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Lung Cancer: What the Patient and Family Need To Know

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In 2005 there were 89,500 new lung cancer cases diagnosed in men, 74,600 in women, and 156,900 lung cancer patients succumbed to their illness. It is sad to say that, even with today's medical advances, only 14% of Americans afflicted will overcome this disease. It is small comfort that this is almost double the survival rate in Europe and the developing world, perhaps because our medical care system provides the most up to date methods of treatment. Yet we have high hopes for today's lung cancer's victims: we are on the brink of great advances in medical care for this tragic disease.

What is lung cancer? To understand the disease, we must understand how we breathe. The two lungs that form the breathing apparatus in humans consist of two parts, a branching tree of airways called *bronchi*, that brings air and oxygen to the innermost part of the lungs, and the spongy tiny cavities known as air sacs or *alveoli* which allow the transfer of oxygen to our blood, and, in return, receive carbon dioxide that is expelled from the body as a waste product.

The vast majority of lung cancers arise in either the tissue lining of these bronchi airways (*squamous cell lung cancer*) or in the glands below the surface of this lining that produce the mucus we cough up when we have a respiratory infection (*adenocarcinoma lung cancer*). With some cancers that arise in the bronchi, we are not precisely sure of the kind of cell from which the cancer originates (*large cell lung cancer*). A tiny proportion of cancers can arise from the cells forming the small air sacs themselves (*bronchioalveolar lung cancer*). Together, all of these tumors can be grouped together as *non-small cell lung cancer*, which comprise 75% of all lung cancer diagnoses. *Small cell lung cancer*, which seems to arise from nerve-like cells in the wall of the bronchial airways, makes up the remaining 25% of diagnoses. The groupings into non-small cell and small cell lung cancers are very important because the therapy used to fight the cancer and the prognosis we can expect are drastically different.

Ninety percent of all lung cancers are caused by smoking in some form. Each year, approximately 15% of the cases diagnosed in lifetime non-smokers can be attributed to exposure to second hand smoke, resulting in about 2000 deaths. This important fact indicates that many people die of lung cancer as innocent bystanders; they have done nothing to impair their own health. While there are other causes of lung cancer,

all are dwarfed by smoking. The risk of contracting lung cancer for smokers is 13 times that for non-smokers (10 times the risk of the nonsmoker for a one pack per day user and 20 times the risk of the nonsmoker for a 2 pack per day user).

There are no nerve endings inside the lungs. Therefore, tumor growth is often painless and undetectable. Signs of the illness can be vague and may include an unexplained cough, frequent episodes of bronchitis or multiple episodes of pneumonia, wheezing, shortness of breath, worsening of emphysema, or the spitting or coughing up of blood. A person may develop unexplained lumps in the neck, pain in the right upper abdomen above the liver area, bone or joint pains or headaches and other neurological symptoms, all of which could indicate the spread of the illness outside the chest cavity (*metastasis*). Sometimes the illness is so stealthy that the only sign might be an unexplained loss of weight, appetite, or energy.

If one develops such symptoms, he or she should immediately seek evaluation by a physician, because for the majority of the non-small cell lung cancer cases, early detection can increase the cure rate from one in seven to an encouraging 70%. Later in this book I will discuss how the patient can get the best possible care in battling his disease by acting as an educated consumer.

The history of the patient's symptoms, together with a physical exam should alert the physician to the possibility of lung cancer. The first step in diagnosis is a chest X-ray, which may or may not show the tumor. Even if the chest X-ray is negative, especially in a smoker, the doctor will order a CT scan (*Computerized Axial Tomography or computerized X-ray scan*) of the chest, a much more accurate diagnostic tool. If a tumor is seen or suspected, the physician will order appropriate blood tests or CT scans of the brain, abdomen, and sometimes pelvis to check for signs of the disease elsewhere in the body, and a bone scan, that will detect diseased areas of the skeleton. Most recently, the PET (*Positron Emission Tomography*) scan and the PET—CT scan, in which a radio-isotope is injected into the bloodstream to look for active areas of chemical metabolism that are characteristic of cancer activity, have been added to the physician's diagnostic resources.

