

CHAPTER 13: MANAGING YOUR HEALTH CARE

INTRODUCTION

Most of us are unfamiliar with the internal workings of the health care system and health insurance providers until we need to use them. This chapter provides basic information about the health care system and how to get the best possible care available. Information is a powerful tool for planning and obtaining good health care. Gaining an understanding of the topics in this chapter will help you explore your options, ask focused questions, and make informed decisions.

BEING AN INFORMED HEALTH CARE CONSUMER

The health care system is a service industry. You are a consumer of the services offered. Informed health care consumers know what they need and how to get it. One of the first steps toward ensuring the best possible care is educating yourself. You will be in the best position to find optimum health care that suits your needs and preferences if you are knowledgeable about lung cancer, the health care system, and your rights as a health care consumer.

The health care system is complex and can be confusing. During the course of your illness, you will meet new people, hear new language, and have new experiences. The newness and complexity of the health care system can seem overwhelming at first. But like anything else, once you become familiar with it, it becomes manageable. Learning the ins and outs of the systems you need to utilize helps ensure you receive the best possible care.

People newly diagnosed with lung cancer are often amazed at the medical knowledge and ease with which others talk about their illness. Rest assured, after a surprisingly short period of time, you will be doing the same.

Gathering Information About Lung Cancer

You can take an active role in obtaining good health care by seeking information and educating yourself. Unless you work in a medical profession, you probably had little knowledge about lung cancer before your diagnosis. Learning about lung cancer is important because it will help you:

- gain a sense of control over the situation you are currently facing
- make treatment decisions
- understand and manage your symptoms
- plan for the future

The more you know about your disease, the less confused and anxious you are likely to feel about your treatment. Reading this book, you have already taken an important step in educating yourself about lung cancer. Many resources are available to add to the knowledge you have already gained.

Your Cancer Care Team

A good place to start gathering information is from the members of your cancer care team. Following is a list of commonly asked questions you might consider asking your doctor or nurse. You may have many other questions of your own. Remember, there is no such thing as a stupid question. If you want to know something, ask.

Questions About Your Diagnosis and Treatment Options

- In non-medical terms, what is wrong with me?
- Is it certain, without any doubt, that I have lung cancer?
- What specific type of lung cancer do I have?
- What is the stage of my disease?
- What are the best treatment options for my stage of disease?
- What treatments do you recommend?
- What are the benefits of the treatment(s) you are recommending?
- Are there any risks or side effects associated with the treatment(s) you are recommending? What are they?

- Are there other treatment options?
- What are the benefits of the other treatments? What are the possible risks and side effects?
- Are there treatments available for my condition that are popular, but not approved by the Food and Drug Administration? If so, why have they not approved? What do you think of them?
- How will treatment most likely affect the course of my disease?
- What is likely to happen if I do not take treatment?
- Would another institution be able to offer me more treatment options?
- Are there clinical trials that might be appropriate for me?

Questions About A Specific Treatment Plan

- What doctors and specialists will be involved in my treatment?
- Who will coordinate my overall care?
- Whom should I contact with questions about my treatment or if I experience a problem?
- What is the goal of my treatment? (cure, pain control, symptom control, enhanced quality of life, etc.)
- How can I expect my life to change during treatment and how should I plan for this?
- Will I be able to work during treatment?
- Will I be able to care for my family during treatment?
- How long will treatment last?
- What is the treatment schedule?
- Can I schedule treatments around my work schedule, special dates, or other events?
- Can I drive myself home after a treatment?
- How long do I need to rest after a treatment session before I can return to work or other activities?
- How will you know if the treatment is working?

- What are the names and dosages of the medications I will be taking?
- What does each medication do?
- What should I do if I miss a dose of one of my medicines?
- What are the side effects of treatment?
- What can be done to control side effects?
- Are there any types of clothes I should avoid wearing?
- Are there foods or liquids I should plan to eat or avoid?
- What costs will I incur from this treatment?

Questions About Care After Treatment Is Completed

- After treatment ends, how often will I need follow-up visits and what will these consist of?
- How will I be monitored for recurrence of my disease or disease progression?
- Are there any specific *signs* or *symptoms* I should look for that may indicate disease recurrence or progression?

Every appointment with your cancer care provider is an opportunity to get answers to questions you may have. It is helpful to organize your thoughts ahead of time since the length of your visit will be limited. Writing your questions down is a good idea. It helps organize your thoughts and prioritize your questions. Put your two or three most important questions at the top of the list.

When you meet with your doctor, hand him or her your list of questions. He or she may see something on the list that is more important than you realized – something that could indicate a problem requiring immediate attention. You may want to give the list to your doctor ahead of time so she or he can be prepared, especially if your question list is lengthy.

