Still I worried about my family and whether I would survive. Some days were better than others. Now I realize that fear is not an overreaction; it is a reality of cancer.

A year, two surgeries, four rounds of chemotherapy, and twenty-five rounds of radiation later, my scans were clear. I still have lots of fearful days, especially around scan appointments. But I also know that the first scan, and the radiologist who noticed the tiny shadow, saved my life.

- Heather Hogan, Woodstock, New Brunswick

## **DIAGNOSTIC TESTS**

### **IMAGING TESTS**

As their name suggests, these tests take an image of the structures inside the body. Just like a photo camera uses light, these procedures use x-rays, sound waves, magnetic fields, or radioactive materials to create an image.

In addition to finding where the cancer might be, imaging tests are also used to monitor how the cancer responds to treatment and if it returns after treatment.

#### **Chest X-ray**

A chest x-ray is often the first test that is done when symptoms point towards lung cancer. It is a quick and painless procedure that takes a picture using a small amount of x-ray radiation.

If the image reveals anything abnormal, other tests will be done to follow up on the findings of the x-ray. When this happens, it is important not to jump to conclusions. Keep in mind that a spot or shadow on the x-ray film might not be cancerous. It may be benign, or an infection, or something else completely. Talk to your healthcare team if you are worried or have any questions about the follow-up tests.

#### **Computed Tomography (CT) Scan**

A CT scan also uses x-rays, but creates more detailed pictures than a traditional x-ray image. For example, CT scans can detect smaller, earlier-stage tumours, as well as whether cancer has spread to nearby lymph nodes or large blood vessels, or to the rib cage. A dye called contrast media is sometimes injected or given orally before the scan to better display certain structures inside the body.

During the scan, the camera rotates around the body and takes pictures of very thin sections of the body. A computer processes these cross-sectional images and can layer them to create a three-dimensional (3D) model. (This is often likened to arranging slices of bread to reveal the structure of the entire loaf.)

#### Positron Emission Tomography (PET) Scan

A PET scan is often combined with a CT scan (called a PET/CT scan). The CT scan shows a detailed view of the structures of the body and the PET scan highlights any abnormalities.

Before the PET scan, a small amount of a radioactive sugar solution is injected into a vein. Cancer cells, which grow and divide rapidly, use a lot of energy and take up more of this radioactive sugar compared to the rest of the body.

Then, like CT scans, a camera that detects radioactivity takes cross-sectional images of the body; and a computer creates 3D models from them. Areas of the body that contain cancer cells, and which have absorbed more of the radioactive sugar, show up as brighter spots.

#### Magnetic Resonance Imaging (MRI) Scan

MRI scans are like CT scans—they both take cross-sectional images that a computer can turn into 3D models. But, instead of x-rays, MRI uses magnetic fields and radio waves to produce an image.

MRIs are rarely used to see abnormalities in the lungs. Instead, their main purpose is to detect whether cancer has spread to the brain, spinal cord, nerves, or large blood vessels.

#### Ultrasound

Ultrasound uses high-frequency sound waves. The sound waves bounce off the structures inside the body and the pattern of echoes is processed by a computer to create images. Ultrasound can be used to detect the presence of excess fluid in and around the lungs, and to find out whether cancer has spread to the liver.

#### **Bone Scan**

Bone scans can detect whether lung cancer has spread to the bones. Your healthcare team may suggest a bone scan if you have bone pain or abnormal blood tests that indicate possible bone metastases.

First, a small amount of radioactive material, known as a tracer, is injected into a vein. Large amounts of the tracer are absorbed by areas of bone that are actively growing or being repaired—for example, as a result of damage from cancer. These active areas show up as hot spots on the bone scan image.

## TAKE CARE OF YOURSELF

**Let people know.** If you feel alone, telling others about your cancer diagnosis can help. Sharing news of your diagnosis will get you support from friends and family, and reduce gossip.



### **BIOPSY PROCEDURES**

The results of imaging tests will help your healthcare team choose which sites in the body should undergo **biopsy**. Also known as tissue diagnosis or pathology diagnosis, biopsy is the process of removing small amounts of tissue or fluid for laboratory testing to confirm whether cancer cells are present. It helps doctors make a more accurate cancer diagnosis. The results of the biopsy are recorded in a pathology report.

#### **Needle Biopsy**

Needle biopsies are carried out under **local anesthetic** and do not need surgical incisions. Imaging techniques, such as ultrasound or CT scan, are often used to help guide the needle.

During a **core needle biopsy**, the doctor inserts a hollow needle into the tumour and removes a long, thin piece of tissue called a core. Several cores may be taken. For **fine needle aspiration**, the doctor uses a very thin needle to remove a small amount of tissue or fluid.

#### **Thoracentesis**

A small amount of fluid between the double-layered pleural membrane that encloses each lung helps with normal breathing. However, the pleural space between the two layers can sometimes fill up with excess fluid in a condition called **pleural effusion**. The excess fluid pushes on the lungs and makes it hard to breathe.

In such cases, **thoracentesis** is done to remove all the excess fluid and treat this condition. After applying a local anesthetic, a needle is inserted into the pleural space through the chest wall (usually from the back and between the ribs). The fluid is removed and checked for the presence of cancer cells.

## **ENDOSCOPIC PROCEDURES**

Endoscopes are devices that allow doctors to see inside the body. Most endoscopes are long, thin tubes with a camera and a light at one end. There is also an open channel through which medical tools, such as forceps and brushes, can be inserted to obtain biopsy samples or perform other surgical procedures. Endoscopes are named after the part of the body they are used to look at—for example, a *bronchoscope* is used to look for tumours or other abnormalities in the *bronchi* and other large airways such as the trachea.

#### **Bronchoscopy**

A bronchoscope can be inserted through the nose or the mouth. Usually a flexible bronchoscope is used, along with local anesthetic for the throat and upper airways and drugs to encourage relaxation and suppress coughing. If a rigid bronchoscope is used, **general anesthetic** will be administered.

For an endobronchial ultrasound (EBUS), the bronchoscope is equipped with a device that emits ultrasound waves. The resulting images help to locate abnormalities in the airways, lung tissue, and nearby lymph nodes. Then, doctors can collect tissue samples from these areas by using EBUS to guide their tools.

Bronchoscopy is also used to perform surgical procedures, known as endobronchial therapies, to clear airway blockages and alleviate symptoms. Tumours can be removed with cutting tools (bronchial debridement), lasers (laser surgery), electric currents (electrocoagulation), or light-sensitive chemicals (photodynamic therapy); or by freezing them (cryosurgery). The doctor can also place stents to keep airways open.

#### Mediastinoscopy

The **mediastinum** is the space between the lungs. It contains the heart, large blood vessels, trachea, esophagus, lymph nodes, and other structures and tissues. General anesthetic is used during a mediastinoscopy. Then, a mediastinoscope is inserted through a small cut at the base of the neck above the breastbone. The device is used to take a sample from the lymph nodes located in the mediastinum.

**Mediastinotomy** is similar to mediastinoscopy, but the endoscope is inserted through a larger incision (about 4 cm long) between the ribs. This lets the doctor reach lymph nodes that cannot be reached by mediastinoscopy.

#### Thoracoscopy

The **thorax** is the medical term for the chest. Thoracoscopy is carried out to examine the chest cavity—the spaces between the lungs and the chest wall, the tissue lining the cavity and lungs, the ribcage, and the diaphragm. Also known as pleuroscopy, this procedure is usually done under local anesthetic.

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In a similar procedure, known as video-assisted thoracic surgery (VATS), the thoracoscope is equipped with a video camera. This device is inserted through a small cut in the side of the chest wall between the ribs; sometimes more than one cut is made to insert other tools. With this device, the surgeon can take samples of lymph nodes and lung tissue, and even remove tumours located near the surface and outer edges of the lungs.

A **thoracotomy** is an incision of the chest wall that is larger than those made during a thoracoscopy or VATS. The larger incision lets the doctor reach areas within the chest cavity that cannot be reached by a thoracoscope.

#### Sputum Cytology

A sputum cytology test is used to detect the presence of cancer cells in the large airways. Lung cancer cells that are shed into the airways can mix with the mucus (sputum) located there. Sputum samples are collected during bronchoscopy by suction or washing the airways with sterile saline solution, or by coughing up sputum (sometimes after breathing in a saline mist).

### **EVALUATION OF TISSUE SAMPLES**

Tissue samples obtained during biopsy and endoscopic procedures are sent to a laboratory where a pathologist will examine them. If they find cancer cells in the sample, they will further examine the cells to determine the type of cancer and how aggressive the cancer is. The information provided by the pathologist is very important for diagnosing the cancer and eventually creating the right treatment plan.

If the tissue sample is too small or was taken from an area that does not represent the entire tumour well, the pathologist may not be able to do all the necessary tests. In these situations, another biopsy may be done.

## LIQUID BIOPSY

Liquid biopsy is a non-invasive way to obtain samples of your cancer cells. With this technique, the pathologist only needs a sample of your blood, pleural fluid, or urine to detect whether you have cancer, and even the mutations that your cancer cells may have.

Liquid biopsies are mainly used in clinical studies, and are available at a few locations in Canada. Ask your doctor if liquid biopsy is an option for you.

#### **Molecular Testing**

All cancer cells have mutations (abnormal genetic changes) that allow them to grow and divide uncontrollably and spread to other parts of the body. Researchers have discovered certain genetic changes that contribute to faster growth and spread of cancer, and have developed a handful of treatments to specifically target some of them.

It is quite commonplace these days for tissue samples to undergo molecular testing to find out whether someone's cancer has one of the genetic changes for which treatments exist. Depending on other features of the lung cancer, tissue samples may be tested for genetic changes such as EGFR mutations, KRAS mutations, and ALK fusions.

Another common test looks for the presence of a molecule called PD-L1 on the surface of cancer cells. PD-L1 plays an important role in the immune system fighting cancer. Chapter 6 discusses the treatments that target PD-L1 and genetic mutations in further detail.

If your doctor has not already discussed molecular testing with you, be sure to ask them if your biopsy sample should be tested once lung cancer has been confirmed.

### GETTING ACCESS TO DIAGNOSTIC TESTS

Some tests, especially the newer molecular tests, may not be available in your area. However, it may be possible to send your samples to another laboratory in Canada that runs the tests you need. You can also ask your doctor about getting tests done through clinical trials.

Your doctor may also suggest out-of-country testing. In such cases, be sure to have your doctor fill out the paperwork that you will need to get reimbursed, if possible, for these tests.

## **BLOOD TESTS**

#### **Complete Blood Count (CBC)**

This test measures the number and quality of cells in the blood (for example, **red blood cells, white blood cells**, and **platelets**), as well as other things like **hemoglobin** levels. A CBC provides information about a person's general health and any underlying medical conditions (for example, **anemia**, clotting problems, or infections) before they start treatment for cancer.

Regular CBC tests may be necessary once treatment starts if the treatment is known to affect the formation of blood cells in the **bone marrow**.

#### **Blood Chemistry Tests**

These tests measure the levels of chemicals in the blood that originate from the bones, liver, kidneys, and other organs. Abnormal levels can indicate problems with the organs, or whether cancer has spread to the bones or liver. Blood chemistry tests help your doctor choose the most appropriate treatment and tailor it for you.

## LUNG FUNCTION TESTS

#### **Pulmonary Function Tests (PFTs)**

PFTs are used to determine how well the lungs work—how much air they can hold and how well you can let air out of the lungs. PFTs will inform decisions about whether surgery is a good treatment option. If the lungs are functioning well, the doctor may consider removing a part of them to take out a tumour. The results of the PFTs will also determine how much of the lung can be safely removed.

#### **Arterial Blood Gas**

This test is used to measure the amount of oxygen and carbon dioxide in the blood. It indicates how well the lungs are working to put oxygen into and remove carbon dioxide from the blood.

Usually, blood tests involve taking blood from a vein—blood vessels in which blood flows slowly and does not contain much oxygen. But, for this test, blood from an artery is taken. This arterial blood has just passed through the lungs and brings fresh oxygen to the organs and tissues.

## QUESTIONS TO ASK YOUR CANCER CARE TEAM DURING DIAGNOSIS

- What type of lung cancer do I have?
- Was my cancer confirmed by tissue diagnosis (that is, from a tissue biopsy) or cytology diagnosis (that is, from fluid samples or samples obtained by brushing or washing)?
- What is the stage of my lung cancer? Where in my body is the cancer located?
- Based on my diagnosis, am I a candidate for surgery?
- Do I need any more tests before making the treatment plan?
- Has a sample of my tumour been sent for molecular testing? Am I a candidate for targeted therapy?
- Has a sample of my tumour been sent for PD-L1 testing? Am I a candidate for immunotherapy?
- Is there anything I can do, such as changing my diet, exercising, or managing stress, to help prepare for treatment?
- Where can I find help with quitting smoking?
- What symptoms should I expect with this type of cancer? What can I do to manage them?
- What should I do if my symptoms get worse or if I develop new symptoms?
- Is this type of cancer hereditary? Is my family at risk?

## AT THIS POINT IN YOUR CANCER JOURNEY...

Your mind is racing with questions. Why did this happen? What will happen to me? What do I do next? What can I expect? How do I cope?

Take a moment and remember you are not alone in this. There is a lot of support available, and you should ask for it. Do not isolate yourself. Talk to your friends and family. Ask your healthcare team to put you in touch with professionals and support groups that can help you find effective coping strategies.

Lung Cancer Canada's Peer Network can connect you to peers who have experienced lung cancer. Peers can provide support, and share insights and experiences from their own lung cancer journey. Go to www.lungcancercanada.ca/Get-Involved/Peer-To-Peer.aspx.

## TYPES AND STAGES OF LUNG CANCER

Identifying the type of lung cancer is essential to developing a treatment plan. The two most common types of lung cancer are non-small cell lung cancer and small cell lung cancer. The words *small* and *non-small* refer to the size of the cells found in the tumour and not the size of the tumour itself.

**Non-small cell lung cancer (NSCLC)** is the most common type of lung cancer around 80% to 85% of all cases. There are three main subtypes of NSCLC.

- Adenocarcinoma usually starts in mucus-producing glands and is often found in the outer edges of the lungs. It is the most common form of lung cancer in general, as well as in women and non-smokers. Adenocarcinomas may result from known genetic changes that can be treated with targeted therapy.
- Squamous cell carcinoma (SCC) usually develops in cells lining the bronchi and larger bronchioles, and is often found in the central areas of the lung. SCC is quite common in smokers. Men are more likely to develop squamous cell carcinoma than women.
- Large cell carcinoma (LCC) can occur anywhere in the lungs but is usually found near the surface and outer edges of the lungs. LCC is the fastest growing subtype of NSCLC and may grow to a very large size before causing any symptoms.