The patient's primary physician may forgo these diagnostic tests and immediately refer the patient to a *pulmonologist*, a specialist in lung disease, who may then order these procedures. This specialist will in most cases also perform a *bronchoscopy*, where a tube of fiber optic light is inserted into the airway to locate the tumor, visualize it and obtain a piece (a *biopsy*) to determine the type of lung cancer present, which, in turn, will determine the appropriate type of therapy to be used to fight the disease. If the tumor is unreachable because it is located on the outer portions of the lungs, the physician may recommend a procedure called a *CT directed needle biopsy*, in which a radiologist, using the CT imaging machine as a guide, directs a slender needle into the tumor for a tissue sample. If it appears that the tumor is surgically

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removable and is still confined to the chest, the pulmonologist will use all of the available clinical findings to make a decision on whether to refer the patient to a *thoracic* (chest) *surgeon*. If the tumor is not confined to the chest, he will refer the patient to a *medical oncologist* who can treat the tumor wherever it is in the body using medications known as *chemotherapy*, or refer the patient to a *radiation oncologist* who will use high energy X-rays (*radiotherapy or radiation*) to attempt to eliminate or shrink the tumor.

The thoracic surgeon generally makes the decision whether the tumor can be completely excised by removing either a part of the lung or the entire lung. If the tumor has spread outside the chest, deep into the lymph nodes or into the most central portion of the bronchial network where the trachea (windpipe) divides into two branches, one to each lung, he will not operate. Nor will he operate if the tumor is found to be of the small cell type, as these tumors always spread outside the chest cavity. Even though such spread may be undetectable at the time of the tumor's diagnosis, the recurrence rate in the chest after surgery involving this form of cancer is so high that surgery is considered ineffective. The thoracic surgeon will attempt to remove the tumor if it is the more common, non-small cell cancer, if the patient is judged medically strong enough to withstand the surgery and if another procedure, the *mediastinoscopy*, done in the operating room prior to the lung operation (*thoracotomy*), confirms that the lymph glands of the central upper chest are free of any visible signs of cancer.

Chemotherapy alone cannot cure lung cancer. The only reliable way to cure lung cancer is to remove it surgically. However, if the patient is not a candidate for *resection*, or removal of the cancer, for the reasons mentioned above, or if the surgeon is unable to remove the cancer completely because it is attached to other organs and structures in the chest or involves too many lymph nodes, the patient will be sent to a medical oncologist for evaluation for chemotherapy. This physician will prescribe a selection of powerful, injectable drugs that single out the abnormal cancer cells for destruction, sometimes in combination with radiation administered by a radiation oncologist, to try to shrink the tumor. In some cases, this shrinkage is sufficient to allow the surgeon to remove the tumor. On rare occasions, radiation therapy, the use of highly energetic X-rays to destroy cancer cells, can cure a patient if the tumor is fairly localized in a small area.

If a tumor is above a certain size, the surgeon will be reluctant to remove it surgically, as the probability of its recurrence is very high due to metastases which may be present in other parts of the body. In those cases, the doctor will try to shrink the tumor with a combination of chemotherapy and radiation treatment, followed by a few months of chemotherapy only. At that point, the patient will be re-evaluated for surgical removal of the tumor. Following surgery, if the oncologist thinks there is a high risk of recurrence, she may prescribe additional rounds of chemotherapy and/or radiation.

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For those patients who have symptoms that cause severe discomfort, such as bone pain, headaches, abdominal pain, difficulty in breathing, spitting up blood or shortness of breath, a course of radiation can be given for comfort and relief. All patients for whom medical technology does not allow for a cure will be offered chemotherapy to stabilize or shrink the tumor. This will afford the patient a fairly long period of comfort and good quality of life.

There is a wide variety of chemotherapy drugs, both injectable and oral and they are used in many combinations. While they are capable of causing severe side effects such as nausea, vomiting, severe fatigue, hair loss, infections, anemia and loss of appetite, other medications have been developed that reduce almost all of these symptoms, except the hair loss, so that enduring a chemotherapy regimen has been made much easier. Over the last 20 years, new forms of chemotherapy have doubled the number of lung cancer patients who live a reasonably normal life for a significant period of time and, in many cases, have tripled their life expectancy.

Unfortunately, when the tumor cannot be removed, it will eventually progress. Also, in the case of small cell lung cancers, even in the 60% to 80% of cases in which radiation and chemotherapy make the tumor disappear completely in what is known as a *complete remission*, the tumor will invariably reoccur. In these unhappy situations, the patient will have to face the final course of their illness. In the past, there was little that could be done to alleviate patients' discomfort in the last stages of lung cancer. Today, however, an entire medical science of palliative and hospice care has been developed using a wide array of medications and therapies, allowing these patients to end their days in peace. Therefore, it is essential that the medical oncologist knows when to stop the chemotherapy. Once the therapy ceases to be effective, he should work closely with the patient, the family and the palliative care and hospice specialist to make the last days of the illness peaceful and comfortable.