You can talk with your oncology nurse or nurse practitioner if your doctor does not

have time to answer all your questions or if you are uncomfortable asking the doctor some of your questions. Oncology nurses are very knowledgeable and can often answer questions about your treatment and care. Most oncology nurses are easy to approach and go out of their way to make sure you get the information you need as quickly as possible. Other members of your cancer care team such as nutritionists, pharmacists, rehabilitation therapists, radiation therapists, and others are also good sources of information. You may want schedule an extra visit with your doctor if you need more time to get your questions answered.

Your cancer care team may have patient education materials in the form of pamphlets, brochures, videotapes, and books. These materials cover many different topics of interest to people with cancer. Ask about other sources of information if the materials available in your oncologist's office are not sufficient to meet your needs.

National Cancer Institute Resources

The National Cancer Institute (NCI) is another good resource for information on lung cancer. The NCI Internet site at www.nci.nih.gov has extensive information about lung cancer, its treatment, and related issues including:

- diagnosis
- *staging*
- treatment
- coping with cancer
- treatment side effects
- clinical trials
- lung cancer statistics
- medical terminology dictionary
- cancer literature
- cancer support groups
- emotional concerns
- finances
- hospice care
- resources for people with lung cancer and their caregivers

One feature of the NCI site is the Physician Data Query or PDQ. PDQ is an NCI database that contains the latest information about cancer treatment, screening, prevention, genetics, and supportive care. There is also a searchable database of active clinical trials. PDQ cancer information summaries are reviewed monthly by cancer care experts. They are updated as needed based on recent developments in cancer care.

CancerFax[®] makes portions of PDQ and other NCI information available to the public via a fax-back document delivery system. Selected information is available in Spanish. CancerFax[®] contains:

- PDQ full-text summaries on cancer treatment, screening, prevention, genetics, and *supportive care*
- fact sheets on current cancer topics
- topic searches from the CANCERLIT (cancer literature) database

CancerFax[®] can be accessed with a touch-tone telephone or fax machine with a telephone handset. Call 800-624-2511 and follow the voice prompts to receive the information you need.

CancerMail uses e-mail to access the same information available through CancerFax[®]. To access CancerMail, send an email message to cancermail@cips.nci.nih.gov with the word "help" in the body of the message. A contents list and instructions will be e-mailed back to you.

All the information available on NCI's Internet site is also available through the Cancer Information Service (CIS).

The Cancer Information Service is NCI's link to the public, interpreting and explaining research findings in a clear and understandable manner. Through a network of 14 regional offices located throughout the country, the CIS serves the entire United States, Puerto Rico, and the U.S. Virgin Islands.

To receive a personalized response to your specific questions about cancer, we encourage U.S. residents to call the Cancer Information Service (CIS) at 800-4-CANCER (800-422-6237) Monday through Friday from

9:00 AM to 4:30 PM local time to speak with a Cancer Information Specialist. Deaf and hard of hearing callers with TTY equipment can call 800-332-8615. Callers also have the option of listening to recorded information about cancer 24 hours a day, 7 days a week.¹

Free NCI publications can be requested by calling CIS, or can be viewed or ordered from the CIS Internet site at www.cissecure.nci.nih.gov/ncipubs.

From either the NCI or CIS Internet homepage, you can receive live, online help through a service called Cancer.gov LiveHelp. LiveHelp can assist you with general cancer questions or provide assistance in navigating the NCI Internet sites. LiveHelp is available Monday through Friday from 9 AM to 10 PM (Eastern Time).

Other Lung Cancer Information Resources

Medical journal articles are good sources of information for the latest in lung cancer research and treatments. However, the information is written in technical language that may be difficult to understand. Members of your treatment team may be able to suggest or provide articles you might be interested in reading. If your treatment team cannot provide you with the materials you are interested in, they can direct you toward where to look for them. A hospital librarian can also help you locate relevant material.

Support groups are another source of information. Talking to others who have been through treatment can help you to gain a better understanding of what to expect before you begin. Your oncology nurse or social worker may be able to help you locate established support groups in your area.

Cancer Care is a non-profit organization that offers a variety of cancer education materials for people living with cancer. Their educational programs include live and previously recorded teleconferences, lung cancer lectures that can be viewed over the Internet, and a variety of downloadable and preprinted materials. For information

¹ From the National Cancer Institute Cancer Information Service Internet site at <http://cis.nci.nih.gov/index.html>.

about CancerCare's educational programs and materials, visit their Internet site at www.cancercare.org/EducationalPrograms/EducationalProgramsmain.cfm, or call toll-free at 800-813-HOPE (4673).

Lung Cancer Online is an Internet clearinghouse of information about lung cancer. The site was created by a lung cancer survivor. It is a gateway to lung cancer resources for the benefit of people with lung cancer and their families. It is intended to facilitate the time consuming and often-frustrating process of learning about lung cancer, treatment options, and support services. The Lung Cancer Online site can be found at www.lungcanceronline.org.