Adenocarcinoma and LCC are often referred to as *non-squamous lung cancer* or *non-squamous NSCLC*.

**Small cell lung cancer (SCLC)** accounts for about 15% of all lung cancers. These cancers usually develop near the centre of the lungs in the bronchi, and invade nearby tissues and lymph nodes. SCLC is also referred to as *oat cell carcinoma* because the cancer cells look flat under a microscope.

SCLC behaves quite differently from NSCLC and is more aggressive. The cancer cells divide more rapidly to form large tumours that can spread throughout the body before being detected.

## OTHER TYPES OF CANCER AFFECTING THE LUNGS

**Soft-tissue sarcomas** in the lung are rare occurrences. They usually develop in the pleural membranes and grow very slowly.

**Carcinoid tumours** in the lung are rare, slow-growing tumours that arise from hormone-producing cells in the lining of the bronchi and bronchioles.

**Pleural mesothelioma** is a rare type of cancer that starts in the pleural membranes that envelope each lung. It is usually caused by exposure to asbestos. Although technically not a type of lung cancer, pleural mesothelioma is treated by the same specialists who treat lung cancer.

The subsequent chapters of this book discuss the treatment of NSCLC and SCLC. For more information on the other types of lung cancer, refer to:

- www.cancer.ca/en/cancer-information/cancer-type/see-all, and
- www.cancer.net/cancer-types

## TAKE CARE OF YOURSELF

**Indulge yourself**. What do you enjoy doing? What leisure activities and distractions have you previously found helpful during stressful times?

## STAGES OF LUNG CANCER

In addition to the type of lung cancer and its location, the stage of a lung cancer also informs treatment decisions and prognosis. Stage indicates how big the tumour is, where it is located within the lung, whether it has invaded tissue outside of the lungs, and whether it has spread to other sites in your body.

#### Non-Small Cell Lung Cancer

The stages of NSCLC are numbered from 0 (zero) to IV (four), from least to most advanced. The stage is determined with **TNM** scores.

T indicates the size of the tumour.

**N** indicates whether the cancer has spread to the lymph **n**odes and how far.

M indicates whether the cancer has spread or metastasized to other organs.

The table on the next page provides a description of the different stages defined by TNM scores. It is a complicated system, and combinations of different TNM scores can be grouped into the same stage. You can discuss the specific stage of your cancer with your healthcare team and ask them any questions you have.

Each type of cancer has its own TNM staging classification; for example, the TNM staging system for breast cancer is much different from the system for lung cancer.

#### Small Cell Lung Cancer

SCLC may be defined with TNM scores or as limited-stage or extensive-stage. Limited-stage SCLC is usually found in only one lung, and may also be found in the lymph nodes in the chest and those near the collarbones. In extensivestage SCLC, the cancer has spread to both lungs, or to distant lymph nodes and organs.

## **GRADES OF CANCER CELLS**

The **grade** of a tumour is another feature of the cancer that helps guide your cancer treatment. Grade describes how different the cancer cells look compared to normal lung cells. It also gives doctors an idea about how fast the cancer cells grow and how aggressive the cancer is. More normal-looking cancer cells have a lower grade and are easier to treat, whereas cells from a more aggressive cancer have a higher grade.

#### Different Stages of Lung Cancer and Their TNM Scores

Occult carcinoma		
Tx <sup>1</sup> ; N0; M0	Cancer cells, but no tumour, found in the lungs. The cancer has not spread to the lymph nodes or other locations.	
Carcinoma in situ		
Stage 0 Tis <sup>2</sup> ; N0; M0	Cancer cells found in the lining of the bronchi, but they have not invaded surrounding tissue. The cancer has not spread to the lymph nodes or other locations.	
Early-stage NSCLC		
<b>Stage IA</b> T1; N0; M0	The tumour is up to 3 cm in size, and contained within the lining of the lungs and chest cavity. The cancer has not spread to the lymph nodes or other locations.	

<b>Stage IB</b> T2a; N0; M0	The tumour is larger than 3 cm and up to 4 cm in size; or involves the bronchus of the same lung (but not the trachea); or it has invaded the lining of the chest cavity; or has blocked the airways causing a collapsed lung or inflammation. The cancer has not spread to the lymph podes or other locations
	nodes or other locations.
	The tumour is larger than 4 cm and up to 5 cm in size;

	The furnour is larger than 4 cm and up to 5 cm in size,
Stage IIA	or involves the bronchus of the same lung (but not the
	trachea); or it has invaded the lining of the chest cavity;
T2b; N0; M0	or has blocked the airways causing a collapsed lung or
	inflammation. The cancer has not spread to the lymph
	nodes or other locations.

 $^{\scriptscriptstyle 1}$  In occult carcinoma, no number is assigned to the T component as only cancer cells, and not a tumour, have been found.

<sup>2</sup> *Tis* stands for *tumour in situ*. *In situ*, in Latin, means *in its original position*.

Stage IIB T1 or T2; N1; M0, or	The tumour is no larger than 5 cm. The cancer may involve the bronchus of the same lung (but not the trachea); or may have invaded the lining of the chest cavity; or may have blocked the airways causing a collapsed lung or inflammation. The cancer has spread to nearby lymph nodes. But it has not spread to other locations; or
T3; N0; M0	The tumour is larger than 5 cm and up to 7 cm in size; or there is more than one tumour in the same lobe; or it has invaded the chest wall or its inner lining, the main nerve to the diaphragm (phrenic nerve), or the lining of the heart (parietal pericardium). The cancer has not spread to the lymph nodes or other locations.

Locally advanced NSCLC	
Stage IIIA T1 or T2; N2; M0, or	The tumour is no larger than 5 cm. The cancer may involve the bronchus of the same lung (but not the trachea); or may have invaded the lining of the chest cavity; or may have blocked the airways causing a collapsed lung or inflammation. The cancer has spread to lymph nodes near the centre of the chest. But it has not spread to other locations; or
T3; N1; M0, or	The tumour is larger than 5 cm and up to 7 cm in size; or there is more than one tumour in the same lobe; or it has invaded the chest wall or its inner lining, the main nerve to the diaphragm (phrenic nerve), or the lining of the heart (parietal pericardium). The cancer has spread to nearby lymph nodes. But it has not spread to other locations; or
T4; N0 or N1; M0	The tumour is larger than 7 cm; or there is more than one tumour in different lobes of the same lung; or it has invaded the diaphragm, mediastinum, heart or its large blood vessels, trachea, the main nerve to the voice box (recurrent laryngeal nerve), esophagus, or spine. The cancer may have spread to nearby lymph nodes. But it has not spread to other locations.

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Stage IIIB T1 or T2; N3; M0, or	The tumour is up to 5 cm in size. The cancer may involve the bronchus of the same lung (but not the trachea); or it may have invaded the lining of the chest cavity; or may have blocked the airways causing a collapsed lung or inflammation. The cancer has spread to lymph nodes near the other lung or to those near the collarbones. But it has not spread to other locations; or
T3 or T4; N2; M0	The tumour is larger than 5 cm; or there is more than one tumour in the same lung. The cancer may have invaded the chest wall or its inner lining, mediastinum, trachea, esophagus, spine, diaphragm, the main nerves to the diaphragm (phrenic nerve) or to the voice box (recurrent laryngeal nerve); the heart, its large blood vessels, or its lining (parietal pericardium). The cancer has spread to lymph nodes near the centre of the chest. But it has not spread to other locations.
Stage IIIC T3 or T4; N3; M0	The tumour is larger than 5 cm; or there is more than one tumour in the same lung. The cancer may have invaded the chest wall or its inner lining, mediastinum, trachea, esophagus, spine, diaphragm, the main nerves to the diaphragm (phrenic nerve) or to the voice box (recurrent laryngeal nerve); the heart, its large blood vessels, or its lining (parietal pericardium). The cancer has spread to lymph nodes near the other lung or to those near the collarbones. But it has not spread to other locations.

Metastatic NSCLC	
<b>Stage IVA</b> Any T; any N; M1a or M1b	The tumour is of any size. The cancer has spread to the other lung or to a single location outside the chest cavity—for example, the liver, adrenal glands, brain, or bones; or fluid containing cancer cells has collected around the lung (pleural effusion) or heart (pericardial effusion). The cancer may have invaded other tissues, structures, and lymph nodes in the chest.
Stage IVB Any T; any N; M1c	The tumour is of any size. The cancer has spread to multiple locations outside the chest cavity—for example, the liver, adrenal glands, brain, or bones. The cancer may have invaded other tissues, structures, and lymph nodes in the chest.

## WHAT ARE MY ODDS?

As soon as your diagnosis was made, you may have wondered about this.

You and your doctor will discuss your prognosis—this is your doctor's best estimate of how your cancer will respond to treatment. It is based on what we currently know about lung cancer and is influenced by the type of cancer; if and how much it has spread; your treatments and how you and the cancer respond to them; and other factors like your age, overall health and other medical conditions.

In discussing your prognosis, your doctor may refer to statistics like the fiveyear survival rate. This rate is derived from studies involving large numbers of cancer patients that measured the number of people who were alive and disease-free five years after their diagnosis.

The five-year survival rate gives us an idea of what may happen to most people with lung cancer. This statistic cannot predict accurately what will happen to you. Keep in mind that with the development of new and better treatments, survival rates continue to improve.



# TREATMENT OF LUNG CANCER

After the type, stage, and grade of your lung cancer have been determined, your healthcare team will develop a treatment plan. The kind of treatment you are offered will depend on several factors, including the type of lung cancer you have; its location, spread, and genetic changes; and the health of your lungs, as well as your overall health. This plan will be unique to you and specifically designed to achieve the best possible outcomes for your particular diagnosis.

Cancer treatments are categorized as either local or systemic. **Local treatments**, such as **surgery** and **radiation therapy**, can be directed at a specific part of the body. They are used when the cancer is limited to a certain area, like the lung. With surgery, the goal is to physically remove tumours and structures, like lymph nodes, to which cancer has spread. Radiation therapy directs high-energy radiation at the tumour to shrink or destroy it.

**Systemic treatments**, such as chemotherapy, targeted therapy, and immunotherapy, affect your entire body. They are often used when the cancer is found in several parts of the body or to reduce the chance of a **recurrence**—that is, the cancer coming back. **Chemotherapy** refers to several different drugs that can kill cancer cells or prevent them from growing and dividing. **Targeted therapy** takes advantage of genetic changes in the cancer cells to home in on them and disrupt essential processes. **Immunotherapy** stimulates the body's natural defence mechanisms so that they can better detect and fight cancer cells.

Many patients receive more than one type of treatment. For example, after the primary tumour in the lung has been surgically removed, chemotherapy may be used to kill any remaining and undetected cancer cells.

Talk to your doctor about what your treatments are meant to accomplish and any side effects you might have. Notify your treatment team as soon as possible if you experience any side effects. These can often be relieved with medications and other measures.

If the cancer is difficult to treat or keeps coming back, your doctor may talk to you about participating in a clinical trial for new, promising treatments that are currently

in development. You may also consider participating in a clinical trial to access a drug that has been shown to be efficacious but is currently not commercially available in Canada. This is entirely voluntary and you should rest assured that your treatment will not be compromised if you choose not to enter a clinical trial. Please refer to the section on clinical trials for more information.

The next section of this guide discusses in detail the treatments for NSCLC. It is followed by a section that summarizes the treatment of SCLC. Some of the treatments for these two types of lung cancer are similar. For further details on any SCLC treatment, please refer to the corresponding NSCLC section.

## WORDS COMMONLY USED TO DESCRIBE CANCER TREATMENTS

Curative therapy — Treatment given with the goal of curing cancer.

**Palliative therapy** — Treatment given with the goal of relieving the symptoms of cancer and improving quality of life. Palliative therapy can prolong life, but it cannot cure cancer.

**Primary therapy** — Initial treatment given with the intention to cure or prolong life.

**Neoadjuvant therapy** — Treatment given before primary therapy (usually chemotherapy before surgery) to shrink a tumour.

Adjuvant therapy — Treatment given after primary therapy (usually chemotherapy after surgery) to kill any remaining cancer cells that may not have been removed by surgery and to help prevent recurrence.

**First-line therapy** — Initial systemic treatment that has been determined to have the best probability of shrinking the cancer.

**Maintenance therapy** — Ongoing use of systemic treatment after first-line therapy to prevent a cancer from progressing (that is, from starting to grow again).

**Second-line therapy** — Systemic treatment that is given if the cancer has not responded to or has recurred after first-line therapy or maintenance therapy.

**Third-line therapy** — Systemic treatment that is given if the cancer has not responded to or has recurred after second-line therapy.

## TREATMENT OF NON-SMALL CELL LUNG CANCER

In the early stages of NSCLC, surgical removal of the tumour offers a potential cure. Treatment plans at this stage may also include radiation therapy and chemotherapy; these are given before or after surgery to make the operation easier or to prevent the cancer from coming back.

Treatment plans for advanced stages of cancer can also include a combination of chemotherapy, radiation therapy, and surgery; or, just one or two of these treatments may be used.

The treatment of metastatic cancers usually includes chemotherapy, radiation therapy, and, in select cases, targeted therapy and immunotherapy.

## SURGERY

The size and location of the tumour, how well the lungs and heart function, and your general health will dictate if surgery is possible and, if so, the type of surgery.

When surgery can be performed in early stages of cancer, it can potentially cure the cancer. More extensive operations (for example, removing the entire lobe rather than a smaller portion of the lobe with the tumour) may have a better chance of curing the cancer. Nearby lymph nodes or tissue samples may also be removed along with the lung tumour to more accurately determine the stage of the cancer.

In certain cases, treating the tumour with radiation or chemotherapy drugs before surgery can shrink it and make operating on it easier. After surgery, you may be given chemotherapy to kill any remaining cancer cells.

Surgery is used less frequently to treat locally advanced cancer, and rarely for metastatic cancers.
### **CHOOSING THE BEST PROCEDURE FOR YOU**

Lung tumours can be removed by several types of surgery. Your surgeon will choose the most appropriate type for you based on various factors, including the stage of your cancer, your pulmonary function tests (PFTs), and your general health. You may have already undergone some of these diagnostic tests to determine which areas and structures in your chest cavity contain cancer and should be removed. Your PFTs will provide information on how much of the lung could be safely removed to allow you to maintain a good quality of life. Other tests may be performed to further assess your tumour and check whether your heart and other organs will be able to withstand surgery.