While today's survival rates suggest that the outlook for lung cancer patients is generally poor, we are actually on the brink of radically advanced new therapies that will be much more effective against the lung cancer cell. These will be discussed later in the book by Dr. Michael V. Smith, who will describe the amazing progress and advances that are starting to improve the outlook for patients with this disease. Furthermore, by being an educated consumer and by adopting a positive, forceful approach to this disease, the outcome can be tipped significantly in the patient's favor.

Taking Charge of Your Care

You are a patient and you have been told that the cause of your shortness of breath, spitting of blood, unexplained weight loss or the shadow on your chest X-ray has been found. Your physician schedules an

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appointment with you to explain the results of the tests. You are hoping for the best but you suspect the news will not be good: most patients whose symptoms require a complex set of medical tests to enable a diagnosis are already thinking and worrying about cancer. Your mind is churning with possibilities. What will the doctor say? How bad is it? Will I die? Are there any treatments available? What will this mean to my family? Your mind is racing with anxiety and fear.

My purpose in writing this essay is to explain to the medical consumer, be it the patient or the patient's advocate or caregiver, how to negotiate the healthcare system, manage the patient's care and maximize the chances of overcoming this disease. The key is to take control, and not let the system control you. The healthcare system is a very complex, intimidating maze of physicians, laboratory tests, facilities, forms, insurance companies and regulations which, to the uninitiated, may present serious obstacles to receiving the best care for and management of the disease. Many simply lack the information to effectively navigate the system. Equally important, no one has told them about the importance of the positive, "kick-ass" attitude needed to beat this illness.

Talking with Your Doctor

Your physician has told you to make an appointment to discuss the results of your chest X-ray, CT scans and biopsy. Your initial impulse is to make that appointment as quickly as possible and hear the information that you are dreading to hear. It is critical to bring along to the appointment another set of eyes and ears, which could be your spouse, a relative, or even a friend who is closely interested in your medical care. Many studies have shown that the high level of stress associated with receiving unfavorable news about your diagnosis often results in your misunderstanding, not hearing, or simply not remembering the vast majority of the information given to you by the physician. Ask your companion to listen attentively and take notes, or even, with the physician's permission, record the conversation. That will enable your companion to help answer any questions you have in the days following the consultation.

When calling to make the appointment, tell the receptionist that your doctor wants to see you for some very serious and important news and you would like to know if it would be possible to schedule you as the last appointment of the day. Why? Because your best chance of getting the doctor to block out sufficient time to answer all of your questions and concerns in a relaxed and unrushed manner is to make sure that he does not have patients waiting to see him after your conference. The receptionist or office manager will most likely check with the physician and this will remind him that he will be having a very sensitive discussion with you. If he cannot schedule your appointment at the end of his patient schedule, he may at least carve out a sufficient amount of time during the day so that he can give you all of his attention, undisturbed.

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Choosing the Right Doctor

How do you judge whether your physician or the specialist who made the diagnosis and who may be in charge of your treatment is the right healthcare professional to manage your disease? She will give you this uncomfortable news as follows: you and your companion will come into her office or a small empty hospital conference room; she will close the door and sit four to six feet from you at eye level. The doctor will first ask for your thoughts about your medical situation and how you size it up. After you answer, she will tell you that she has reviewed your file, gone over all of the laboratory information and medical imaging tests, spoken with the necessary consultants and that she has some serious or difficult news to give you. She will tell you that you have a diagnosis of lung cancer that was made on the basis of all the medical information that has been collected about your case. She will then pause to give you some time to absorb the news and react. Your reaction could be anything, from intent listening, to crying, anger, fear, guilt or a range of other emotions. When the physician sees that you have recovered somewhat, more explanations will follow. She will explain that, while the diagnosis is serious, there are treatments that can either eliminate or control the disease and afford you a longer and better quality of life. Ideally, the physician will talk to you in a slow, soft, sympathetic manner, giving you and your companion the opportunity to ask questions at any time, all of which she will answer in a calm, easy-to-understand manner. The physician will have taken steps to minimize interruptions such as beepers and telephone calls. She may offer to have you come back at another time or contact her by telephone with additional questions.

The physician who tells you about the diagnosis may be your family practitioner or internist and it may not be the physician who treats your illness; it therefore may not be possible for him to go into detail about your therapy regimen. It is important to keep in mind, however, that your internist or family practitioner will remain an important part of your healthcare team. If the physician has presented this difficult news in the fashion that I described, you will want to see him on a regular basis. Even if he does nothing more than talk to you, he will keep tabs on your other, peripheral medical problems and explain to you what the treating physicians are doing. That way, you will be informed of communications between your doctors. At this stage, it is extremely important not to abandon your personal physician simply because he may not be the doctor treating your lung cancer.