There are many other informative books, Internet sites, and literature from various organizations that address lung cancer and related cancer care issues. The *Resource Directory* at the end of this book has contact information.

Patients' Rights

As a health care consumer, you have the right to speak out on your own behalf to ensure you receive quality health care. This right applies to all health care consumers regardless of the source of payment for services. Whether you have fee-for-service health care insurance, are a member of a health maintenance organization (HMO), are insured by Medicare, or are uninsured – you have a right to receive quality health care.

In November 1997, then president William Clinton established the Advisory Commission on Consumer Protection and Quality on the Health Care Industry. The Commission was co-chaired by the Secretary of Health and Human Services and the Secretary of Labor, and was comprised of 34 members including consumers, business owners, labor leaders, health care providers, health plan representatives, and health care quality and financing experts. The Commission issued the Patients' Bill of Rights and Responsibilities. The Commission's final report, "Quality First: Better Health Care for All Americans," was issued in March 1998.²

² The complete report is available online at www.hcqualitycommission.gov/final.

The Patients' Bill of Rights and Responsibilities has three goals: to strengthen consumer confidence that the health care system is fair and responsive to consumer needs; to reaffirm the importance of a strong relationship between patients and their health care providers; and to reaffirm the critical role consumers play in safeguarding their own health. While the Commissions' recommendations are not legally binding, they express the collective wisdom of some of the nations' leading health care stake-holders. The Patients' Bill of Rights and Responsibilities outlines seven sets of rights and one set of responsibilities:

The Right to Information — Patients have the right to receive accurate, easily understood information to assist them in making informed decisions about their health plans, facilities, and [health care] professionals.

The Right to Choose — Patients have the right to a choice of health care providers that is sufficient to assure access to appropriate high-quality health care including ... giving patients with serious medical conditions and chronic illnesses access to specialists [such as oncologists, pulmonologists, and thoracic surgeons].

Access to Emergency Services — Patients have the right to access emergency health services when and where the need arises.

Being a Full Partner in Health Care Decisions — Patients have the right to fully participate in all decisions related to their health care. Consumers who are unable to fully participate in treatment decisions have the right to be represented by parents, guardians, family members, or other conservators.

Care Without Discrimination — Patients have the right to considerate, respectful care from all members of the health care industry at all times and under all circumstances. Patients must not be discriminated against in the marketing or enrollment or in the provision of health care services, consistent with the benefits covered in their policy and/or as required by law, based on race, ethnicity, national origin, religion, sex, age, current or anticipated mental or physical disability, sexual orientation, genetic information, or source of payment.

The Right to Privacy — Patients have the right to communicate with health care providers in confidence and to have the confidentiality of their individually-identifiable health care information protected. Patients also have the right to review and copy their own medical records and request amendments to their records.

The Right to Speedy Complaint Resolution — Patients have the right to a fair and efficient process for resolving differences with their health plans, health care providers, and the institutions that serve them, including a rigorous system of internal review and an independent system of external review.

Taking on New Responsibilities — In a health care system that affords patients rights and protections, patients must also take greater responsibility for maintaining good health.

In recent years, most states have passed legislation addressing specific aspects of patients' rights, especially with respect to members of health maintenance organizations. Several federal patients' rights bills have been introduced. However to date, the bills have failed to pass both Houses of Congress. Many health care professional organizations and patient advocacy groups continue to push for a federal Patient Bill of Rights to establish minimum standards for all health care insurance plans.

Informed Consent

Your doctor is responsible for providing you with enough information about your treatment options for you to make an informed decision about what treatment you want to pursue. Your doctor cannot legally perform any non-emergency procedure on you without having a signed consent form.

Informed consent has several purposes. It specifies your doctor's responsibility to explain:

- what the treatment or procedure involves
- what the likely effects will be
- possible side effects and complications

- why the treatment or procedure is being done
- the expected outcomes with and without the treatment or procedure
- alternatives to having the treatment or procedure

When you sign a consent form, you are indicating you understand all the information listed and give your consent to proceed with the treatment or procedure. Take the time to read the informed consent form carefully. If there is anything you do not understand or do not agree with, discuss it with your doctor. You do not have to sign the consent form if you are uncertain about a recommended treatment or procedure. You always have the right to refuse a treatment or procedure. You may want to take more time to investigate and consider your options. If you decide later that you want to go through with the treatment or procedure, you can reschedule it.