### WHAT TO EXPECT

Most major lung cancer surgery uses a general anesthetic to put you to sleep. A specialist, called an anesthesiologist, will administer the anesthetic and monitor you during the operation. After the anesthetic takes effect, a breathing tube will be inserted down your throat to help you breathe. The surgeon will open the chest cavity with a thoracotomy, an incision into the side of the chest and between the ribs, and spread your ribs to gain access to the lung. Video-assisted thoracic surgery (VATS), which is described later in this chapter, is less invasive and requires only small incisions.

At the end of the surgery, the incision is closed. But one or more flexible chest tubes are left inside and may be held in place with stitches. The tubes will be connected to a canister and a machine to drain excess fluid and air from your chest cavity by suction. The tubes are removed when the fluid drainage and air leak stop and the lung can fully expand, usually after a few days.

Specially trained nurses, physiotherapists, respiratory therapists, and social workers will help care for you during your recovery. Once you are ready to leave the hospital, you will be given pain medication, instructions on how to care for your wound and how to modify your activities, and a follow-up appointment with your surgeon.

While you recover, participating in a pulmonary rehabilitation program or physiotherapy can improve your ability to breathe and perform daily activities. These programs are usually available through hospitals, but can also be found at public health units and recreation centres. Your doctor can give you a referral. Like any kind of major surgery, operations to remove lung tumours carry risks. These risks are related not only to the extent of the operation but also to your overall health. For example, smokers are at higher risk than non-smokers. So, if you currently smoke, you can lower your risk by quitting immediately. Age alone is not a major risk factor; but diseases of the heart, lung, and blood vessels are common in older people, and do increase the risks of surgery.

### TAKE CARE OF YOURSELF

**Accept help**. When someone offers help, accept it. Your friends and family are likely willing to help, but may not know specifically what you need or when. Let them know how they can help you.

### **TYPES OF SURGICAL OPERATIONS**

The procedures described below are carried out to remove lung tumours, as well as nearby lymph nodes. Other operations may be performed to confirm a diagnosis, or to relieve symptoms such as shortness of breath caused by an airway blockage or by fluid pressing on the lung.

A **wedge resection** or **segmentectomy** is the removal of a part of a lobe. This procedure is performed if the tumour is very small and has not spread, or if removing a larger portion of the lung is not advisable based on PFTs and other evaluations.

A **lobectomy** is the removal of a complete lobe of the lung. You might recall that the right lung has three lobes and the left lung has two. A **bilobectomy** is the removal of two of the three lobes of the right lung. If the tumour has grown close to the centre of the chest or affects all lobes of a lung, then a **pneumonectomy** (or pneumectomy) is done to remove the entire lung.

A **sleeve resection** removes a tumour from the large airways. If you think of the airway as a shirtsleeve with a spot on it, then this procedure removes the spot by cutting across the sleeve above and below the spot, and sews the cut ends back together. Because this procedure removes only an entire lobe and a part of the bronchus, it preserves more lung function compared to a pneumonectomy.

If the tumour has grown into the diaphragm or chest wall, some structures in the chest may be removed as a whole (or en bloc).

To ensure that all the cancer was removed, the surgeon will also remove some healthy-looking tissue around the edge of the tumour. A pathologist will examine these edges, or **margins**, to check if they contain any cancer cells. If there are clean, clear, or negative margins, usually no additional surgery is needed. If the margins are close or positive, then you may need more surgery.

#### Video-Assisted Thoracic Surgery

Removal of tumours by video-assisted thoracic (or thoracoscopic) surgery (VATS) is less invasive than a thoracotomy. There is usually less pain after the operation and a shorter recovery time.

VATS is performed under general anesthetic. The surgeon will insert a thoracoscope through a small incision in the chest wall (smaller than a thoracotomy incision). The thoracoscope has a video camera that lets the surgeon see inside the chest cavity. Sometimes multiple small incisions are made to insert other small surgical tools.

Lobectomies and segmentectomies, preferably for tumours growing near the surface and outer edges of the lung, can be performed with this technique.

### **Robotic-Assisted Thoracic Surgery**

Another minimally invasive surgical technique is robotic-assisted thoracic surgery (RATS). With this technique, the surgeon performs the operation by controlling robotic arms equipped with surgical tools.

Robotic surgery is commonly used to carry out lobectomies to treat stage I NSCLC. However, doctors may also use this technique to perform other types of chest surgery and treat more advanced cancers.

### SIDE EFFECTS OF SURGERY

After the operation, you will experience some side effects from general anesthesia and from surgery. Your treatment team will brief you on the potential side effects and what to look out for during your recovery.

Common side effects of anesthesia are a sore throat from the breathing tube, nausea, vomiting, confusion, muscle aches, and itchiness. Side effects of surgery include pain and swelling, which will be worse right after surgery and will lessen over the next few weeks. You will have scars from the incisions. Numbness near the surgical area may be long-lasting. Depending on your lung function prior to surgery, you may be short of breath during certain activities.

There is also a risk of complications such as pneumonia, wound infection, collapsed lung due to leakage of air into the chest cavity (called pneumothorax), excess bleeding, heart attack, irregular heartbeat, blood clots in the legs or lungs, inability to completely empty the bladder (known as urinary retention), and urinary tract infection.

### QUESTIONS TO ASK YOUR CANCER CARE TEAM ABOUT SURGERY

- Am I a good candidate for surgery?
- Will I be able to return to my normal life after surgery?
- How will surgery affect my breathing?
- What are the chances that surgery will remove all my cancer?
- Should I consider undergoing chemotherapy or radiation therapy either before or after surgery?
- What can I do to help prepare for surgery?
- What can I do to help my recovery after surgery?
- Can I join a respiratory rehabilitation or physiotherapy program to help with my recovery?
- Can I exercise after surgery? Should I?
- Am I eligible to participate in any clinical trials?

# **RADIATION THERAPY**

Radiation is the main treatment for early stages of cancer that cannot be surgically removed for reasons such as proximity of the tumour to vital organs, poor general health, or decreased lung or heart function. Chemotherapy may be used at the same time as radiation therapy or afterwards to kill any remaining cancer cells.

Radiation therapy uses high-energy beams of radiation to cause damage to the DNA of cancer cells. This sort of damage either kills the cells or keeps them from making new cancer cells.

Radiation can be used to treat tumours within the lung or in other parts of the body. It can be used before surgery to shrink your tumour and make operating on it easier, or after surgery to improve your chances of recovery by killing any cancer cells that might remain.

Your oncologist may also recommend radiation if you have other medical problems that make surgery too risky. Radiation treatment is also used palliatively to relieve symptoms, such as cough, shortness of breath, and bone pain.

Curative radiation treatments are delivered in small daily doses over five to six weeks. Occasionally, chemotherapy is given together with radiation to enhance its effect. Radiation used for symptom relief is usually given for a shorter time, between five or ten daily treatments.

Radiation can also harm some healthy tissue surrounding the tumour; but the treatments are given in such a way as to minimize this damage. Newer treatments are in development to reduce the damage even further.

## TAKE CARE OF YOURSELF

**Just say no**. Lung cancer and its treatments can make you feel exhausted. Try to conserve your energy by scaling back some of your activities.

### **EXTERNAL BEAM RADIATION THERAPY**

As its name suggests, **external beam radiation therapy (EBRT)** focuses a beam of radiation on the tumour from *outside* the body. EBRT is a painless procedure, and the treatment itself generally takes only a few minutes. It is like a chest x-ray but uses more powerful radiation.

It will, however, take a bit longer to set up the machine to aim the radiation directly at your tumour. Before you receive radiation therapy, you will have a **CT simulation**, a planning session in which the radiation oncologist designs your radiation treatment. Certain devices may be used to keep you in position and to ensure that the radiation hits the tumour. The doctor will also place some marks on your skin to help get you in the right position during radiation therapy.

You will receive radiation therapy within a few weeks of the simulation. During treatment, you will lie still on a table in the same way you did during simulation. You will be alone in the room during treatment but will be able to communicate with the radiation therapists, technicians who administer the radiation therapy.

#### **Stereotactic Body Radiation Therapy**

Stereotactic body radiation therapy (SBRT) is a specialized form of EBRT in which very large radiation doses are given in a short treatment time (one to eight treatments). It is also known as **stereotactic ablative radiotherapy (SABR)** or **radiosurgery**. This method can effectively control the tumour in most cases.

The advantage of SBRT is that the very high dose of radiation targets the tumour in such a way that areas surrounding the tumour receive much less radiation and, consequently, less damage is done to normal tissue. Since SBRT can be done over a very short time, it is usually very well tolerated.

SBRT is generally used to treat very small lung tumours that are too risky to remove by surgery because of other medical conditions that can complicate an operation. It can also be used to treat small tumours that have spread to the brain, lung, liver, or spine.

### BRACHYTHERAPY

In contrast to EBRT, **brachytherapy** or **endobronchial radiation** uses *internal* radiation. Brachytherapy is used to treat tumours that block the airways and cause problems like shortness of breath or coughing up blood (hemoptysis). It may also be done at the site of a tumour after it has been surgically removed. This will ensure that any remaining cancer cells not removed surgically are killed by radiation. In rare cases, brachytherapy may be used as primary treatment if EBRT cannot be done because of poor lung function.

The procedure is done using local anesthetic to the upper airways, and performed by a thoracic surgeon or respirologist, and a radiation oncologist. Using a bronchoscope, the doctor will place a catheter (a tiny, hollow tube) where the tumour is located. Then, the radiation oncologist will mark the precise spots to be treated after visualizing the tumour and catheter with an x-ray machine called a fluoroscope. The doctor will then insert radioactive seeds, which deliver an intense dose of radiation, into the catheter and place them near the tumour. In most cases, the radiation treatment is given for several minutes; then, the seeds are removed through the catheter. Less commonly, the seeds are left in the lung, and over time the radiation becomes weaker.

Since the radiation from brachytherapy is primarily aimed at the tumour and travels a short distance, the surrounding normal tissue can be spared from unnecessary, high doses of radiation.

### SIDE EFFECTS OF RADIATION THERAPY

After radiation therapy, you will experience some side effects. Your treatment team will brief you on the potential side effects and what to look out for during your recovery.

A potential side effect of radiation therapy is a sunburn-like irritation of the skin in the treatment area. Your skin will look red and can feel dry and painful. You may also have hair loss in the same area. Other side effects include fatigue, loss of appetite, nausea, pain while swallowing, cough, and shortness of breath. These side effects are usually short-lived and can often be lessened with medication.

Possible side effects of brachytherapy include infection, fever, cough, and shortness of breath due to inflammation or swelling of the airways.

In addition to these side effects, radiation therapy to the brain can also cause memory loss, headaches, vision changes, trouble thinking, difficulty hearing, confusion, and reduced sexual desire.

### QUESTIONS TO ASK YOUR CANCER CARE TEAM ABOUT RADIATION THERAPY

- What is the goal of this treatment?
- What are the key differences between radiation and chemotherapy?
- How long will my radiation treatments last?
- Is there anything I should do to prepare for treatment?
- Will I be able to return home by myself after treatment, or will I require assistance?
- Are there any side effects or complications I should watch out for after the procedure?
- Are there any medications that help with the side effects of radiation?
- Will I be able to return to my normal life after radiation?
- Is there anything I can do, such as changing my diet, exercising, or managing stress, to help cope during therapy or to help my recovery?
- Am I eligible to participate in any clinical trials?

# **CHEMOTHERAPY**

Chemotherapy is an option for all stages of NSCLC except for stage IA; and is often used in combination with localized therapies, such as surgery and radiation therapy.

In choosing the chemotherapy drugs that will be right for you, the doctor will consider how the chemotherapy will be used, and its place within the treatment plan and the stage of your cancer. For example, is the chemotherapy meant to assist surgery or radiation treatment? Or, is the chemotherapy the primary treatment for an advanced cancer? The type of NSCLC you have also determines the chemotherapy drugs you will receive. For example, the drug pemetrexed is less effective for squamous cell carcinoma.

### HOW DOES CHEMOTHERAPY WORK?

Chemotherapy refers to a group of drugs that disrupt the life cycle of cancer cells and keep new cancer cells from being made. They may damage the DNA or prevent the cells from making new DNA; or, they may interfere with other cellular processes involved in the creation of new cells.

To take advantage of the different ways in which these drugs exert their effect, chemotherapy is often given as a combination of two different drugs. A common combination, composed of a platinum-containing chemotherapy drug and a second chemotherapy drug, is known as a platinum **doublet**. Doublets are often referred to as the backbone of first-line therapy for NSCLC. The platinum-containing drug binds to the DNA of fast-growing cells (like cancer cells) in such a way that the DNA cannot be repaired or used to create new cells; eventually, the cells die from the damage to their DNA.

If combination treatment is not tolerable, or if the cancer does not respond to doublet chemotherapy or stops responding and gets worse, a different chemotherapy drug may be tried. These subsequent treatments are usually a single chemotherapy drug.

### TAKE CARE OF YOURSELF

**Set a schedule**. Use a calendar or planner to keep track of appointments, treatments, and other commitments. Make a list of priorities, and do only those things that must be done. Keep track of who is helping with what chore and when.

### WHAT CHEMOTHERAPY DRUGS ARE AVAILABLE?

Cisplatin or carboplatin are commonly used platinum-containing chemotherapy drugs.

Other drugs you may receive include vinorelbine, etoposide, gemcitabine, docetaxel, paclitaxel, and pemetrexed.

### WHAT TO EXPECT

You will usually receive chemotherapy in an outpatient clinic, meaning you will come in just for the day. Most chemotherapy drugs are given intravenously (injected into a vein), but a few are available as pills that are taken orally. With both methods, the chemotherapy drugs circulate throughout the body via the bloodstream to reach cancer cells, even if these cells are not visible on scans. For the duration of your treatment with chemotherapy, you will have regular blood tests, x-rays or scans, and check-ups to monitor your progress.

Chemotherapy is administered in cycles—there will be treatment days and rest days. Because chemotherapy is a systemic treatment, it does cause some damage to normal cells. The rest days will allow your normal cells, especially your blood cells, to recover.

### SIDE EFFECTS OF CHEMOTHERAPY

During and after chemotherapy, you may experience some side effects. The side effects you may experience will depend on the specific drug, how much of it you received, and for how long, as well as on your own general health. Side effects may be transient or long-lasting; immediate or slow to develop; mildly unpleasant or very serious. Many side effects can often be prevented or controlled with medication and other approaches. Before you start treatment, a member of your healthcare team will discuss the potential side effects with you.

