



## Lung Cancer Kit

### Introduction

We created the *Lung Cancer Kit* to highlight the key principles for you as you manage the cancer decision-making process. In it, you will find tools designed to present you with insightful information you as a patient or caregiver will find helpful in your own search for the best cancer treatment available.

Undoubtedly, many unfamiliar issues surface after a cancer diagnosis – questions and concerns you never imagined you would have to face. It's OK to feel overwhelmed, angry or upset. Your situation requires you to make a multitude of tough decisions, often immediately. But you *do* have the power to make sharp, informed decisions. You have the power to take charge of your situation – but to do so, you need to sort through all of the emotions – yours and your loved ones' – assess all of the facts and identify a solution to help you get back on track.

As you flip through the following pages, you will find five sections. “Understanding Lung Cancer,” “Overview of Treatment Options,” “Questions to Ask Your Doctor,” “Selecting Your Treatment Hospital,” and, most importantly, the final piece entitled the “Decision Guide.”

*The Decision Guide is not for everyone.* It is a worksheet we want you to use to help you gain additional control and take a more active role in the decision-making process. It requires you to begin asking questions – hard questions – that ask what you are looking for in a hospital and a physician, the goals and expectations you bring to the treatment process and the steps you need to take to make your goals a reality. If this sounds different to you, it's because it *is* different! We believe you *must* be a key player and a decision-maker, in order to find and secure the treatment that's right for you.

At the very least, the *Lung Cancer Kit* contains useful information about hospitals, treatment options and questions you may use to assess the doctors and hospitals you visit throughout this experience. Good luck!

### Understanding Lung Cancer

Lung cancer represents the most common form of cancer diagnosed in the United States. Understanding lung cancer requires you to become familiar with some *basic* information regarding how and why lung cancer develops in the body. Like all cancers, lung cancer originates at the cellular level. Your body consists of *countless* numbers of cells. Generating new cells to replace old or damaged cells allows the body to continually restore itself through this natural maintenance process. But sometimes, normal cells *mutate*, or change, and begin growing and dividing at uncontrollable rates. This uncontrolled cellular growth is called *cancer*.

Four factors increase a person's lung cancer risk – *age*, *gender*, *genetics* and *environmental carcinogens*. As a person ages, the immune system diminishes, reducing its ability to recognize, attack and kill damaged cells. Left untouched, these damaged cells can take root and multiply, resulting in cancer. Gender, too, plays a role in lung cancer risk. Studies show a woman's body exhibits greater susceptibility to cancer-causing substances, called *carcinogens*, than a man's body. Apart from age and gender, genetic make-up, including a *family medical history* of cancer, may actually increase a person's likelihood of developing cancerous cells. But *environmental* carcinogens primarily instigate the process of cellular mutation. Assisted considerably by age, gender and an individual's unique genetic risk factors, environmental carcinogens like tobacco smoke, asbestos and radon gas contaminate healthy cells with cancer-causing chemicals.

### Small Cell and Non-Small-Cell Lung Cancer

A lung cancer diagnosis may leave you with many unanswered questions. Uncovering some of these answers begins by

learning about the specific *type* of lung cancer diagnosis you receive. Two main types of lung cancers exist: *small cell* and *non-small-cell*.

Derived from the lung's hormonal cells, *small cell* lung cancers (SCLC) represent fifteen to twenty percent of all newly diagnosed lung cancer cases. Sometimes called *oat cell* cancer because of its oat grain-like shape, SCLC typically grows faster and is more aggressive than its non-small-cell counterpart. A person diagnosed with SCLC may hear the terms "*limited*" or "*extensive*" associated with the diagnosis. A "limited" SCLC means the cancer exists only in the chest cavity with no signs of metastasis elsewhere in the body. An "extensive" SCLC represents an umbrella term for all other small cell lung cancers that have spread *beyond* the chest.