YOUR CANCER CARE TEAM

Quality lung cancer care requires a team of dedicated, expert, cancer care providers. Your cancer care team will include many different health professionals from a variety of health care fields. Each member of your cancer care team plays a critical role in your treatment. Depending on the treatments you decide to pursue, your cancer care team may include many or all of the following health care professionals.

dietician: a specialist trained to assist in determining dietary needs and planning; also called a nutritionist

dosimetrist: a person who determines the proper radiation dose for treatment

medical oncologist: a doctor who specializes in the non-surgical treatment of cancerous and non-cancerous tumors; he or she usually leads the treatment and supportive care team

oncology nurse: a nurse who specializes in the care and treatment of people with cancer; there may be one or more oncology nurses on your treatment team

oncology advance practice nurse (APN): an oncology nurse who has at least a master's degree and has participated in specialized education and training in the

treatment of cancer; advance practice oncology nurses are usually called oncology nurse practitioners or clinical nurse specialists; oncology APNs work with oncology doctors, but also often work independently

pathologist: a doctor who specializes in disease diagnosis through analysis of body fluids and tissues; examines tissues under a microscope to determine the presence of cancer cells

pharmacist: professional trained to prepare and dispense medications

primary care provider: medical professional responsible for an individual's overall care; may be a family physician, internist, gynecologist, or nurse practitioner

pulmonary rehabilitation specialist: a pulmonologist who specializes in rehabilitating people with lung diseases including lung cancer

pulmonologist: a doctor who specializes in the diagnosis and treatment of non-cancerous lung disorders; often the specialist recommended for people with lung symptoms; frequently the specialist who diagnoses lung cancer

radiation oncologist: a doctor who specializes in the use of radiation therapy to treat cancer

radiation physicist: a professional trained in the clinical uses of radiation therapy; the person who makes sure the radiotherapy equipment is working properly and delivering the correct radiation dose

radiation technologist or therapist: a technician who prepares and positions people for radiation therapy treatments and runs the equipment that delivers the radiation

radiation therapy nurse: a nurse who provides care and information about *radiotherapy*, including how to manage radiation side effects

radiologist: a doctor who specializes in the use of x-rays and other forms of radiation to diagnose and treat disease

social worker: a person trained to help people deal with the emotional aspects of having a disease; assists patients in accessing medical, social, financial, and supportive services; oncology social workers specialize in working with people living with cancer

surgeon: a doctor who specializes in the treatment of disease by surgical operations

thoracic surgeon: a surgeon who specializes in operations involving the chest including lung surgery

My oncology nurses were certainly very well trained and they always made me feel comfortable. But I felt closer to my radiation team. I got to know the technologists very well since I saw them every day for 28 days. They were very kind, helpful, and they were always happy to answer any questions I had. In fact, they encouraged me to ask questions.

– Barbara, diagnosed with stage IB NSCLC in 2000 at age 56

Physician Qualifications

As a health services consumer, you have the right to choose your health care providers. Your cancer care team will help you make decisions that greatly affect your life. It is important to feel comfortable with your providers and confident about the quality of care they provide. You are hiring health care providers to work with you to accomplish the goals you set forth.

Studies have shown the level of experience of both doctors and institutions where you receive health care for lung cancer affects procedure and treatment outcomes.¹⁻⁵ It is important to have health care providers who are skilled and experienced in the treatment of lung cancer. One way to assess a doctor's skills are to check his or her credentials.

Medical Licensure

Most doctors in the United States treating people with cancer are *allopathic physicians*. Allopathic physicians (doctors) have earned a medical doctor or MD degree. The education and training for an MD includes four years of premedical education at a college or university, four years of medical school to earn their degree, and 3-7 years of postgraduate education and training (a residency) in a specific medical specialty. Doctors must pass a licensing exam to practice medicine in their state. Each state or territory has its own requirements for licensing doctors. You can check to make sure your doctor is licensed by calling your state medical licensing board.

Board Certification

Doctors who have completed their residency training in a specific medical specialty can opt to become board-certified in that specialty. Independent specialty boards (unaffiliated with state medical licensing agencies) certify doctors if they fulfill specific requirements. In general, requirements include having a valid medical

license, meeting specific educational and training criteria, and passing an examination given by the specialty board. Doctors who pass the exam and meet the other requirements become board-certified in their specialty. They are then considered a *diplomate* of the specialty board. Board-eligible doctors have the required education and training to take the specialty board exam, but have not yet done so.

There are 24 medical specialty boards recognized by the American Board of Medical Specialties (ABMS) and the American Medical Association. Many of these specialty boards also have subspecialty exams. To be eligible for a subspecialty exam, the doctor must first be board certified in the umbrella specialty. ABMS boards of interest to people with lung cancer include:

- American Board of Internal Medicine; subspecialties include:
 - medical oncology
 - pulmonary diseases
- American Board of Pathology
- American Board of Radiology; subspecialties include:
 - diagnostic radiology
 - radiation oncology
 - radiologic physics
- American Board of Surgery
- American Board of Thoracic Surgery

Professional Medical Society Membership

Membership in professional medical specialty societies is another benchmark of expertise for a doctor. There are different requirements for membership in various professional medical societies, but they all require verification of specific education and training. Many medical societies have different levels of membership.