Because chemotherapy attacks cells that are growing and dividing, they can also affect some healthy cells which tend to normally grow at a fast rate, like the cells in your hair, digestive tract, and blood. So you may temporarily lose your hair. You may also experience nausea, vomiting, loss of appetite, mouth sores, fatigue, and become prone to bruising.

One of the most serious side effects of chemotherapy is lower numbers of a type of white blood cell known as the neutrophil. Neutrophils are part of your body's natural defence mechanism, and low levels of these cells may increase your risk of developing an infection. If you develop a fever during your treatment, it is very important that you notify your healthcare team immediately. In some cases, your healthcare team may ask you to go to an emergency room if you develop a fever.

Some chemotherapy drugs can do damage to the kidneys, nerves, and your hearing. Some may cause permanent side effects such as premature menopause or infertility.

### QUESTIONS TO ASK YOUR CANCER CARE TEAM ABOUT CHEMOTHERAPY

- What is the goal of chemotherapy treatment? Will it cure my cancer or just slow it down?
- What are my treatment options?
- What drugs will I receive and how do they work?
- How long will my chemotherapy treatments last and how often will I receive treatment?
- Will I be able to return home by myself after treatment, or will I require assistance?
- What side effects might occur? How long will they last?
- What can I do to prevent or cope with side effects?
- Are any of the side effects permanent?
- Who can I contact if I develop any side effects?
- Are there medications to help with side effects?
- When will I be able to return to my normal activities after chemotherapy?
- Is there anything I can do, such as changing my diet, exercising, or managing stress, to help cope during chemotherapy or to help my recovery?
- Am I eligible to participate in any clinical trials?

# TARGETED THERAPY

Targeted therapies are mainly used to treat advanced and metastatic lung cancers. They are generally given alone. Occasionally, targeted therapy is given in combination with chemotherapy, or used as adjuvant therapy after surgery to try and keep the cancer from coming back.

The molecular tests of your lung tumour, which check whether your cancer cells express any of the targets of this type of therapy, will determine if you can receive a targeted therapy as your primary therapy. If you have previously received other types of treatments, your doctor may suggest targeted therapy as a subsequent treatment.

This chapter discusses the targeted therapies for lung cancers with EGFR, ALK, ROS1, and BRAF mutations, as well as for VEGF. However, new therapies that target mutations in genes such as HER2, cMET, RET, NTRK, and many others are in development. If you are not a candidate for one of the targeted therapies available in the market, you may be eligible for a new therapy being tested in clinical trials. Molecular testing for these new gene targets may be available only as part of a clinical trial, so be sure to discuss the options with your doctor.

### HOW DOES TARGETED THERAPY WORK?

These drugs target and disrupt key processes of cancer growth—for example, the formation of new blood vessels that bring nutrients to the tumour, or the action of cellular molecules that cause cancer cells to grow and divide quickly.

This interference of cellular processes is known as *inhibition*. When targeted therapies inhibit their targets, they cause tumours to slow down their growth, stop growing, or shrink.

Like chemotherapy, these treatments are systemic—some must be injected into a vein, and others are capsules or tablets that can be taken orally. Unlike standard chemotherapy, these drugs attach to or block targets that appear on the surface of cancer cells or the blood vessels in the tumour. Because they have specific molecular targets, targeted therapies generally affect fewer healthy cells and cause less severe (and different) side effects than chemotherapy. When studied in clinical trials, targeted therapies were also more effective—compared to chemotherapy, they were more likely to shrink tumours and control the cancer for a longer time.

### WHAT TARGETED THERAPIES ARE AVAILABLE?

#### **EGFR Inhibitors**

EGFR stands for *epidermal growth factor receptor*. These are molecules found on the surface of certain cells in the body, and they transmit signals that tell these cells to grow.

Some lung cancer cells contain EGFR molecules with mutations that make them overactive. Mutated EGFR molecules constantly signal the cancer cells to grow and divide, making the tumour larger. EGFR inhibitors block this signal.

In Canada, around 14% of adenocarcinomas, a subtype of NSCLC, have EGFR mutations; that is, they are EGFR-positive (EGFR+). EGFR+ adenocarcinomas are more common in women, non-smokers and light smokers, and East Asians. Afatinib (Giotrif<sup>®</sup>), erlotinib (Tarceva<sup>®</sup>), and gefitinib (Iressa<sup>®</sup>) are oral EGFR inhibitors that are taken on their own as initial treatment for advanced EGFR+ adenocarcinoma.

After treatment with EGFR inhibitors, lung cancers may become resistant to treatment. They can do so by developing resistance mutations to counteract the effect of EGFR inhibitors. Encouragingly, in recent years, new drugs have been—and continue to be—developed to overcome these resistance mutations.

Osimertinib (Tagrisso<sup>®</sup>) is an oral drug that acts on the T790M resistance mutation, which appears in about half of the people treated with afatinib, erlotinib, or gefitinib. To find out whether your cancer will respond to osimertinib, you will have to undergo a blood test or another biopsy to check for the T790M mutation. In the future, osimertinib may also be used as initial treatment for EGFR+ lung cancer.

#### **ALK Inhibitors**

ALK stands for *anaplastic lymphoma kinase*. Some cancer cells contain ALK genes that are mixed or *fused* with another gene—this is known as an ALK *fusion*. The rearranged ALK gene produces an altered ALK molecule that promotes the growth and spread of cancer cells.

ALK fusions occur in about 3% to 5% of NSCLCs. They are more common in younger people with adenocarcinoma who have never smoked or used to be light smokers.

ALK inhibitors block these defective ALK molecules. Crizotinib (Xalkori®), ceritinib (Zykadia<sup>®</sup>), brigatinib (Alunbrig<sup>™</sup>), and alectinib (Alecensaro<sup>®</sup>) are all oral ALK inhibitors. Crizotinib is usually given as a primary treatment, whereas ceritinib, brigatinib, and alectinib are options for subsequent treatment if the cancer has progressed during treatment with crizotinib. (Although, alectenib may be given as primary treatment in the future.) Lorlatinib is a newly developed ALK inhibitor that also shows promise.

Crizotinib is also used to treat lung cancers with the rare ROS1 fusion. This mutation is found in only 1% of NSCLCs; like ALK mutations, it is more common in younger people, non-smokers, and light smokers.

### **VEGF** Inhibitors

VEGF stands for *vascular endothelial growth factor*. As its name suggests, VEGF stimulates the growth of blood vessels. Cancer cells grow very fast and need a lot of nutrients to do so. They produce a lot of VEGF to create a dense network of blood vessels that brings them these nutrients.

By blocking the action of VEGF, VEGF inhibitors essentially starve the tumour of nutrients. VEGF inhibitors are also known as angiogenesis inhibitors. (Angiogenesis is the medical term for the formation of new blood vessels.)

Currently, there are no tests to determine the best candidates for treatment with VEGF inhibitors. However, those who have a tumour in the centre of the chest or are coughing up blood should not receive a VEGF inhibitor.

Bevacizumab (Avastin<sup>®</sup>) is an injectable VEGF inhibitor that is occasionally used to treat lung cancer. VEGF inhibitors are usually given in combination with chemotherapy, but bevacizumab may be given on its own later to maintain a good response after initial treatment.

## TAKE CARE OF YOURSELF

**Reach out**. Whether you are a patient or a caregiver, talking to others in similar situations can help you learn strategies to cope during this time. You should also enlist the experts in your cancer care team—tell them how you feel, what you need, and what you are worried about. They can answer many of your questions, and refer you to professionals who can offer additional help.

#### **BRAF Inhibitors**

The BRAF molecule is one of many that control the normal growth of healthy cells. Approximately 1% to 3% of NSCLCs have a BRAF mutation known as V600E. These cancers may be treated with a combination of two oral drugs—the BRAF inhibitor dabrafenib (Tafinlar<sup>®</sup>) and another oral drug called trametinib (Mekinist<sup>®</sup>). Trametinib inhibits a molecule called MEK, which works with BRAF to control cell growth.

### SIDE EFFECTS OF TARGETED THERAPY

You may experience some side effects while taking targeted therapy. Each drug has its own set of unique side effects, many of which can be proactively managed and are often well tolerated. Common side effects include diarrhea, rash, mouth sores, loss of appetite, and fatigue.

Occasionally, these drugs cause more serious side effects. Be sure to talk to your doctor about the specific targeted therapy you are taking. Your treatment team will brief you on the potential side effects and what to look out for during treatment.

### QUESTIONS TO ASK YOUR CANCER CARE TEAM ABOUT TARGETED THERAPY

- What mutations were found in my biopsy sample? What are my treatment options?
- Should my cancer be tested for other mutations?
- What is the goal of targeted therapy?
- How long will this treatment last and how often will I receive it?
- What drugs will I receive and how do they work?
- What side effects might occur and what can I do to cope?
- Are any of the side effects permanent?
- Who can I contact if I develop any side effects?
- Are there drugs to help with side effects?
- Am I eligible to participate in any clinical trials?

### NEW TREATMENTS: KNOW YOUR OPTIONS AND HOW TO GET THEM

Back in 2011, even the gold standard for chemotherapy in Canada could not keep my metastatic lung cancer from growing. Molecular tests I had done in the US showed that my cancer had a rare mutation, one for which targeted treatment existed—but it hadn't yet been approved for use in Canada.

In fact, at the time I started taking these drugs, none of my three subsequent treatments were approved in Canada. I bought the initial doses of my first drug in the US, while my doctor in Canada worked with the drug manufacturer and Health Canada to get me the treatment on compassionate grounds. In the years that followed, I received two more new drug treatments—one through a clinical trial in Canada and another that, once again, I had to initially purchase in the US.

After chemotherapy, I was put on another drug that I was told would most likely not work. It didn't. But I was very fortunate that there were treatments out there for my specific cancer. So I fought to get them—and got them.

- Miriam David, North York, Ontario



# **IMMUNOTHERAPY**

Immunotherapies are used to treat locally advanced and metastatic NSCLC. Depending on the immunotherapy drug being considered for your treatment plan, you may first need to undergo a diagnostic test to check for the presence of certain molecules on the surface of your cancer cells.

The effectiveness of giving immunotherapy after surgery or in combination with **chemoradiation** (a combination of chemotherapy and radiation), chemotherapy, or other immunotherapies is currently being studied in clinical trials.

### HOW DOES IMMUNOTHERAPY WORK?

Immunotherapy increases the activity of your body's natural defence system—the immune system—so that it can better find and destroy cancer cells. Because immunotherapy simply enhances the performance of your own immune system, the treatment is generally well tolerated.

Under normal circumstances, the immune system keeps the body clear of infection-causing entities such as viruses and bacteria, and abnormal cells like cancer cells. But first, it must identify whether a cell is foreign or normal. This process of checking whether a cell is foreign or not is controlled by an *immune checkpoint*. These checkpoints ensure that the immune system does not accidentally attack healthy, normal cells.

Some cancer cells exploit an immune checkpoint process involving two cell surface molecules—PD-L1 and PD-1. They produce lots of PD-L1, which binds to PD-1 on the surface of T cells, a specific type of immune cell. When cancer cells interact with T cells in this way, they trick the immune system into identifying the cancer cells as normal cells.

# WHAT IMMUNOTHERAPY DRUGS ARE AVAILABLE?

The two main immunotherapy drugs are nivolumab (Opdivo<sup>®</sup>) and pembrolizumab (Keytruda<sup>®</sup>), and they fall into a category of drugs called *immune checkpoint inhibitors* or PD-1/PD-L1 checkpoint inhibitors. Atezolizumab (Tecentriq<sup>™</sup>), avelumab (Bavencio<sup>®</sup>) and durvalumab (Imfinzi<sup>™</sup>) also belong to the same category. Immune checkpoint inhibitors prevent the interaction between PD-1 and PD-L1 so that the immune cells can destroy the cancer cells. This mechanism is often described as "taking the brakes off the immune system."

Immunotherapy drugs are usually given after an advanced lung cancer has progressed during or after treatment with chemotherapy or certain targeted therapies. However, pembrolizumab may be given as a first treatment for advanced cancers with high levels of PD-L1; and durvalumab may be given after completion of chemoradiation for the treatment of stage III lung cancer. Immunotherapy treatments are given intravenously every two to three weeks.

#### **Other Immunotherapies**

Cancer vaccines and adoptive T cell transfer are active areas of research in immunotherapy clinical trials. Just like regular vaccines, cancer vaccines are used to train the immune system to better recognize molecules found on the surface of cancer cells. In adoptive T cell transfer, some T cells from the body are removed, treated in a lab so that they can identify cancer cells better, and then re-injected into the body.

### SIDE EFFECTS OF IMMUNOTHERAPY

You may experience some side effects from taking immunotherapy. Your treatment team will brief you on the potential side effects and what to look out for during treatment.

Given the way immunotherapies work, the immune system could attack normal cells. However, this is uncommon. Most side effects of immunotherapy can be reversed, especially if caught early. Communicating with your healthcare team about any new symptoms while you receive immunotherapy is very important.

Because immunotherapies make your immune system work harder, you may have side effects in your bowels, liver, lungs, skin, kidneys, glands, and other organs. These side effects may be mild, or may become serious or life-threatening in rare cases. Side effects can occur during treatment, or even weeks or months after stopping treatment.

### QUESTIONS TO ASK YOUR CANCER CARE TEAM ABOUT IMMUNOTHERAPY

- What is the goal of immunotherapy?
- Am I a candidate for immunotherapy? What are my treatment options?
- How long will this treatment last and how often will I receive it?
- What drugs will I receive and how do they work?
- What side effects might occur and what can I do to prevent or cope with them?
- Are there any side effects for which I should go to the emergency room? Should I bring anything with me (like an information card) to let the ER doctors know about my immunotherapy?
- Are any of the side effects permanent?
- Who can I contact if I develop any side effects?
- Are there medications to help with side effects?
- When will I be able to return to my normal activities after immunotherapy?
- Is there anything I can do, such as changing my diet, exercising, or managing stress, to help cope during therapy or to help my recovery?
- Am I eligible to participate in any clinical trials?

# COMMON COMPLICATIONS OF LUNG CANCER

### **BONE METASTASES**

Bones are a common area to which lung cancer can spread. The most common symptom is pain in the bone. Some symptoms of bone metastases can be quite serious. If you have bone metastases, ask your healthcare team if there are any particular symptoms that should be brought to their attention as soon as you experience them.