*Non-small-cell* lung cancers (NSLC) encompass seventy-five to eighty percent of all new lung cancer diagnoses. Unlike small cell lung cancer, a NSLC classification includes three major subtypes: *adenocarcinoma*, *squamous carcinoma* and *large cell carcinoma*.

- **Adenocarcinoma** represents the most common form of NSLC diagnosed in the United States – especially amongst women. Adenocarcinoma comprises forty percent of all lung cancer diagnoses. When adenocarcinoma develops in the lung's tiny air sacs, called *alveoli*, the diagnosis shifts to *bronchioalveolar adenocarcinoma*.
- **Squamous carcinoma** represents the second major NSLC subtype, accounting for thirty to thirty-five percent of lung cancer diagnoses. Linked closely with cigarette smoking, squamous carcinoma usually originates in the lung's large breathing tubes, called *bronchi*.
- **Large cell carcinoma**, the final NSLC type, typically begins growing in branches of the smaller breathing tubes called *bronchioles* and may migrate towards an area behind the breastbone termed the *mediastinum*. The esophagus, windpipe, bronchi and heart are contained in the mediastinum.

Talking to a doctor about something as serious as cancer can be intimidating, especially if you feel overwhelmed or upset about confronting the disease. Weaving an understanding of your type of lung cancer, together with knowledge of how and why the disease developed in your body, can equip you with a greater sense of control when interacting with physicians.

## | An Important Note on Lung Cancer Staging

Deciding upon a course of treatment may be the hardest, yet most important life choice a person makes during this time. Making educated treatment decisions begins by learning about the stage, or *progression*, of lung cancer in the body. A properly staged lung cancer, backed by second or third opinions from different oncologists, presents you with a more clear-cut picture of where the cancer exists in your body – the first important step you can take in determining the best treatment options available to help you beat cancer.

The United States currently uses the *TNM staging method* to stage cancer. TNM stands for "Tumor," "Node" and "Metastasis." Properly staging lung cancer requires the know-how of a *Pathologist* – a doctor with special training and expertise in analyzing human cell structure. Using a microscope, the pathologist closely examines your tissue samples, documenting cell structure, tumor size and evidence of lymph node involvement. Before handing this *pathologic information* to the oncologist, the pathologist assigns a tumor *Grade (G)*. The tumor grade reflects the *appearance* of the cancer cells under the microscope. A cancer cell that appears very similar to a normal, healthy cell is said to be *well-differentiated (G1)*. In contrast, an *undifferentiated (G4)* cancer cell might have an altogether different size, shape or appearance than a normal cell. More aggressive tumors generally contain a high number of undifferentiated cancer cells.

Combining this pathologic information with data obtained from surgery and other scans, helps the oncologist determine the overall progression, or *stage*, of cancer in your body. Inserting the information reflecting Tumor, Node, Metastasis and Grade into a comparative table helps your oncologist consolidate this information into a Roman numeral that indicates the extent of your disease. The Roman numerals 0, I, II, III and IV represent the various stages of cancer, with Stages 0 and I representing *early stage* cancers and Stages III and IV representing *late stage* cancers. Different stages of cancer call for different treatments.

A listing of the tools needed to diagnose and stage lung cancer follows:

## Physical Exam

A physical exam consists of a one-on-one examination between the patient and physician. Throughout the exam, the physician will ask questions designed to clarify your current level of health and identify any symptoms pointing to potential areas requiring further examination.

The physician will listen to your breathing patterns and may ask you to perform a variety of breathing tests to assess lung function. Apart from breathing tests, the physician also examines the abdomen and *lymph nodes*. Lymph nodes collect and transport excess fluid, bacteria and cellular waste from the body in a yellow-tinted fluid called *lymph*. Examining the lymph nodes, located around the neck and collarbone, allows the physician to check for evidence of lymph node tenderness or swelling – possible indicators of advanced lung cancer.

## Diagnostic Tests

Diagnostic tests provide images of the human body utilizing x-rays, magnets, radioisotopes, special video equipment or actual tissue samples to present physicians with an “inside” view of the lung.