Generally, fellowship in a professional society indicates a higher level of professional achievement than regular membership. Some societies offer the distinction of mastership to a few members who have achieved superior accomplishments in their field. A sample of professional medical societies for physicians of interest to people with lung cancer includes:

- American College of Chest Physicians
- American College of Radiology
- American College of Surgeons
- American Society of Clinical Oncology
- American Society of Clinical Pathologists
- American Society of Internal Medicine
- College of American Pathologists
- Radiological Society of North America
- Society of Thoracic Surgery

Many public libraries have guidebooks such as the American Medical Directory, Directory of Medical Specialists, and Top Doctors of America that may be good sources of information on specialty physicians.

Choosing Your Doctors

Assembling your cancer care team usually begins with selecting a *medical oncologist* who will coordinate your care. Finding a medical oncologist may begin with a referral from your primary care doctor or pulmonologist. You may also want to ask other people with lung cancer or other health care professionals for referrals to medical oncologists, thoracic surgeons, and radiation oncologists. Cancer survivors can be very helpful because they have been in your situation. Health care professionals can supply useful information based on their knowledge of other providers in your area. Be aware that some health care professionals may not feel comfortable criticizing one of their colleagues. If the person you are speaking with seems uncomfortable, vague, or unenthusiastic about another professional, this may suggest an unspoken concern. It is important to have people on your cancer care team who specialize in lung cancer.

Local hospitals often have a patient referral service, as do some local medical societies.

Many other resources are available for finding doctors to treat your cancer including:

National Cancer Institute

- Cancer Information Service at 800-4-CANCER (800-422-6237)
- A listing NCI Cancer Centers and doctors at those institutions is available on the Internet at cis.nci.nih.gov/fact/1_2.htm

American Board of Medical Specialties

- The Official ABMS Directory of Board Certified Medical Specialists is available at most public libraries.
- You can find a doctor's board certification status by calling 866–275–2267 (866–ASK–ABMS) or checking online at www.abms.org/login.asp. These services are free, but the Internet service requires registration.

American Medical Association

- Physician Select is a free, online search service that offers basic professional information on nearly all licensed physicians in the United States. This service can be accessed at www.ama-assn.org/aps/amahg.htm.

American Society of Clinical Oncologists (ASCO)

- ASCO offers a free, searchable, online list of ASCO members available at www.asco.org/ac/1,1003,12-002215,00.asp.

Your insurance coverage may limit your choice of physicians. Health maintenance organizations (HMOs), preferred provider organizations (PPOs), and other types of managed care plans usually have a list of member providers from whom you must choose. Many insurance companies require a referral from your primary care provider in order for you to see a specialist. Be sure to get this referral. Your insurance company may not pay for the office visit without the required referral.

Your first meeting with someone you are considering to be your doctor is an opportunity to collect valuable information that will help you later decide whether you want him or her on your cancer care team. Questions you might consider asking a doctor you are considering for your cancer care team include:

- Do you accept my insurance?
- Are you board certified in your specialty?
- How much experience do you have treating lung cancer?

- How frequently do you treat people with lung cancer?
- Is lung cancer your primary interest?
- How do you stay up-to-date on new lung cancer treatments?
- Do you have patients who participate in clinical trials?
- What hospitals and/or treatment centers do you work with?
- Are you comfortable with me seeking other treatment opinions?
- How quickly will my telephone calls be returned?
- If I want to include complementary therapies in my care plan, will you work with nontraditional practitioners such as naturopaths, herbalists, acupuncturists, and Chinese medicine specialists?

When interviewing a surgeon, consider asking:

- Do you specialize in thoracic surgery?
- Are you board certified in thoracic surgery?
- How often do you perform the procedure I will be having?
- Will you work with my oncologist to coordinate my care?

The initial interview is a good time to discuss issues such as pain management and *advance directives*. It can be challenging to change your primary cancer provider later if you find you have differences of opinion about these crucial issues.

After you have met with someone you are considering for your cancer care team, you may want to ask yourself some of these questions:

- Are you comfortable with him or her?
- Does he or she seem interested in your needs?
- Did he or she treat you with respect?
- Did he or she answer your questions willingly and completely?
- Did you agree on issues about which you hold strong opinions?
- Does he or she seem knowledgeable about lung cancer staging and treatment?

I already had a primary care doctor, and luckily, I like him a lot. I had been seeing him for several years. During the process of being diagnosed with lung cancer, I was referred on to a pulmonologist, then a surgeon, and so forth. Through that [process], I asked who they thought was the best in the lung cancer field. I also did research on my own and found many leads through talking with people, one of them being my Phone Buddy. As I was getting second, third, and fourth opinions from medical oncologists, I found I really needed a doctor that was willing to answer my questions or at least some of them. I also needed a doctor who would answer them in a straightforward manner. Luckily, after having met with five medical oncologists, I have found a doctor who not only does this, but he is also compassionate. I feel he really cares and he certainly takes the time to go over things with me.