There are a few different treatments for bone metastases. Denosumab (Xgeva®) and bisphosphonates, such as zoledronic acid (Zometa®) are injectable drugs that slow the breakdown of bone, prevent fractures, and reduce pain. Radiation treatment and chemotherapy are used to relieve pain and shrink tumours. Surgery and bone cement are used to fix broken bones and prevent future fractures in bones weakened by cancer.

A healthy diet and regular weight-bearing exercise (like walking) can help maintain strong bones. Calcium and vitamin D supplements are also recommended, especially during treatment with denosumab, bisphosphonates, or steroids. Talk to your healthcare team about whether these approaches will be helpful for you.

### LOW BLOOD OXYGEN LEVELS

If your blood oxygen level is significantly low (this condition is called **hypoxemia**), your doctor will suggest using oxygen to supplement your breathing capacity. Breathing in extra oxygen raises low blood oxygen levels, makes breathing easier, and lessens strain on your body. Because your body cannot store oxygen, this therapy works only when you use oxygen.

Like any other prescription medicine, oxygen must be used very carefully and only as prescribed. Your doctor will tailor your oxygen prescription to your needs. You should never change the flow of oxygen unless directed by your physician. When oxygen will be delivered to your home, you and your family will receive instructions on how it should be used and how to clean the equipment.

See Chapter 10 for other strategies to manage shortness of breath.

### PNEUMONIA

Pneumonia is an infection of the lung tissue. It may be due to a weakened immune system, a complication of chest surgery, or a result of the tumour taking up space in your lung. Depending on the severity, pneumonia may be treated with antibiotics at home or at a hospital.

Many of the symptoms of pneumonia overlap with those of lung cancer, such as chest pain, difficulty breathing, coughing, and coughing up pus or blood. However, pneumonia will also cause symptoms like fever, chills, headache, and confusion. If you have any of these symptoms, you should let your healthcare team know right away.

### PLEURAL EFFUSION

Pleural effusion is the build-up of fluid in the chest that makes breathing difficult. The fluid collects in the pleural space between the double-layered membranes lining the lungs. Because the fluid pushes on the lungs and flattens the diaphragm, they cannot expand and contract properly to move air in and out of the lungs.

The excess fluid can be removed by thoracentesis, a procedure in which a needle is inserted into the chest cavity and fluid is suctioned out.

**Pleurodesis** is a procedure in which the two membranes lining the lung are sealed to each other so that fluid can no longer collect between them. This involves putting a powder or drug in the pleural space through a flexible chest tube. After the surgery, the chest tube may be left in place for a few days to drain any new fluid that might collect.

Another way to relieve pleural effusion is by using a soft tube called a tunnelled pleural catheter. The tube lies under the skin and inserts into the pleural cavity from which it drains excess fluid. The tube is inserted using local anesthetic during an outpatient procedure that last about 90 minutes. Then, a nurse can help drain the fluid at home until pleurodesis happens naturally.

### **BLOOD CLOTS**

People with cancer have a high risk of developing blood clots. Blood clots can be a result of the cancer, its treatments, or a range of other causes including extended bed rest. They are treated with blood thinners.

There are a few different names for conditions involving blood clots. A blood clot inside a blood vessel (usually a vein) is called a **thrombus**. If a thrombus forms in a vein deep inside the body (usually the legs), this is known as **deep vein thrombosis (DVT)**. Symptoms of DVT include swelling, warmth, or a cramp-like pain in the leg; discolouration of the skin; and prominent veins.

Sometimes a piece of the clot, an **embolus**, breaks away and travels through the bloodstream. As it travels, an embolus may lodge itself in a smaller blood vessel and block blood flow. When an embolus lodges itself in the lungs, this is known as **pulmonary embolism (PE)**.

Symptoms of PE include unexplained or sudden shortness of breath; pain in the chest or upper back, especially when you cough or take a deep breath; feeling faint or actually fainting; a rapid pulse; and coughing up blood.

PEs can be life-threatening. Let your doctor know as soon as you develop these symptoms.

### QUESTIONS TO ASK YOUR CANCER CARE TEAM ABOUT FOLLOW-UP VISITS

- Who will be in charge of my long-term care?
- How often should I return for follow-up visits? Is there a regular schedule?
- Who will arrange these visits?
- What do you look for at follow-up visits? Will I have to do any tests?
- What long-term side effects might occur, and what can I do to prevent or cope with them?
- What symptoms should I look out for? Who should I contact if I develop any of them?
- Is there anything I can do, such as changing my diet, exercising, or managing stress, to help my recovery and keep my cancer from coming back?
- Will I receive any support and care at home?

# TREATMENT OF SMALL CELL LUNG CANCER

Chemotherapy is the main treatment for limited- and extensive-stage SCLC. Since SCLC grows quickly and is usually diagnosed in the later stages when it has already spread, systemic treatments like chemotherapy are more effective than localized treatments like radiation and surgery.

Treatment of limited-stage SCLC begins with chemoradiation—a combination of chemotherapy and radiation. If the lung tumour responds well to this regimen, your doctor may recommend preventative radiation to the brain. Surgery is rarely part of the treatment plan, and is always used in combination with other treatments. In the extensive stage, chemotherapy is given first.

There are currently no effective targeted therapies or immunotherapies for SCLC, but these are areas of active research in clinical trials.

### CHEMOTHERAPY

Usually a combination of two chemotherapy drugs—commonly etoposide and a platinum-containing drug such as cisplatin or carboplatin—is used. Some combination regimens may use a chemotherapy drug called irinotecan instead of etoposide. If you cannot tolerate combination treatment, you will be treated with only etoposide.

Recurrent cancer is also treated with etoposide, topotecan, or with a combination of three chemotherapy drugs—cyclophosphamide, doxorubicin, and vincristine.

### **RADIATION THERAPY**

For limited-stage cancer, radiation treatment will be part of the chemoradiation regimen.

For extensive-stage cancer, radiation treatment may be palliative—that is, with the goal of shrinking tumours to relieve symptoms like trouble with swallowing or breathing problems.

**Prophylactic cranial irradiation (PCI)** is a type of radiation treatment used to kill cancer cells in the brain. PCI may be included in the treatment plans for limited-stage cancer that has responded well to chemoradiation, and for extensive-stage cancer that has responded well to chemotherapy.

As its name suggests, PCI treatment is *prophylactic* — that is, it is used to *prevent* the spread of cancer to the brain, a common site of metastasis in SCLC. So, PCI may be used even if cancer cells do not show up on x-rays or scans of the brain, and can significantly reduce the chance of developing brain metastases. If the presence of brain metastases has been confirmed, external beam radiation therapy is used.

### SURGERY

Currently, surgery is not a standard part of treatment plans for SCLC. If SCLC is diagnosed in the limited stage, *and* the tumour is small and can be completely removed, *and* pulmonary function tests (PFTs) indicate that it is feasible to remove all or part of a lung, then surgery might be the first treatment given. But such cases are rare.

When surgery is part of the treatment plan, an entire lobe of the lung is usually removed. Doing this offers a greater chance of removing all the cancer compared to when smaller parts of the lung are removed. Nearby lymph nodes or tissue samples are also removed at the same time.

### DRUGS USED TO TREAT LUNG CANCER

The drugs marked with an asterisk (\*) below are not commercially available for the treatment of lung cancer as of August 2017; and must be obtained by special access or through a clinical trial.

Encouragingly, development of treatments for lung cancer is a fast-moving area of research. In time, more treatments will become available.

Chemotherapy	Carboplatin Cisplatin Cyclophosphamide Docetaxel Doxorubicin Etoposide	Gemcitabine Irinotecan Paclitaxel Pemetrexed Topotecan Vincristine Vinorelbine
EGFR Inhibitors	Afatinib (Giotrif®) Erlotinib (Tarceva®)	Gefitinib (Iressa®) Osimertinib (Tagrisso®)
ALK Inhibitors	Alectinib (Alecensaro®) Brigatinib (Alunbrig™)* Ceritinib (Zykadia®)	Crizotinib (Xalkori®) Lorlatinib*
VEGF Inhibitors	Bevacizumab (Avastin®)	
BRAF Inhibitors	Dabrafenib (Tafinlar®)	
MEK Inhibitors	Trametinib (Mekinist®)	
<b>ROS1</b> Inhibitors	Crizotinib (Xalkori®)	
Immune Checkpoint Inhibitors	Atezolizumab (Tecentriq™)* Avelumab (Bavencio®)* Durvalumab (Imfinzi™)*	Nivolumab (Opdivo®) Pembrolizumab (Keytruda®)

# **CLINICAL TRIALS**

A clinical trial or study is a carefully controlled way to research the effectiveness and safety of new treatments. By the time a treatment is ready for clinical trials, it has already undergone exhaustive testing in the laboratory and in studies with animals. Clinical trials themselves are conducted under the close supervision of doctors and other research professionals, and have been vetted by Health Canada. The trial is also reviewed by a Research Ethics Board (REB), an independent group of research professionals. The REB ensures that the trial meets the highest ethical standards and is conducted safely.

A common myth is that clinical trial volunteers are guinea pigs, or that clinical trials are used as a last resort. This is not true. If your doctor has recommended a particular clinical trial to you, then it may be the best option for your particular situation, or stage or type of cancer.

You can learn about clinical trials in your region at

**www.canadiancancertrials.ca** and **www.clinicaltrials.gov**. If you would like to participate in a clinical trial or learn more about whether a specific trial would be right for you, discuss it with your healthcare team. Ask them any questions you have, as they can best advise you about your treatment plan and options.

### CLINICAL TRIALS: OPENING NEW DOORS

The fact that I'm here today as a lung cancer survivor shows the progress that has been made, and continues to be made, in treatments for this disease. When I was diagnosed with stage IV lung cancer, I did not know of anyone who had survived this advanced disease. So when I heard the words "There is no hope", I believed them; because at that time, it was true.

Now, the words are "There *is* hope!" Thanks to clinical trials, breakthroughs are happening every day. Once you open the door to a new treatment, other doors slowly start opening too. Without clinical trials, these doors will stay closed.

If an opportunity comes along to open a new door, don't be afraid. Embrace it. And carry on the words—*There is hope!* 

- Lorne Cochrane, Atmore, Alberta

### **RISKS AND BENEFITS**

Some risks and benefits will be unique to your specific clinical trial, but some factors are common across all trials. When you participate in a clinical trial, you can play a more active role in your care and help others by contributing to medical research. A clinical trial will give you access to new experimental treatments before they are widely available. You will receive expert care from medical professionals at top healthcare facilities.

On the flip side, because the treatment you receive will be new and experimental, it may or may not be more effective than the standard of care—that is, the best available current treatment. This treatment may also have unknown side effects, which may or may not be worse than those of the standard of care.

A clinical trial may also place greater demands on your time. The clinical trial team may want to monitor you very closely, and ask you to visit more often or to stay at the healthcare facility. You may have to follow a more complicated treatment regimen or undergo extra tests.

Choosing to participate in a clinical trial is a big decision. Talking to your healthcare team, and equipping yourself with the pertinent information can help you make this decision and feel comfortable with it.

## **INFORMED CONSENT**

The informed consent form is a resource that can help you evaluate the risks and benefits of a clinical trial. Informed consent is part of the ethical standards followed by clinical trials. In addition to the risks and benefits, this document contains important details of the study, such as treatments, tests, side effects, duration, and who to contact if you have questions.

If you choose to participate in a clinical trial, you will have to sign the informed consent form. You will also have the right to withdraw consent and remove yourself from the clinical trial at any time.

### PHASES OF CLINICAL TRIALS

All clinical trials are assigned a phase. Only those drugs that meet the strict goals for safety and effectiveness may move on to the next phase. This process means that a drug that has just entered clinical trials can take up to five or more years to become commercially available for everyone.

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Phase 1 (or I) trials determine safe doses of a drug or a combination of drugs, how often it should be taken, and its side effects. These trials may also test the effectiveness of a different formulation of an existing drug, or test the effects of an already approved drug on a different type of cancer.

Phase 2 (or II) trials assess how effective a drug is against a certain type of cancer using the safe dosage determined in the phase 1 trial. Researchers may also compare the effectiveness of different dosages to each other. They will, of course, continue to monitor the safety and side effects of the drug.

Phase 3 (or III) trials compare the new drug to the standard of care. The drug may be tested on its own or in combination with other drugs. These trials usually involve a large number of participants (hundreds to thousands) and are carried out at many different hospitals at the same time (a multi-site trial).

Phase 4 (or IV) trials are conducted once a drug has been approved by regulatory bodies such as Health Canada. Researchers gather more information about the drug's effectiveness and side effects with longer-term use in a real-world clinical setting. Phase 4 trials also involve a large number of participants, sometimes including those who took part in phase 3 trials of the drug.

### WORDS USED TO DESCRIBE CLINICAL TRIALS

**Protocol** — A document written before a clinical trial begins that contains detailed information such as why a clinical trial is being done, its goals, who can participate (known as the **eligibility criteria**), how it will be conducted, and how it will determine the effectiveness of the experimental drug.

**Endpoints** — Measurable factors that allow researchers to determine whether the experimental drug is effective and whether the goals of the trial have been met. These are determined and defined before the clinical trial begins.

**Randomized** — Participants are randomly assigned to different groups. Those in the **experimental** group are given a new drug or a combination of drugs, whereas those in the **control** group are given the current standard of care treatment or a placebo. A placebo is an inactive substance that looks like the experimental treatment and is administered in the same way. Using a placebo prevents the patient and healthcare team from knowing which treatment is being given. This is another way in which trials avoid bias. **Open-label** — Participants, and researchers, know which treatment they are receiving. No placebo is used.

**Blind** — Participants do not know whether they are receiving the experimental drug, another treatment, or a placebo. In a **double-blind** trial, neither the participants nor researchers know which group they have been assigned to. This is one way in which trials avoid bias.

### **TYPES OF CLINICAL TRIALS**

**Treatment trials** evaluate new treatments for cancer. These are the most common trials for people with cancer.

**Prevention trials** look at ways to prevent cancer in healthy people, in those who have a high risk for developing cancer, or in those who have a history of cancer. Participants in such trials do not have cancer at the time of the trial.

**Screening trials** evaluate ways to detect cancer in the early stages, even before they cause any signs or symptoms. Participants in such trials have a high risk for developing cancer.

**Diagnostic trials** look for better methods to diagnose cancer or determine its stage.

**Supportive care trials** or **quality of life trials** look at how to improve the life and comfort of people with cancer and cancer survivors; for example, with new techniques to reduce symptoms and side effects.