- **Chest x-ray** – A chest x-ray employs conventional x-rays to produce a two-dimensional picture of the lungs on x-ray film. Viewing the x-ray film sometimes allows oncologists to identify the actual tumor site. In other cases, chest x-ray reveals fluid build-up, enlarged lymph nodes or other symptoms associated with lung cancer. Using chest x-rays during and after treatment presents oncologists with a pictorial history that charts your progression through the treatment process.
- **Computerized Tomography (CT) Scans** – Computerized tomography scans utilize x-rays to create cross-sectional images of the body. Computerized tomography works by fusing x-ray technology with sophisticated computer imaging systems. Recent advances in CT scanning-speed and imaging capabilities produce precise four-dimensional images in a fraction of the time older CT machines require.
- **Positron Emission Tomography (PET) Scans** – Positron emission tomography differentiates normal cells from rapidly dividing cancer cells by measuring cellular *activity*. Injecting a small amount of a sugar-bound radioisotope into the patient’s vein allows the PET scan to distinguish between normal and abnormal cellular activity by recording how the different cells burn sugar. Rapidly dividing cancer cells burn sugar at a faster rate than normal cells, distinguishing the cancer cells from healthy tissue.

PET scans enable doctors to identify distant metastatic cancer sites, providing patients and their physicians a level of information not achieved by CT scans or x-rays. Very few facilities offer this technology – you might wish to consider this when pursuing treatment options or second opinions.

- **Sputum Cytology** – Sputum cytology utilizes a mucus sample, called *sputum*, coughed up from the bronchial tubes to identify cancer in the bronchi. Sputum cytology allows physicians to identify abnormal cell growth (*dysplasia*) and early cancerous growth (*in situ*) well before the existence of a visible tumor.
- **Biopsy** – A biopsy employs surgery, needle aspiration or bronchoscopy to remove a tissue sample from the suspected disease site. Examining the tissue through a microscope helps the *Pathologist* – a doctor with special training and expertise in analyzing human cell structure – to identify a specific type and stage of cancer.
- **Bronchoscopy** – Bronchoscopy employs a small, flexible camera, called a *bronchoscope*, to provide doctors with a view of the main breathing tubes, or *bronchi*. Bronchoscopes may also collect tissue samples from suspect areas detected during the procedure. Mild sedation is used to make the patient feel more comfortable while the bronchoscope navigates the air passageways.
- **Fluorescence Bronchoscopy** – Fluorescence bronchoscopy evolved from night-vision technology. By exposing tissue to a special blue light, abnormal cells fluoresce a rust color while normal cells glow green. Fluorescence bronchoscopy can identify lung cancer in its earliest, most treatable stages by revealing problem areas invisible under a standard “white light” bronchoscopy.
- **Mediastinoscopy** – Mediastinoscopy utilizes a tiny camera called an *endoscope* to view the area behind the breastbone known as the *mediastinum*. Inserted into the mediastinum through a tiny surgical incision in the neck or chest, the endoscope helps oncologists determine disease progression to the lymph nodes near the trachea.
- **Pulmonary Function Test** – The pulmonary function test assesses a person’s normal breathing function by measuring the amount of air moving in and out of lungs on a machine called a *spirometer*. Pulmonary function plays an important role in determining your ability to tolerate some surgical procedures.

## Overview of Treatment Options

Today, more than ever, patients have access to an array of lung cancer treatment options. The sheer number of available options makes understanding the basic treatments an extremely important component of your decision-making process. Exploring this wide range of treatment options requires a *general* understanding of three traditional treatment modalities – surgery, radiation therapy and chemotherapy. New, emerging therapies constitute a fourth group of therapies you may examine prior to selecting a treatment option that’s right for you.