Choosing the Right Surgeon

Your case will fall into one of two broad, general categories. You have either a lung cancer that is curable and can be removed or eliminated, or one that can only be controlled, shrunk or improved.

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In the case of a relatively small tumor with a high probability of malignancy or which was biopsied and found to be malignant, the tumor would be removed with surgery. Your regular physician would most likely refer you to a chest (thoracic) surgeon. The three most important factors to consider in deciding if this individual is right for you are his technical expertise, his medical background and his bedside manner. Also important in making this decision is the quality of the facility at which this physician performs surgery. If possible, obtain references from a few of his other patients or other healthcare providers who have worked with him in the past.

You will want someone who is skillful in conveying bad news and capable of dealing honestly yet tactfully with sensitive, life-threatening issues. In addition, he must be able to clearly explain the nature of your medical problem, the type of surgery that needs to be done, and any special issues that are important to your particular case using no technical jargon, so that you and your companion have a crystal clear understanding of the surgery, why it is needed and of any possible complications. You should be able to ask questions and receive clear, unhurried responses. You must not feel like you are just simply a number among many thousands of his patients. The following are warning signs that a surgeon you are considering may not be right for you:

- Lack of a reliable, positive recommendation or negative reports about the surgeon from other, reliable healthcare practitioners.
- A very busy office in which the atmosphere is so rushed that it appears you will not get the time to have your concerns addressed.
- He does not like to answer questions.
- He is evasive or his answers to your questions are fuzzy.
- The surgeon seems to recommend surgery without giving you time to consider other options or to get a second opinion.
- The surgeon gets annoyed when you indicate that you might wish to consider a second opinion.

Any of these issues should cause you to think about seeking your medical care elsewhere.

Getting a Second Opinion

In my opinion, the best practice is to get a second opinion regarding proposed lung surgery. If the surgeon appears to present some of the danger signs mentioned in the preceding paragraph, a second opinion is mandatory. If he suggests in any way that your case is unusual or if you are at a particularly high risk

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because of an unusual medical situation, you need a second opinion. If there is a question whether the abnormality on the chest X-ray or CT scan is malignant or whether you need surgery, you need a second opinion. If you are unsure of how to proceed or are especially worried about the outcome of the surgery, get a second opinion.

You are not required to use the services of the chest surgeon who gives you the second opinion. Many second opinion specialists aggressively seek to convince you to allow them to perform the surgery by making negative remarks about the first surgeon. It may also seem easier to stick with the second surgeon. However, if the second opinion gives you the same analysis and treatment plan as the first and your initial surgeon satisfied all of your criteria, I recommend sticking with the first surgeon, especially if he is closer to where you live. If the surgeon giving the second opinion says something radically different from the first and you believe it to be the best course of action, or if your case requires technology or treatment that can only be had where the second surgeon practices, that is where you should have your surgery. You also have the option of getting a third opinion if the first two opinions are contradictory or very different. Surgery for lung cancer is not usually a medical emergency and taking a few weeks to get additional opinions on your medical situation can be worthwhile.

Choosing an Oncologist

What if your tumor cannot be removed surgically because of its location or because it has metastasized, spread outside the original site of the cancer? You will probably be referred to a medical oncologist, who generally directs the care of a lung cancer patient facing this type of situation. This specialist determines and administers the medical treatment used to shrink or eliminate the tumor and conducts periodic diagnostic testing to determine your body's response to the therapy and the course of the illness. In addition, she will refer you to other specialists, such as the radiation oncologist, to treat certain aspects of your illness when necessary.

In selecting the best oncologist for you, use the criteria previously mentioned for picking any physician involved in your medical care. In addition, keep in mind that chemotherapy treatments can be physically taxing and you need to conserve your limited strength to fight your illness. Therefore, you should avoid long commutes to your chemotherapy sessions and, if at all possible, find a local facility. There are many well qualified medical oncologists with excellent bedside manners who practice in small to mid-sized communities and hospitals. It is not necessary to get an extended period of chemotherapy care at a large institution that is far away from home. Besides, if you need emergency assistance, it is almost impossible to get back quickly to a distant major medical center for care. You may end up in the local emergency room

without the medical records available on your case, and a new group of physicians must start your treatment from scratch.