### QUESTIONS TO ASK YOUR CLINICAL TRIAL TEAM

- Why is this study a good option for me?
- What is the purpose of the study?
- Who is going to be in the study?
- Why do researchers believe the experimental treatment may be effective? Has it been tested before?
- What kinds of tests and experimental treatments are involved?
- How do the possible risks, side effects, and benefits of the experimental treatment compare with my current treatment?
- What happens if I receive the placebo, control drug, or chemotherapy instead of the experimental treatment? Will I get a chance to get the experimental treatment later?
- Who will be in charge of my care?
- How might this trial affect my daily life?
- How long will the trial last?
- Will hospitalization be required?
- Will I be reimbursed for expenses?
- What type of long-term follow-up care is part of this study?
- How will I know that the experimental treatment is working?
- Will I be given the results of the study?

### PALLIATIVE CARE IS NOT END-OF-LIFE CARE

A palliative care referral does not mean that your oncologist is giving up on you. In fact, many people with cancer receive palliative care early and at the same time as other treatments such as chemotherapy or radiation therapy.

The goals of palliative therapy are to improve quality of life by reducing symptoms and delaying cancer growth. Palliative therapy can include surgery, radiation therapy, chemotherapy, and targeted therapies, as well as pain management, oxygen therapy, psychosocial support, and many other approaches.

Palliative care is organized in different ways in different hospitals but may include in-patient consultation service, where patients admitted to hospital are seen; out-patient consultation service, where the patient comes to a clinic; or home visit services.

Just like your usual cancer treatment team, the palliative care team is also multidisciplinary and composed of different members. It will include a palliative care physician and a nurse, and may also include a social worker and a psychiatrist. You may also benefit from any local resources that may be available.



# LIVING WITH LUNG CANCER

A lung cancer diagnosis and the treatments that follow are a heavy burden to carry. Although it may feel like it at times, you should know that you do not have to carry this burden alone. Your family and friends want to be there for you and help you in meaningful ways during this difficult time. Sometimes, those around you may not be sure of what they can do, but they do very much want to help.

Reach out and ask for help. Do not isolate yourself. Let people know what you need and when you need it. It could be anything from going with you to a doctor's appointment, to getting some groceries, to picking up the phone when you need someone to talk to. You can also get help from the many organizations and services that specialize in assisting people who have cancer and their loved ones.

### YOUR MENTAL HEALTH

The ways in which cancer and your treatments affect you physically, emotionally, and socially are bound to create a lot of psychological stress. It is common to feel anxious, afraid, and depressed during this time. And it is especially important to seek help and to find effective strategies to cope with these feelings.

Do not bottle up your feelings and put on a happy face because you want to protect those around you. Your loved ones care about you very much and want to help you no matter how you feel.

Support can come from trained professionals in your treatment team, from your loved ones, and from support groups. Together you can work out effective strategies to help you cope. These can include relaxation, stress management techniques, medication, and counselling.

Lung Cancer Canada's Peer-to-Peer Navigators are lung cancer survivors and supporters (family members and caregivers) who have walked the lung cancer path. They know how difficult dealing with lung cancer can be. These volunteers offer mentorship, encouragement, advice, experience, and hope to anyone who has been newly diagnosed or who needs additional support through a one-on-one, personal connection. Go to **www.lungcancercanada.ca/get-involved/peer-to-peer.aspx**.

### COMPLEMENTARY AND ALTERNATIVE MEDICINE

Many people with cancer find it helpful to engage in complementary and alternative medicine (CAM) to help them better manage and cope with their cancer. Popular CAM therapies include acupuncture, massage, meditation, qigong, and yoga. If you are thinking about any of these activities, ensure that you find qualified practitioners and centres that can take your needs into consideration.

It is also very important to tell your doctor about your activities, especially if you take nutritional or herbal supplements. Some supplements, including vitamins and antioxidants, can interfere with the medications that your doctor gives you.

### LIVING WITH LUNG CANCER: TOUGH TIMES WILL PASS

I am not going to sugarcoat it—living with lung cancer has been the hardest thing I have ever faced. But it has also been rewarding. It has changed my perspective on the world and allowed me to see things differently. There will be some tough times, but these will pass. I know from personal experience that life will become "normal" again.

Staying mentally strong and optimistic is not easy when you are battling cancer, but it is important to make the effort. Never hold your emotions in. Reach out to your support system of family, friends, and physicians about how you are feeling—good and bad.

Undergoing cancer treatment as a mom with a young child, I also struggled physically with intense fatigue and shortness of breath. That was just my body telling me that I needed to rest. And that was okay! Asking for help when I needed it was okay too!

Lung cancer has tested the strength of my spirit and my family's. We are stronger because of it!

- Kayla Bradford, Ottawa, Ontario



# **MANAGING DAILY ACTIVITIES**

When living with lung cancer, you will sometimes feel short of breath and very tired, and find that you cannot do all the things you could before. These symptoms will affect your lifestyle, your mood, and may even affect your ability to carry out some day-to-day routines.

The good news is that there are simple changes that you can make that will let you save your time and energy for the activities that you really enjoy and love to do. It is essentially a common-sense approach to living. It will help you maintain control over your life and activities, rather than letting the symptoms decide what you can and cannot do.

Use the steps outlined below to discover which activities you can do and what sort of schedule you can keep. You do not have to do this alone. Work with your family or caregiver to see what will work best for you.

**Examine your lifestyle.** Walk through a typical day and list the activities that you find difficult and the ones that seem to worsen your symptoms. For example, bending to reach low surfaces, or standing or walking for a certain period of time.

**Identify problem activities.** Review the activities you have just listed and try to find a common theme. For example, activities that cause you to hurry, like rushing to pick up the phone; or a time of day when you feel more tired.

**Alter your environment.** For example, place your phone near areas where you tend to spend the most time, or place things within easy reach so that you do not have to strain to get them.

**Use self-care equipment.** For example, if you find it hard to stay standing while you shower, get an adjustable bath chair or bench.

**Pace yourself.** Give yourself enough time to complete a task or activity. Do not rush or feel pressured to keep up with others. Be forgiving of yourself. Learn your tolerance for activities like sitting, standing, walking, and talking. If you can recognize your abilities and limitations, you will know when to stop before you become too tired or short of breath.

**Eliminate unnecessary tasks.** Plan ahead. Organize supplies and your work space to cut down on extra trips. If you store items on the same floor or room as the area in which they will be used most often, you will minimize unnecessary walking or stair-climbing. You can also do several tasks in a row in one area before you move on to the next.

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**Ask for and accept help.** Your friends and family want to help and support you, but may be unsure about what they can do for you in particular. Talk to them and make a plan together.

**Save your energy.** Lung cancer and its treatments can make you feel extremely tired. During this time, it is okay to scale back your activities and say no to things. Save your energy for what you really enjoy.

**Set priorities.** Look at your activities for the day and put them in order of importance. It is important not to spread yourself too thin.

**Create schedules.** Plan each day and organize your week to include only what you can realistically accomplish. For example, alternate difficult tasks with light tasks, schedule your rest periods, and consider the best time of day for your activities, including social activities and visiting with friends.

**Have something to look forward to.** When you make your schedule, try to include daily or weekly activities that you really love—perhaps a weekly dinner, a game night, a hobby, or spending time with a loved one. Looking forward to an activity may make you feel more energetic, or provide a welcome distraction.

**Modify your routines gradually.** Start slow and easy; and then see if you can do a little more each day. If you cannot, know that this is completely okay. If you feel tired or unwell after making a change to your routine, do a little less for a day or so.

### TAKE CARE OF YOURSELF

**Keep records.** Keep good records of your tests, treatments, and prescriptions. Write down the contact information of the members of your healthcare team.

## MANAGING SYMPTOMS OF LUNG CANCER

The symptoms outlined below are commonly experienced by people who have lung cancer. However, everyone with cancer has a different experience; and your experience of these symptoms, their intensity, and their duration will be different as well. Palliative care can help you manage your symptoms better and address any unresolved concerns you may have. It is important to remember that treating your symptoms with palliative care does not mean that your doctor has stopped treating the cancer itself. In fact, receiving palliative care early can improve your quality of life, mood, and ability to cope with your treatments.

There are many ways in which symptoms can be managed. Changes to your lifestyle, symptom relief techniques, and medications can all help to minimize the effect of the symptoms on your well-being and quality of life. Your treatment team will work with you to find the ways that work best for you. The better your symptom management, the better your quality of life and treatment outcomes will be.

Some symptoms, like shortness of breath, can become life-threatening if left untreated. So it is very important to keep an open dialogue with your treatment team about your symptoms and their treatments (and side effects of the treatments themselves). It may be helpful to keep track of your symptoms, when and where they happen, how often and how badly. You can use a notebook or a smartphone app, whichever will be the most accessible and easiest for you to refer to.

### PAIN

Pain can be a symptom caused by the lung cancer itself—for example when a tumour pushes against other organs or nerves in your body; or it could be a side effect of a treatment, like surgery.

There are many ways to relieve pain: medical procedures, medications, palliative radiation, chemotherapy, alternative therapies like acupuncture and massage therapy, and behavioural strategies like meditation. Your healthcare team will help you find approaches that will be most helpful for you and can discuss with you their benefits and risks.

Aside from hurting you physically, pain can also take a toll on your mental wellbeing. In turn, feeling emotionally upset can make your physical pain feel worse. It is very important that you talk to your treatment team and your loved ones. You do not have to go through this alone.

### SHORTNESS OF BREATH

Shortness of breath, or dyspnea, can be mild and make you feel just a bit breathless or happen only occasionally; and in extreme cases, it can feel suffocating or be constant. Being short of breath may make it hard to do regular activities like getting dressed and cooking. It may make you feel more tired, worried, and upset. When you are short of breath, you may tighten up your chest muscles to breathe; breathe faster; or feel afraid, anxious, panicked, or uneasy.

Depending on the cause of your shortness of breath, your doctor will use a combination of treatments. For example, if your symptoms are constant, your doctor may prescribe opioid painkillers; or you may undergo medical treatments or procedures to shrink or destroy tumours that block your airways, to relieve pressure from fluid that may have collected in your chest cavity, or to hold your airways open. You may also receive extra oxygen from an oxygen tank, or medications to help you relax and feel less anxious.

The doctor will also suggest things that you can do every day to make breathing easier. For example, light exercises to improve the flow of oxygen to your blood, meditation, and using a humidifier. You should also avoid smoking and smoky places.

More tips and advice about things you can do to help with this symptom can be found at **www.bit.ly/LCCSoBrt**.

### FATIGUE

Fatigue is a very common symptom of cancer as well as a side effect of many lung cancer treatments. Your body is under a lot of physical stress. It is fighting the cancer, fighting to heal itself, and competing with the cancer for nutrition. It is also trying to heal itself from the side effects of your lung cancer treatments. Common symptoms of lung cancer like shortness of breath, coughing, weight loss, and sleeplessness can make fatigue worse.

Feeling tired all the time will also strain your emotional well-being. Be kind and gentle with yourself at this time. Make sure you eat well and eat enough. Give yourself enough time to do the things you need to do and the things you love to do. Do not force yourself to do too many activities. Rest for short periods and get plenty of sleep.
Sometimes, doing nothing all day can make the feeling of tiredness worse; a regular, light exercise routine, like light walking, can help. Moderate activity—that is, something you can do while still being able to have a conversation—for up to 30 minutes most days can decrease fatigue.

## **BEING ACTIVE**

You're probably already aware of the usual mental and physical benefits of exercise. The role of exercise during and after cancer treatment is just as important.

**Check with your doctor.** Before you start an exercise program, talk to your doctor about how much you should exercise and the kind of physical activity you should or should not do.

**Start slow and easy.** Even simple activities like walking can help. Walking is a weight-bearing exercise, which can strengthen your bones. This is especially important if you have bone metastases.

**Do a little bit every day.** It's more important to exercise a little bit daily rather than doing a lot more but less often. You can even break up your daily exercise into a few small sessions throughout the day.

**Make it enjoyable.** You don't have to do a typical workout. Physical hobbies like gardening, hiking, dancing, or swimming work just as well.

## COUGHING

A cough can be caused by a number of problems common to lung cancer, such as the tumour irritating an airway, airway blockage, pneumonia, and fluid in the chest cavity.

Depending on the cause, there are several different ways to treat a cough. These include clearing airway blockages, or using antibiotics, cough suppressants, and opioid medications. At home, you can try using a humidifier to alleviate your cough.

Tell your healthcare team if you notice that your cough has changed, or you have developed a new cough.

## WHEN TO CALL YOUR HEALTHCARE TEAM

- When your breathing has become more difficult over a short period of time.
- Along with breathing problems, you feel dizzy, or notice an increase in your heart rate or that your skin is very pale. This may be a sign that your blood counts are low and you may need a blood test.
- You struggle to breathe and feel very nervous.
- You have sudden, new, or increasing chest pain.
- You have a fever of 38°C or higher.
- You feel suddenly short of breath after you wake up.
- You have a new or worsening cough.
- Your breathing is noisy.

## NUTRITION

Your body will need a lot of energy to deal with the effects of lung cancer and its treatments. During this time, make sure you eat enough, eat well, and stay hydrated. This may be hard to do. You may feel that you do not have enough energy, or appetite, or time to keep up with your nutritional needs. But it is very important that you maintain your strength. This will also help you feel less fatigued and keep up with your daily activities.

Planning ahead will make it easier to get through the rough spots when you will not have the energy to shop and cook. You can prepare meals and freeze them, or stock up on ready-made frozen dinners before your treatment. These meals should be mild in flavour and soft, in case you have side effects like a sore throat, mouth sores, or an upset stomach.

During treatment, accept (and ask for) help from your family and friends. Together you can make a list of tasks they can do to make life easier. Let the friend who is a good cook bring you a meal. A pot of soup or a casserole delivered to your door when you are tired can mean the difference between eating and missing a meal. A friend who does not like being in the kitchen can pick up groceries.

If you have a lot of trouble maintaining a proper diet, ask to see a dietitian at your treatment facility. You can also find a registered dietitian who specializes in cancer on the Dietitians of Canada website (**www.dietitians.ca**).

## MINIMIZING WEIGHT LOSS

It is important that you maintain a healthy weight. Because of the energy demands that cancer and its treatment put on your body, you will need to take in a lot of calories.