– Lovelle, diagnosed with stage IIIA NSCLC in 2002 at age 57

People with lung cancer can live for many years, but some have a more limited survival time. The doctor you choose as your primary cancer doctor will probably be involved your care through the end of your life. When choosing a doctor, think about whether you want him or her to provide your health care throughout your lung cancer experience.

The Rest of Your Cancer Care Team

Quality cancer care requires a team of expert health care professionals. Each member of the team has special training and expertise that he or she contributes to your care. While doctors lead your cancer care team, it is usually the non-physician health care professionals (called *allied health professionals*) who interact with you and provide the majority of your care on a day-to-day basis. Some of the many functions of the allied health professionals on your cancer care team are presented on the following pages.

Oncology Nurses

Oncology nurses are vital members of the cancer care team. Oncology nurses are usually the providers who administer chemotherapy and counsel you about treatment-related side effects. They are often your primary point of contact with your oncologist. Oncology nurses are the people you will most likely talk with if you call your doctor's office with a problem. Nurses often coordinate your care with other providers including nutritionists, rehabilitation therapists, oncology social workers, and others. The further you get in your lung cancer journey, the more you will come to appreciate the many contributions of your oncology nurses.

Although my oncologist was great, I spent a LOT more time with Lucy, my oncology nurse. We developed a very special friendship - not outside of the office, she is too professional for that. But she became a very special person during my treatment and I still care for her a great deal. I still get that wonderful smile from her every time I have a check up. I can tell she is genuinely happy for me with each year that passes.
– Patti, diagnosed with limited SCLC in 1998 at age 48

Oncology Advance Practice Nurses (APN, oncology nurse practitioner, or oncology clinical nurse specialists)

Oncology nurse practitioners' functions on the cancer care team vary but can include physical examinations, diagnosis, prescribing care and treatment, and monitoring of the effects of treatment. APNs work with oncology nurses, doctors, and other health care professionals to promote the best care of people with cancer. The services provided by oncology APNs vary across the United States depending on state laws that govern their work and authority. If you have an oncology nurse practitioner on your cancer care team, talk with him or her about what types of services he or she will be providing. An oncology nurse practitioner can be a very helpful and knowledgeable addition to your cancer care team.

Oncology Social Workers

Oncology social workers are helpful, versatile members of the cancer care team. They act as patient advocates responding to the unique needs of patients, and their families and caregivers. Oncology social workers provide psychosocial counseling to help people cope with a variety of issues related to living with cancer and adjusting to a new lifestyle. They provide expert information and referrals to essential community, state, and national resources. They also coordinate services such as lodging, transportation, home health care, and hospice care that may be needed to support patients throughout their cancer treatment. Social workers often serve as facilitators of lung cancer support groups.

Nutritionists/Dieticians

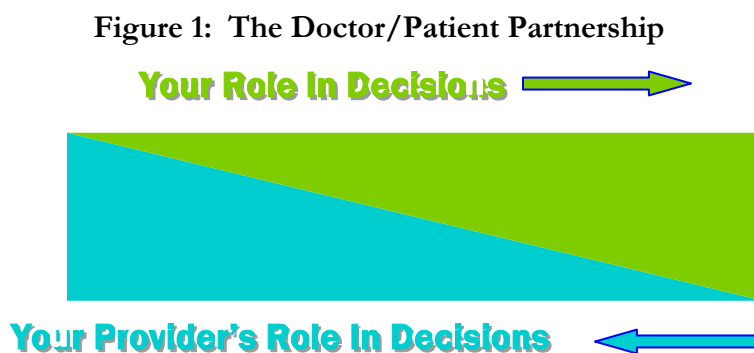
Nutritionists and dieticians are experts in the nutritional needs and problems associated with a variety of illnesses and conditions. Nutritionists help people deal

with the many challenges to good nutrition that come up during their lung cancer experience.

YOUR PARTNERSHIP WITH YOUR DOCTOR

People with lung cancer are often in the position of making life-changing decisions. The process by which we make such decisions is unique to each one of us. Some people want to learn everything there is to know about their disease and make all their own treatment decisions. Others entrust treatment decisions to their doctors because they feel their doctors have far more knowledge, experience, and expertise on which to base their recommendations. Many people make decisions collaboratively with their doctors.