Here is some *basic* information about the four treatment categories. Keep in mind, selecting a treatment is not only important but a *highly personal* decision. Lung cancer takes *years* to develop from a single cell into its present state. Taking extra time to review treatment options with family members or other close friends may help you feel more comfortable and confident before proceeding with treatment.

### Surgery

Surgery is the oldest and, perhaps, the most widely practiced form of cancer treatment. Nearly sixty percent of *all* cancer patients undergo some form of surgical treatment. Surgery is often used in conjunction with radiation therapy and/or chemotherapy. Before pursuing surgical treatment, patients should *always* obtain a second medical opinion from a *different* specialist. Surgery is permanent – therefore, it is critical for care providers to conduct *thorough laboratory* and *diagnostic work* to ensure the cancer is confined to the surgical area.

A brief listing of lung cancer surgical procedures follows:

- **Lobectomy** – A lobectomy is an inpatient procedure involving the removal of a complete section, or *lobe*, of the lung. Typically, two lobes make-up the left lung; three lobes comprise the right lung. The surgeon also removes some lymph nodes to test for evidence of cancer.
- **Pneumonectomy** – A pneumonectomy is an inpatient procedure consisting of the *complete surgical removal* of the cancerous lung.
- **Wedge Resection** – A wedge resection is an inpatient procedure involving the surgical removal of a small section, or *wedge*, of the lung. Wedge resection limits the amount of lung tissue removed during surgery, preserving valuable lung capacity for smokers or other people with limited lung function.
- **Thoracoscopic Resection** – A thoracoscopic resection is an inpatient procedure consisting of the surgical removal of the tumor and a layer of healthy lung tissue surrounding the tumor site. Three small one-inch incisions – one on the chest, one on the back and one under the arm – permit the surgical oncologist to insert a tiny camera, called a *thoroscope*, into the chest cavity to view the affected area of the lung. The minimal size of each incision helps speed a patient’s recovery time after completing surgery.

Currently, surgery offers the highest chance of success for stage I and stage II lung cancers. Surgery may also benefit select stage III lung cancers. In rare circumstances, surgery, in conjunction with other *adjuvant* therapies like radiation or chemotherapy, present the best option for treating stage IV lung cancers.

### Radiation Therapy

There are two types of radiation therapy – internal and external. Both forms irradiate *localized* regions of the body. External radiation works by utilizing high-powered x-rays, gamma rays or electron beam radiation to target and destroy rapidly dividing cancerous cells located in a specific site of the body. Internal radiation employs tiny radioactive seeds, pellets, capsules or needles to deliver an *internal* dose of radiation for a predetermined period of time.

Recent technological advances in diagnostic imaging machinery allow *Radiation Oncologists* – doctors who specialize in the planning and delivery of radiation therapy – to map a cancerous site and deliver precise beams of radiation right where patients need it most. Differences *do* exist in the quality of radiation equipment; therefore, patients should always look for a treatment facility with the latest diagnostic equipment and radiation machinery. Radiation therapy is often used in conjunction with surgery and/or chemotherapy.

- **3-D Conformal Radiation Therapy** – 3-D conformal radiation therapy is an *external* form of radiation therapy utilizing computed tomography (CT) planning to image and reconstruct the tumor and surrounding normal tissues in three dimensions using a computer program. This technology allows the radiation oncologist to *conform* the radiation beam(s) to specific target areas. Because the radiation beams are precisely focused, your nearby normal tissue is spared.

- **Intensity Modulated Radiation Therapy (IMRT)** – IMRT represents an advanced form of *external 3-D* conformal radiation therapy. Employing a powerful computer program to plan the precise dose of radiation in three dimensions, radiation oncologists may vary the *intensity and conformance* of pencil-thin radiation beams onto specific cancerous sites. Our cancer experts tell us they are able to use higher radiation doses than traditional methods would allow in these areas, and yet spare more of the surrounding healthy tissue, compared to standard radiation therapy.
- **Lung High-Dose-Rate (HDR) Brachytherapy** – Lung HDR brachytherapy represents a form of *internal* radiation therapy and may be used any time a visible tumor exists in an airway on bronchoscopy. During bronchoscopy, the oncologist places a thin plastic tube down the nose, into the diseased breathing tube or *bronchus*. After removing the bronchoscope, a thin tube remains over the diseased site for approximately thirty minutes, delivering a small radioactive dose directly to the affected area.