Eating energy-rich foods that are high in carbohydrates and fats will help. These include foods like muffins, bread, pasta, granola bars, ice cream, milkshakes, nuts and nut butters, and cheese.

You can also incorporate high-calorie ingredients into recipes. Fry foods in oil or add butter to soups, stews, and casseroles. Put gravy and butter over mashed potatoes. Use regular mayonnaise in salad dressing and sandwiches. Eat jam, honey, and syrup with breakfast. Top dishes with cheese. Snack on nuts and dried fruit. Put ice cream and whipped cream on desserts. Put peanut butter, whole milk, or cream in your smoothies.

Do not wait till you feel hungry to eat. Eat whatever you are hungry for now. Your appetite is usually greatest at the beginning of the day. Take advantage of your appetite by making breakfast your largest meal of the day. Then, eat small amounts throughout the day. You may find it easier to eat several small meals throughout the day rather than a few large meals.

Talk to a dietitian about nutritional supplements (such as Boost<sup>®</sup> or Ensure<sup>®</sup>) if you cannot eat enough throughout the day. They can also advise you about vitamin and mineral supplements.

## EATING ENOUGH PROTEIN

Protein is very important for healing your body—it is essential for growing new, healthy cells, repairing damaged tissue, and maintaining a strong immune system.

Make sure you eat plenty of foods rich in protein—fish, poultry, lean red meat, eggs, whole milk, yogurt, cheese, nuts and nut butters, beans, peas, lentils, soy foods, and gelatin. Incorporate these foods into your recipes. For example, you can add powdered milk to creamy dishes, cream soups, and mashed potatoes; put cheese in your scrambled eggs and casseroles; and add eggs to sandwiches and salads.

If you find that meat tastes metallic, you can still eat fish, eggs, dairy products, beans, tofu, and soy milk. You can mask the metallic taste by marinating the meat in orange juice, lemon juice, Italian dressing, vinegar, sweet and sour sauce, wine, soy sauce, or teriyaki sauce. Using plastic utensils and glass cooking pots can also help lessen the metallic taste.

## **STAYING HYDRATED**

Your body will need plenty of fluids to stay healthy, to recover from side effects like vomiting or diarrhea, and to flush out any harmful by-products of medications.

It might be quite easy to accidentally become dehydrated, so drink plenty of liquids—about eight to twelve cups a day. You can drink water, milk, and juice, as well as foods that contain water, like soups, popsicles, and gelatin. Stay away from drinks that contain caffeine, like tea, coffee, and some sodas. Talk to your treatment team about having alcohol; you may be on medication that interacts with it.

## MANAGING LOSS OF APPETITE

It is quite common to discover that your tastes and food preferences have changed after you receive treatment. You may be hungry for foods you rarely ate in the past, and you may no longer tolerate some foods you used to enjoy.

If you feel sensitive to food odours, try eating foods that are cold or at room temperature. Foods served hot often have a strong smell. You can also choose foods that do not need to be cooked, such as cold sandwiches, crackers and cheese, yogurt and fruit, and cold cereal and milk.

Brush your teeth and floss to get rid of bad tastes in your mouth. Rinse your mouth with a baking soda solution (1/4 teaspoon in a cup of water) to clear your taste buds before and after you eat.

## **TALKING ABOUT CANCER**

Talking about your cancer can be very difficult to do. Those around you will have a lot of questions—about your cancer, your treatment, how you feel, and what you need. Your healthcare team will tell you a lot of information about your condition and might ask you to make decisions about your treatment. And you might be wondering how to tell people how you feel, physically and mentally. It can be overwhelming.

If you are not sure exactly what to say, or how to say it, or even when to bring it up, know that you are not alone. Many people with cancer feel this way. It is important to know that there is no right or wrong way to talk to people about your cancer. Each relationship is unique and has its own dynamic. We hope the information below helps you find what will work for you.

## TALKING WITH YOUR HEALTHCARE TEAM

Talking with your cancer care team is very important. The information they provide will help you make important decisions about your treatment. And letting your team know about relevant matters in your life will help them understand the unique way in which lung cancer affects you.

Being a new patient and getting introduced to the many healthcare providers who make up your treatment team may be a lot to take in. Feelings of fear and anxiety may make it hard to understand and remember what they say during appointments. The tips below can help you feel in charge and more prepared during your appointments. Your caregiver or a family member can help you at appointments too.

**Keep a list.** Know the names of each member of your cancer care team, their specializations, and their phone numbers.

**Speak up.** If you do not understand something, say so. It might help if you tell your doctor specifically what you need, such as a more detailed explanation or less medical jargon. Check to make sure you have understood correctly. You can say things like "What I hear is that this kind of cancer usually responds better to surgery than chemotherapy or radiation. Am I understanding this correctly?"

**Ask questions.** You will have many questions throughout the various stages of your treatment. Asking questions will help you get the information you need and help you feel in control.

**Put it on paper.** Jot down the questions you want to ask at your next appointment and take the list with you. Take notes to help you remember what the doctor or nurse said. Bring along a friend or family member who can make notes and help interpret what you were told.

**Record it.** Instead of writing things down, you may find it easier to just listen and make an audio recording of your appointments. You can listen to the recording later if you are unsure about anything that was discussed. If you choose to do this, always inform your healthcare provider before you hit record.

**Share.** Let your healthcare team know who the important people in your life are and to whom they may or may not communicate. Tell them if you want detailed information on all aspects of your medical situation or if you prefer general information only.

## TALKING WITH FAMILY AND FRIENDS

Talking to your family and friends can help you process your own feelings about your cancer. When you have decided to let them know, think about how much you would like to share with them and how. You may choose to speak to some close family and friends yourself, and have a loved one inform some others.

Learning about your cancer diagnosis will also be overwhelming for your family and friends. They will cope with the news in different ways and may need time to come to terms with their own feelings about your diagnosis.

**Be yourself.** Although this may be a very difficult conversation, keep in mind that you and the person you are speaking to are still the same people.

**Be honest.** You should tell your family and friends as little or as much about your cancer as you are comfortable with. But you should not feel that you need to hide any details to protect them from painful feelings.

**Ask them what they already know.** Some people might know bits and pieces about your diagnosis or treatment. Instead of starting from scratch, you may find it easier if they first tell you what they already know. Then, you can fill in the gaps as you wish.

**Have someone with you.** If you have already told a close family member or friend about your diagnosis, it may help to have them with you for support during this new conversation.

**Do not worry if they are quiet.** Some people may not know what to say right away, and some may be afraid of saying the wrong thing. Sometimes being with each other quietly may be enough. If you are uncomfortable with the silence, you can ask them what they are thinking or if there is something they would like to know.

**Talk about how they can help.** Your family and friends will want to support and care for you during this time. But they might not know how. Let them know about things they can help with, like running errands, doing chores, going with you to appointments, or lending an ear when you need it.

Let them know if there are things they should not do. Some people may have many questions about your health; but you may not always want to talk about it. With some others, this may be the beginning of a conversation that will continue over the course of your treatment. Let the person you are speaking with know if it is okay for them to ask you about your health, or if you would rather they wait till you broach the topic with them first.

## TALKING WITH YOUNG CHILDREN

When talking to young children about your cancer, take into consideration their ages and developmental stages. It is also essential to tell them the truth. Your children will sense something has been kept from them if they overhear you telling others different or more information.

Social workers at your children's school and at your cancer centre can help you decide what to say to your children. It may also be possible to set up a tour of the location where you will have your appointments and treatments. Seeing this place and meeting the staff may relieve some of your children's unspoken anxieties and fears about what you may experience during treatment.

**Do not be afraid to use the word cancer.** Clearly describe where your cancer was found. Some children may find it helpful if you draw simple pictures to show them where the *lump* is.

**Dispel myths.** Tell your children very clearly that they did not cause your cancer, and that it is not contagious. Although your children may not ask you about this, many children have unspoken beliefs that their past misbehaviours or outbursts harmed you in this way.

**Talk about your treatment plan.** You can describe radiation treatments as being *like* x-rays and chemotherapy as *special medicine*. It is, however, important to distinguish that your cancer treatments are not the same as your children's medicine or their dental x-rays, for example. Tell them about how often you will be at appointments, and if you will need to spend nights at the hospital.

**Prepare them for side effects.** Help your children understand what to expect when you come home after your treatment. Let them know about some of the side effects you may have, like fatigue, hair loss, and nausea.

**Tell them who will take care of them.** A simple explanation of the plans in place for their care and day-to-day routines will go a long way in making them feel more secure and unafraid.

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**Keep the conversation going.** Encourage your children to come and talk to you if they hear something that differs from what you have told them. Assure them that you will always be honest. At the same time, explain to their caregivers, teachers, and your family members what you have told them. Letting the people around your children know this information will help them support your children and keep an eye out for any changes in their mood or behaviour.

## TALKING WITH COWORKERS

Your cancer diagnosis and treatments are very personal matters. Who you tell, how much you say, and how you tell them will vary based on where you work and your relationships there. You may want to tell all or some of your coworkers, or only your supervisor or someone in Human Resources. At the least, you will have to explain any long absences or changes to your appearance.

Worrying about whether telling people at work will make things awkward or make people avoid you is completely normal. On the other hand, you may find it therapeutic and get support from your colleagues when you tell them.

You will also have to consider how you tell people at work about your cancer. You could tell a few people in person, or more at a bigger meeting. You could send an email, or have an email sent on your behalf.

## WHEN YOU DO NOT WANT TO TALK

Although it is very important to keep an open dialogue with your loved ones, it is understandable if you do not want to talk about your health with everyone or all the time. You may feel that it is easier to cope if you focus on your activities and keep busy. (It is important, however, to distinguish this sort of coping mechanism from intentionally bottling up your feelings.)

In these situations, it is okay to tell people that you do not feel up to talking. You could let them know that you would rather talk about or do something else right now, or that you will feel more comfortable talking to them later. In certain situations, it may be easier for you to provide a little bit of information about your health or how you feel and then change the topic.



## END-OF-LIFE PLANNING

Sometimes cancer continues to grow aggressively despite the best medicine and care available. When you are told that cure is no longer the goal of treatment, you will experience a range of emotions. You, and your loved ones, will feel overwhelmed and will deal with this news in different ways.

Acceptance will come with time. And it will allow you to focus on what is important and how best to spend the time you have left.

## **ADVANCE CARE PLANNING**

Based on your medical history, your doctor may give you an estimate for how long you may live. However, no one can predict this exactly. Some people live much longer than expected, and others may die sooner.

It might be prudent to create your advance care plan (ACP), a record of your wishes about your future healthcare decisions. This plan will guide your substitute decision-maker or the person to whom you have given power of attorney if you are unable to make your own decisions—for example, if you fall into a coma, or your illness impairs your ability to make decisions.

You will create your ACP through conversation with your healthcare team and your loved ones, and by reflecting on your own values and beliefs. Take this opportunity to discuss your preferences and fears. For example, many people with cancer have fears about living their last days in pain or feeling short of breath. An honest discussion will help alleviate these fears.

You can learn more by going to www.advancecareplanning.ca.

It is advisable at this time to make decisions regarding power of attorney, a will, and organ, tissue, or body donation. You may also choose to pre-plan or speak to your family about your wishes for a funeral or memorial service.

## **END-OF-LIFE CARE**

You will continue to receive palliative care to relieve symptoms and give you the best possible quality of life. You can receive this care at home, at a clinic or hospital, or in a hospice. It is important to remember (and let your loved ones know) that choosing to stay at a hospice does not mean that you do not want to spend time at home or that your family is failing to take care of you.

Conversations with your family and your healthcare team can help you determine which type of care you would like and when. You may feel most comfortable at home and want to be there as long as possible; or you may want to take advantage of the extra medical support and care available for you and your loved ones at a hospice.

If you are considering medical assistance in dying, a member of your healthcare team can provide more information for you and your loved ones. Information is also available at **www.canada.ca/en/health-canada/services/medical-assistance-dying.html**.

## GRIEF

You and your loved ones will feel profound grief at this time—not just extreme sadness, but also anger, guilt, confusion, and denial. It is important not to ignore these feelings and not to isolate yourself.

Talking to your family, a close friend, or a mental health professional will help you process the complicated and painful emotions that you have. This will take time, but by sharing your grief you can help each other heal and ease your burdens.

## PREPARING YOUR CHILDREN

Many parents, of all ages, avoid talking about their illness or about dying, simply out of love and a need to protect their children from harm. Children, however, do better and are more resilient when their parents explain to them the nature of the disease, and assure them that they will not be abandoned. If your cancer is no longer responding to treatment, telling your children about it will help them adjust and prepare for the future. Regular family discussions about what is happening in each of your lives can be a natural opportunity to keep your children informed. Social workers at your children's school can also help and support your children during this difficult time.

Use gentle, direct, age- and stage-appropriate language to explain the changes. With young children, you can use phrases such as *mommy is getting sicker*, *mommy is getting very sick* as things change, and later *mommy is very, very sick and will not get better*. These phrases convey a message of increased illness and help move the children along in their understanding of the illness.

## PRESERVING MEMORIES

During this time, there are many things you and your children can do together to recall, reflect on, and create new memories. The suggestions below can be an investment in your children's futures and can make an enormous difference to their well-being and adjustment after you are gone.

- Make a photo album to capture favourite moments; or talk about these memories and write about them together in a memory book.
- Fill a memory box together with favourite things that will remind your children of your best times together. Jot down thoughts and stories on small cards.
- Write on greeting cards for future occasions and milestones where your children will think of you and miss you—birthdays, holidays, graduations, weddings, and the births of their own children. You can also leave them gifts or mementos for important events.
- Write letters or record videos telling your children your hopes for their futures, and advice they will need at different stages of their lives. Although you may not be there in body, you will be there in spirit and in their thoughts.

# RESOURCES

There are many excellent organizations that support and provide resources and a network for people with cancer and their loved ones. Some are listed below.

## LUNG CANCER CANADA

#### www.lungcancercanada.ca

Lung Cancer Canada is a national charitable organization. We are Canada's leading resource for lung cancer education, support, research, and advocacy. We offer a variety of resources to educate and support those with lung cancer and their families:

- Our website is a trustworthy and timely source of lung cancer information and news
- Our newsletter, *Lung Cancer Connection*, explores topics of interest to the entire lung cancer community
- Our Resource Library allows access to specialized information
- Our social media presence, discussion forums, and patient stories on our website provide opportunities to connect with and offer support to one another

Lung Cancer Canada's Peer-to-Peer Navigators are lung cancer survivors and supporters (family members and caregivers) who have walked the lung cancer path. They know how difficult dealing with lung cancer can be. These volunteers offer mentorship, encouragement, advice, experience, and hope to anyone who has been newly diagnosed or who needs additional support through a one-on-one, personal connection. Go to **www.lungcancercanada.ca/get-involved/peer-to-peer.aspx**.