There is no right or wrong way to approach your treatment choices. You should make your decisions based on what is most comfortable for you. Figure 1 shows that the partnership you choose with your health care providers is a complementary one. As your role in the decision-making process increases, your provider's role decreases and vice versa. It is important for both you and your providers to feel comfortable with this balance. The far left of the figure represents a doctor/patient partnership in which the patient has entrusted all treatment decisions to the doctor. The far right of the figure shows a doctor/patient partnership in which the patient is making all the final treatment choices. And of course, there is the large area in between these two extremes that shows varying roles in the doctor/patient partnership.



It is helpful to put some thought into the kind of doctor/patient partnership that will be most comfortable for you. These questions may help you think through this important aspect of your care.

- Do you want an equal partnership with your doctor wherein you review information and make decisions together?
- Do you want to rely on your doctor's experience and expertise to choose the treatments he or she judges to be best for you?
- Do you want your doctor to give you facts without interjecting his or her opinions so you can come to your own conclusions and decisions?
- How important is your doctor's personality to you?
- What is more important to you, your doctor's personality or his or her experience and expertise in the treatment of lung cancer?
- Are there any personal qualities you are looking for in a doctor?

There are potential advantages and disadvantages to different types of doctor/patient partnerships. People with cancer sometimes feel they have lost control of their lives. Taking a role in the decision-making process can help some people regain a sense of control over the situation. On the other hand, trying to learn all the details of the many different aspects of cancer care can be an overwhelming burden for some people. You may feel you already have enough on your hands trying to deal with the everyday changes having cancer has introduced into your life without taking on the added task of becoming an expert in lung cancer care. In this situation, you may find leaving treatment decisions to your cancer care team frees your mind and time to spend on other things that are more important to you. Keep in mind, the doctor/patient partnership is much like other human relationships in that it changes depending on the circumstances you are facing. In some situations, you may want to make decisions largely on your own. In other circumstances, you may want to defer to your doctor.

Two weeks after I saw my first surgeon, I fired him. I wanted someone who would believe in me and fight for me. My new surgeon was the head of the Thoracic Department. He was very aggressive with my care not only with chemo and radiation, but I have also had four surgeries with him. He was there to fight for me. You need someone who won't give up on you. When I got my brain metastasis and went in for brain surgery, he found out where I was and held my hand through the

surgery. He even came to see me every day while I was in recovery even though I was not under his care with the brain mets. It was real special.
– Sue, diagnosed with stage III NSCLC in 1997 at age 48

Regardless of your personal decision-making approach, your doctors will be part of the process. It is important to establish a relationship with your doctors that compliments your personality and decision-making style. Your relationship with your cancer care team is an important factor in your satisfaction and comfort with your treatment and ongoing care.

Communicating With Your Doctors

Clear and open communication between you and your doctor is an important component of quality care. Some key elements of effective communication are:

- the ability to be open and honest with your doctor about any topic that may come up
- feeling free and unembarrassed to ask questions about things you do not understand
- a sense of mutual respect

Effective communication requires the effort of both you and your doctor. It will take some time for you to get to know one another and establish a good working relationship.

Actions that can enhance your working relationship with your doctor include:

- Talk with your doctor about what kind of health care partnership you want to have with him or her.
- Tell your doctor what you already know about lung cancer. Let him or her know if you want to learn more about the disease or prefer not to get involved in the details. Most doctors will look to their patients for guidance about how much detail they want to know.
- Let your doctor know if he or she says something you do not understand. Your doctors think and talk about cancer every day, so they sometimes forget that not everyone is as familiar with cancer-related terms and topics as they are. It is important to understand your doctor correctly. It may be helpful to repeat back

what you hear so your doctor can correct anything that may have been misunderstood. Take the time you need to understand the topic you are discussing.

- Be open with your doctor about fears or concerns you may have about your condition, treatments, or procedures. You may also have concerns about topics such as hospital care, pain management, or end of life issues.
- Discuss topics about which you have strong feelings early in the care process. For example, you may have strong feelings about the use of pain medications, *resuscitation*, advance directives, the use of blood transfusions, or other forms of treatment. It is best to discuss these topics and come to an agreement about them when you first establish your doctor/patient partnership. This can go a long way toward avoiding misunderstandings and possible disruptions of care in the future.

The same principles that apply to communicating effectively with your doctor can also be utilized in communicating with the other members of your cancer care team.

Important conversations with your doctor should take place in a private, quiet area. If you are in a noisy or public setting, suggest moving to some place more private before continuing your conversation. Be sure to tell your doctors and other members of your cancer care team if there is specific information you want kept private. It is best to identify clearly what information can be shared with family members and friends about your condition and treatment. This prevents a possible breach of your privacy and helps your providers respect your wishes.

If you have established someone as your health care agent by granting them medical power of attorney, be sure to provide your doctors with a copy of your advance directive, power of attorney documents, and contact information for your health care agent. People who do not have a health care agent should name someone with whom your doctor can speak if you are unable to communicate on your own behalf. See *Chapter 15: Planning for the Future* for information about advance directives and medical power of attorney.