## Chemotherapy

Chemotherapy is a broad term relating to a group of medications designed to damage a cancer cell's ability to grow. *Medical Oncologists* – doctors who specialize in treating cancer with different types of drugs and chemotherapy – oversee this aspect of cancer treatment. Patients may receive chemotherapy orally or through an intravenous (IV) administration. Chemotherapy may be administered throughout the treatment process. Sometimes, *neoadjuvant chemotherapy* – chemotherapy administered *prior* to a primary treatment like surgery – can increase the effectiveness of the primary treatment. Likewise, chemotherapy administered *after* a primary treatment, called *adjuvant chemotherapy*, can reduce the likelihood of tumor spread or cancer recurrence.

Unlike radiation therapy, conventional chemotherapy is a *systemic* treatment carried throughout the entire body by the bloodstream. New medications help to control side effects and, with the proper comprehensive team of experts, the side effects can usually be managed and minimized. Chemotherapy is often used in conjunction with surgery and/or radiation therapy.

Today, you and your doctors may choose from an array of chemotherapies. Each unique case requires the oncologist to identify the *most effective* form of chemotherapy available to treat your particular form of lung cancer. Determining the appropriate chemotherapy sometimes requires oncologists to test tissue samples for *chemosensitivity*. Chemosensitivity testing reveals *how* your cancer cells react to various chemotherapeutic agents *prior to* administering the actual dose. Information obtained via chemosensitivity testing allows the oncologist to select only those chemotherapeutic agent(s) showing positive results when delivered to your tissue samples.

Chemotherapy can also be delivered differently to enhance effectiveness:

- **Fractionated Dose Chemotherapy** – Fractionated dose chemotherapy utilizes a standard dose of chemotherapy and divides this standard dosage over a three-to-five day period. The smaller dosages minimize the side effects of this powerful medicine while maximizing the intensity of the treatment by exposing cancerous cells to chemotherapy for a longer period of time.

## Emerging Therapies

In the hands of a skilled physician, emerging therapies represent promising new treatment options available in select hospitals across the country. Immunotherapy, photodynamic therapy (PDT) and hormone therapy illustrate some of the more prominent emerging therapies now available to patients. Typically, you and your physicians may turn to emerging therapies in three different situations: after exhausting all surgical, radiation and/or chemotherapy options; when your physician determines traditional therapies will no longer improve your condition; or when you may benefit from an emerging therapy used in conjunction with other conventional treatments.

A brief listing of emerging therapies follows:

- **Photodynamic Therapy (PDT)** – Like brachytherapy, PDT can be used to help open up a blocked airway, to treat a very early (*in situ*) lung cancer or to treat a previously treated lung cancer. PDT involves injecting a chemical substance, called *photoporphyrin*, into the bloodstream. Tumor cells absorb the photoporphyrin, priming the site for treatment. After 24 to 48 hours, a red laser light, directed through a bronchoscope, activates the photoporphyrin, killing the exposed tumor.

## Special Services

Apart from the four main treatment modalities, you should also consider pain management and *palliative care* services.

### Palliative Care

Palliative Care is a specialized form of medicine focused upon alleviating pain, nausea or any number of other side effects you may experience during treatment. Few hospitals offer a dedicated Palliative Care Department – but regardless of this trend, effectively managing a cancer patient’s pain is necessary for optimal treatment. Unmanaged pain may interfere with your sleep patterns, appetite and treatment schedule. It will be very helpful to you in deciding where to go for treatment, to inquire about the Palliative Care or Pain Management programs available in the hospitals you assess.