Where to Seek Treatment

If your case is unusual, if there is some doubt about the best possible option for you to pursue, or if you require technology or a special drug that is not available in your geographical area, then a large, major metropolitan medical center may be right for you, despite its distance from your home. However, if the treatment can be done locally, that is probably your best option. You can always go back to the major medical center periodically for follow-up by their physicians, especially if you are in an experimental study or special treatment protocol. The local oncologist, if he is the type of physician that I described above, will have no reservations about working with the specialist at the medical center to get your therapy accomplished. You should also know that many major medical centers have recognized the undesirable medical effects of making ill patients travel long distances and have opened up satellite units in smaller suburban and rural areas.

What if Chemotherapy Doesn't Work?

Unfortunately, many lung cancer patients cannot have surgery, and chemotherapy or radiation therapy rarely produces a cure. When the chemotherapy or other treatment is no longer able to keep the disease from progressing, the patient and his or her family or advocate must talk about options with the oncologist and/or the patient's internist or family practice specialist. There are many things that can be done to help a patient in these circumstances.

If a patient's medical condition still allows it, the oncologist sometimes recommends trying another type of chemotherapy. Normally, after two or three different types of chemotherapy treatments, most patients are unable to endure another round with yet another drug. For that reason, while experimental drugs may also be considered, this option should only be considered if the patient is still strong enough to tolerate it. At this point, you may wish to seek a second opinion to explore options that your oncologist is not using or is unfamiliar with.

Palliative Care

For my patients who have been treated without success, I use the following benchmark to determine if he or she should go forward with a different course of chemotherapy: if the patient is able to spend half a day out of the house walking and being with the family, then that patient has enough physical strength and reserve

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to continue to be treated. On the other hand, because each successive new treatment for lung cancer produces less effective results and with each new treatment the wear and tear on the patient becomes more severe, I find that those patients who are so ill that they are virtually homebound or can only get out of their house in a wheelchair are not suitable candidates for additional aggressive therapy.

For patients whose lung cancer can no longer be treated, there is one type of therapy still available—palliative care. Palliative care is the science of symptom control. The patient and family or patient advocate need to consult with the treating physician about living with the illness and controlling its symptoms. Once the medical team must give up trying to shrink or eliminate the tumor, i.e., “curative” therapy, it can begin to aggressively treat the patient with a variety of drugs and technologies to minimize the discomfort of the symptoms. With the highly effective treatment options currently available to the palliative care specialist, who may be your oncologist or even your own private physician, a person can spend an extended period of time at the end of the illness, which could last many months or perhaps a year or two, in complete comfort.

Hospice Care

In dealing with the final course of the disease, your medical team will eventually talk to you about hospice. That word, when first mentioned sometimes means the final step before death. However, hospice has evolved into an extension of your physician’s treatment to provide the most sophisticated and aggressive therapies available to almost eliminate most of the troublesome symptoms that lung cancer can cause in its later stages. Hospice does not always mean the end of life. The intense treatment given to relieve physical symptoms and psychological, emotional and spiritual distress improves the physical and the emotional state of the patient. At times, the improvement may be enough to allow the patient to come off the program for an additional attempt at chemotherapy. If such an attempt is successful, the patient may not need to use the resources of hospice for long. If the new attempt at treatment is unsuccessful, the patient can come back to hospice. There have been some cases, although rare, in which a patient’s terminal illness was so improved that she was able to enter into a prolonged period of stability.

The hospice team usually includes highly trained palliative care nurses, social workers for family counseling, a volunteer companion program, a spiritual worker, a bereavement specialist and the hospice team’s palliative care medical director. This team will give the patient and family the most advanced care. 24-hour live on-call staff, including physician backup is always available, preventing trips to the emergency room and admissions to the hospital. If a patient must be hospitalized because of an especially severe symptom or problem, most hospices have specially designed inpatient units with a home-like environment to deliver the necessary medical care. Hospice will provide this therapy and support in an atmosphere of hope where the patient feels that an entire medical team is still working for him or her with

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only one purpose, to make their remaining life as fruitful, productive and comfortable as possible. There is simply no better substitute for care of the patient in the last stages of lung cancer.

Never Lose Hope

I have given you a plan to allow you to get the most out of the healthcare system and maximize the benefits of treatment. Hopefully, this information will increase the odds of a successful outcome in your fight. The important thing is to never lose hope; to maintain the belief that you will beat this illness, to ask questions constantly and to stay informed. Be aggressive in getting what you need to get out of the healthcare system. But most important of all, be positive and determined about your illness, its treatment, your doctors and the outcome. Having a positive attitude, questioning your doctors, getting second opinions and pushing, pushing, pushing can and has often meant the difference between life and death.

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