## **CANADIAN CANCER SOCIETY**

#### www.cancer.ca

The Canadian Cancer Society is a national, community-based organization of volunteers. They work to prevent cancer; fund cancer research; and empower, inform, support, and improve the lives of Canadians living with cancer. They offer:

- Answers from their Cancer Information Service
- Support from their online community of patients and caregivers

- Rides to treatment
- Practical support for people at some treatment centres and lodges
- Help with quitting from their Smokers' Helpline (1-877-513-5333; www.smokershelpline.ca)

### WELLSPRING

#### www.wellspring.ca

Wellspring is a network of community-based support centres that offer programs and services to meet the emotional, social, practical, and restorative needs of people with cancer and those who care for them. Wellspring programs are offered free of charge.

## **CANADIAN LUNG ASSOCIATION**

#### www.lung.ca

The Canadian Lung Association promotes lung health, and prevention and management of lung disease. They fund research, advocate for policies, and provide support for patients.

## **GILDA'S CLUB**

Gilda's Club provides a social community for people with cancer, and their families and friends. Local chapters offer support and education in a home-like setting and are free of charge.

# **GLOSSARY**

#### Adenocarcinoma (A-deh-noh-KAR-sih-NOH-muh) The most common type of non–small cell lung cancer.

#### Adjuvant therapy (A-joo-vunt THAYR-uh-pee)

Treatment given after primary therapy (usually chemotherapy after surgery) to kill any remaining cancer cells that may not have been removed by surgery and to help prevent recurrence.

#### Alveoli (al-VEE-oh-lie)

Microscopic air sacs where oxygen from the air that is breathed in enters the blood, and where carbon dioxide leaves the blood. Plural form of *alveolus*.

#### Anemia (uh-NEE-mee-uh)

Condition in which blood is deficient in red blood cells, in hemoglobin (oxygentransporting molecule), or in total volume.

**Benign** (beh-NINE) Not malignant or cancerous.

#### **Bilobectomy** (by-loh-BEK-toh-mee) Surgery that removes two lobes of a lung.

**Biopsy** (BY-op-see) Removal of tissue from the body to test for cancer.

#### Bone marrow (bone MAYR-oh)

Tissue that occupies the cavities of most bones. Red bone marrow makes the cells found in blood.

#### Brachytherapy (BRAY-kee-THAYR-uh-pee)

Treatment with radiation in which the source of radiation is placed in or close to the area being treated. The treatment site is accessed via the bronchi. Also known as *endobronchial radiation*.

#### Bronchi (BRON-ky)

The major airways that branch off from the trachea (windpipe) to the lungs. Plural from of *bronchus*.

**Bronchiole** (BRON-kee-ole) Minute thin-walled branch of a bronchus.

Bronchus (BRON-kus) See bronchi.

**Carcinogen** (kar-SIH-noh-jin) Substance that is known to cause cancer.

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#### Carcinoid tumour (KAR-sih-noyd TOO-mer)

Rare, slow-growing tumour that arises from hormone-producing cells that line the bronchi and bronchioles.

**Chemoradiation** (KEE-moh-RAY-dee-AY-shun) Treatment that combines chemotherapy and radiotherapy.

#### Chemotherapy (KEE-moh-THAYR-uh-pee)

Treatment of cancer with chemical agents that destroy or inhibit the growth and division of malignant cells.

**Core needle biopsy** (kor NEE-dul BY-op-see) Removal of tissue from the body with a hollow needle.

**CT simulation** (CEE-TEE SIM-yoo-LAY-shun) The process of planning radiation therapy in which the doctor locates and marks the target area. Also known as *simulation*.

**Curative therapy** (KYOOR-uh-tiv THAYR-uh-pee) Treatment given with the goal of curing cancer.

**Deep vein thrombosis (DVT)** (deep vayn throm-BOH-sis) Blood clot inside a vein deep inside the body (usually the legs).

#### Diaphragm (DY-uh-fram)

A thin sheet of muscle and tissue that separates the chest cavity and the organs in it from the organs below it in the abdomen.

**Doublet chemotherapy** (DUH-bliht KEE-moh-THAYR-uh-pee) Combination treatment with two chemotherapy drugs.

Embolus (EM-boh-lus)

An abnormal particle, like an air bubble or piece of a blood clot, circulating in the blood.

**Endobronchial radiation** (EN-doh-BRON-kee-ul RAY-dee-AY-shun) See *Brachytherapy*.

**Endobronchial therapies** (EN-doh-BRON-kee-ul THAYR-uh-pees) Various procedures performed inside the bronchi to remove airway blockages and make breathing easier.

**Extensive stage** (ek-STEN-siv stayj) Stage of small cell lung cancer that has spread from one lung to other areas in the body.

#### External beam radiation therapy (EBRT) (ek-STER-nul beem RAY-dee-AY-shun

THAYR-uh-pee)

Treatment with high-energy beams of radiation that are aimed directly at a tumour to kill cancer cells.

#### Fine needle aspiration (fyn NEE-dul AS-pih-RAY-shun)

Removal of tissue of fluid from the body with a thin needle.

**First-line therapy** (first-lyn THAYR-uh-pee) Initial systemic treatment that has been determined to have the best probability of shrinking the cancer.

#### General anesthetic (JEH-neh-rul A-nes-THEH-tik)

Drugs that create a state of unconsciousness and absence of pain in the entire body.

Grade (grayd)

Term used to describe how close to abnormal (or different from healthy cells) cancer cells look under a microscope.

Hemoglobin (HEE-moh-GLOH-bin) Molecule in red blood cells that transports oxygen.

**Hypoxemia** (HY-pok-SEE-mee-uh) Condition in which there is an insufficient amount of oxygen in the blood.

**Immunotherapy** (IH-myoo-noh-THAYR-uh-pee) Treatment of cancer that involves the stimulation, enhancement, suppression, or desensitization of the immune system.

Large cell carcinoma (LCC) (larj sel KAR-sih-NOH-muh) An uncommon type of non–small cell lung cancer.

Larynx (LAYR-inks) Voice box; upper part of the respiratory passage that contains the vocal chords.

Limited stage (LIH-mih-ted stayj) Stage of small cell lung cancer that is confined to one lung or the area near that lung.

#### Lobe (lohb) A compartment of the lung.

**Lobectomy** (loh-BEK-toh-mee) Removal of a lobe of a lung.

Local anesthetic (LOH-kul A-nes-THEH-tik) Drugs that create loss of pain and feeling in a small area of the body.

Local treatment (LOH-kul TREET-ment) Treatment directed at and limited to a specific part of the body.

Lymph nodes (limf nohds) Fluid-filtering glands located throughout the body.

Maintenance therapy (MAYN-teh-nunts THAYR-uh-pee) Ongoing use of systemic treatment after first-line therapy to prevent a cancer from progressing (that is, from starting to grow again).

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#### Malignant (muh-LIG-nunt)

Cancerous; capable of invading surrounding tissue and spreading to other areas of the body.

#### Margin (MAR-jin)

The edge of tissue removed during surgery. Margins are examined under a microscope to determine whether all cancerous tissue was removed.

**Mediastinotomy** (MEE-dee-A-stih-NAH-toh-mee) Surgical incision of the mediastinum.

**Mediastinum** (MEE-dee-uh-STY-num) Area in the middle of the chest between the lungs that contains structures such as the windpipe, lymph nodes, heart, and gullet.

**Metastasis** (meh-TAS-tuh-sis) Spread of cancer to other organs through the lymphatic system or bloodstream.

Metastatic lung cancer (meh-tuh-STA-tik lung KAN-ser) Advanced lung cancer that has spread from the primary tumour in the lung to other

parts of the body.

Mutation (myoo-TAY-shun) A change in the DNA sequence that may cause cancer or other diseases.

**Neoadjuvant therapy** (NEE-oh-A-joo-vant THAYR-uh-pee) Treatment given before primary therapy (usually chemotherapy before surgery) to shrink a tumour.

#### Non-small cell lung cancer (NSCLC) (nahn-smahl sel lung KAN-ser)

A major class of lung cancer. It has three main subtypes: adenocarcinoma, squamous cell carcinoma, and large cell carcinoma.

#### Palliative therapy (PA-lee-uh-tiv THAYR-uh-pee)

Treatment given with the goal of relieving the symptoms of cancer and improving quality of life.

#### Platelets (PLAYT-lets)

Cell fragments in the blood that help with blood clotting.

#### Pleura (PLOOR-uh)

Thin double-layered membrane that covers the outer surface of the lung and the inner surface of the chest wall.

**Pleural effusion** (PLOOR-ul eh-FYOO-zhun) Collection of fluid between the two layers of the pleural membranes.

#### Pleural membrane (PLOOR-ul MEM-brayn)

Thin, double layer of tissue that envelopes the lungs and the inside wall of the chest cavity.

GLOSSARY

#### Pleural mesothelioma (PLOOR-ul MEH-zoh-THEE-lee-OH-muh)

Cancer that develops in the pleura and is usually related to asbestos exposure. It is not a lung cancer but is treated by many of the same specialists that treat lung cancer.

**Pleural space** (PLOOR-ul spays) Area between the two pleural membranes.

**Pleurodesis** (PLOOR-oh-DEE-sis) Treatment of severe pleural effusion by sealing the pleural membranes together to remove the cavity between them.

**Pneumonectomy** (NOO-moh-NEK-toh-mee) Surgical removal of an entire lung. Also known as *pneumectomy*.

**Primary therapy** (PRY-mayr-ee THAYR-uh-pee) Initial treatment given with the intention to cure or prolong life.

**Primary tumour** (PRY-mayr-ee TOO-mer) Site in the body where cancer first started.

**Prophylactic cranial irradiation (PCI)** (PROH-fih-LAK-tik KRAY-nee-ul ir-RAY-dee-AY-shun)

Radiation treatment given to the brain to treat microscopic cancer cells that may have spread to the brain but are undetectable.

**Pulmonary embolism** (PE) (PUL-muh-NAYR-ee EM-boh-lih-zum) Blockage of an artery in the lung or one of its smaller branches by a blood clot.

**Radiation therapy** (RAY-dee-AY-shun THAYR-uh-pee) Treatment that uses high-energy rays to destroy cancer cells.

**Radiosurgery** (RAY-dee-oh-SER-juh-ree) See Stereotactic body radiation therapy (SBRT).

**Recurrence** (ree-KER-ents) Return of cancer after treatment.

**Red blood cells** (red blud sels) Cells in the blood that carry oxygen.

**Remission** (reh-MIH-shun) Absence of cancer.

**Secondary tumour** (SEH-kun-dayr-ee TOO-mer) Cancer that has spread from where it first started to another part of the body.

#### Second-line therapy (SEH-kund-lyn THAYR-uh-pee)

Systemic treatment that is given if the cancer has not responded to or has recurred after first-line therapy or maintenance therapy.

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#### Segmentectomy (seg-men-TEK-toh-mee)

Surgery to remove part of a lobe of a lung. Also known as wedge resection.

**Simulation** (SIM-yoo-LAY-shun) See *CT simulation*.

#### Sleeve resection (sleev ree-SEK-shun)

Surgery to remove a tumour that has grown in a lobe of the lung and a part of a bronchus. The two cut ends of the bronchus are then reattached and the remaining lobes are reconnected to the airways.

Small cell lung cancer (SCLC) (smahl sel lung KAN-ser)

A major class of lung cancer.

**Soft-tissue sarcoma** (soft TIH-shoo sar-KOH-muh) Rare cancer that usually develops in the pleural membranes and grows very slowly.

Squamous cell carcinoma (SCC) (SKWAY-mus sel KAR-sih-NOH-muh) Type of non-small cell lung cancer.

**Stage** (stayj) Describes the size and extent of a primary tumour and whether it shows evidence of metastasis.

**Stereotactic ablative radiotherapy (SABR)** (STAYR-ee-oh-TAK-tik a-BLAY-tiv RAY-dee-oh THAYR-uh-pee) See *Stereotactic body radiation therapy (SBRT*).

## **Stereotactic body radiation therapy (SBRT)** (STAYR-ee-oh-TAK-tik BAW-dee RAY-dee-AY-shun THAYR-uh-pee)

Type of external radiation in which very large radiation doses are given in a short treatment time. Compared to other types of radiotherapy, this technique delivers less radiation to normal tissue. Also known as *radiosurgery* or *stereotactic ablative radiotherapy* (SABR).

**Surgery** (SER-juh-ree)

An operation to remove or repair a part of the body.

**Systemic treatment** (sis-TEH-mik TREET-ment) Treatment with drugs that enter the bloodstream and affect the entire body.

Targeted therapy (TAR-geh-ted THAYR-uh-pee)

Type of cancer treatment that works directly on specific molecules in cancer cells. These drugs do not interfere with normal, healthy cells in the body (or do so to a lesser extent).

Third-line therapy (third-lyn THAYR-uh-pee)

Systemic treatment that is given if the cancer has not responded to or has recurred after second-line therapy.

GLOSSARY

#### **Thoracentesis** (THOR-uh-sen-TEE-sis) Removal of fluid from the chest with a needle.

**Thoracotomy** (THOR-uh-KAW-toh-mee) Surgical incision of the chest wall.

Thorax (THOR-aks) The chest.

**Thrombus** (THROM-bus) Blood clot inside a blood vessel (usually a vein).

#### TNM staging system (TEE-EN-EM STAY-jing SIS-tem)

A system used to classify the extent of cancer. It considers the size of the tumour and the spread of cancer to lymph nodes and other parts of the body.

**Trachea** (TRAY-kee-uh) The windpipe.

#### Video-assisted thoracic surgery (VATS) (VIH-dee-oh-uh-SIS-ted thor-A-sik

SER-juh-ree) Chest surgery carried out with the help of a video camera.

Wedge resection (wej ree-SEK-shun) See Segmentectomy.

White blood cells (wyt blud sels)

Cells of the immune system found in the blood. They help fight infections and disease.

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## NOTES


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Lung Cancer Canada is a national charity and the only one dedicated solely to lung cancer. It relies on donations to offer programs and services, such as this booklet, to patients and their families.

Donations are greatly appreciated and a tax receipt is issued for a donation of \$20 or more. Donations can be made online at **www.lungcancercanada.ca**, or by calling the numbers above.