Getting Your Questions Answered

Most people come to the experience of having lung cancer with little prior knowledge of the disease, its treatments, and medicine in general. As a result, you are likely to have many questions over the course of your disease. It is important for your peace of mind and comfort with your treatment decisions to get your questions answered satisfactorily. Tips to help ensure your questions are answered include:

- Write down questions as they occur to you between office visits.
- Take someone with you to office visits who can act as a second set of ears to help you remember the answers to your questions.
- Take a pad and pencil to your appointments so you can jot down notes. Some people take a tape recorder to their appointments. They replay the conversations later in a more relaxed environment to help reinforce what was discussed. Ask your doctor if he or she minds you recording the conversation.
- Let your doctor know if he or she uses a word you do not understand. Ask your provider to explain medical terms in language you understand.
- Talk with your oncology nurses about your questions. Oncology nurses are very knowledgeable and may have more time to talk with you than your doctors do. Be aware that if something comes up in a conversation with your oncology nurse that he or she judges to be important to your care, he or she is obliged to share that information with your doctor.
- Do not be embarrassed to ask questions. There are no such things as silly questions. You may need to ask a question more than once before feeling confident you understand the answer.

Working Through Communication Difficulties

All human relationships occasionally have rough spots. Your relationships with your cancer care providers are no different. There will probably be days when you are not feeling very well, or are feeling rather sad or distressed. Your doctor may have days when he or she is feeling rushed or worried. These circumstances and many others can influence the nature and quality of the interaction between you and your doctor on any given day. When you encounter tension in your communication with your doctor or another health care provider,

it is important to work through it so it does not interfere with your peace of mind or treatment.

When interacting with your health care providers, it may be useful to keep the following thoughts in mind.

- Try not to take it personally if your doctor seems more distracted or less friendly on one day than another. It probably has nothing to do with you. Your doctor is a human being just like you with varying moods, energy levels, and outside concerns. Try to treat your doctor with the same consideration and respect with which you want to be treated.
- Doctors can seem emotionally distant at times, which is troubling to some people. The unemotional appearance of a health care provider does not mean he or she does not care about you. Cancer care providers work in a very emotional job. They see people every day who are in potentially life-threatening circumstances. They often must face the loss of people they have come to know and care about in a personal way. In order to provide the best care possible, cancer care providers must learn to keep their emotions in check so they can think clearly and work effectively. An unemotional exterior can be mistakenly perceived as a lack of compassion or empathy.
- Express your appreciation for extra efforts your providers make on your behalf. A word of sincere thanks can be very meaningful to a health care provider.
- Tell your provider if there are things about his or her style of working with you that are particularly helpful. This will let him or her know more about how best to interact with you. It may also help him or her interact more effectively with other people living with cancer.

Sometimes the doctor/patient partnership does not develop as you want it to, or it may get temporarily off track. This can lead to feelings of dissatisfaction and possibly anger. These feelings can disrupt an effective working relationship. Therefore, they must be resolved. If you become angry with your doctor during an appointment, try not to make statements or ask questions in a way that attack your provider in a personal way. It is often best when you

are angry to wait until you have calmed down before discussing the matter that caused your anger to flare. In the heat of the moment, people often say things they later regret. Rather than putting yourself in this situation, you may want to express your feelings to a family member, friend, or a member of your support group. Talking with a trusted confidant allows you to vent your feelings and discuss the situation with someone who can offer objective insight and advice. Releasing your feelings and gaining objectivity about the situation puts you in a much better position to approach your doctor with clear statements and specific requests that can resolve the problem.

It is usually best to talk with your doctor in person if you are bothered by something that has occurred, are uncomfortable with your doctor/patient partnership, or are not satisfied with the care you are receiving. You may need to schedule an appointment for this purpose if you think the problem cannot be resolved during a regular office visit. Be sure to tell the scheduler how much time you want for the appointment so your discussion will not be interrupted or ended prematurely.

Prepare for the meeting by thinking through or writing down your concerns in advance. Be specific about your concerns and specify the changes you would like to see occur. You might:

- Describe specific behaviors that bother you and how you feel in response to them. Try not to use negative words to personally describe your doctor.
- Describe specific incidents you found upsetting as accurately as possible.
- Admit any responsibility you may have had for the problem.
- List specific actions you are requesting to resolve the problem(s).
- Invite your doctor to come up with his or her own ideas about how to resolve the problem(s).

You can present your concerns in a letter if you cannot meet with your doctor personally or are uncomfortable doing so. This approach can be useful because it gives your doctor time to think about things before getting back to you. You may want to follow-up the letter by scheduling a phone call or discussing your concerns at your next appointment. Regardless of

how you present your concerns, it is important for you and your doctor to discuss and resolve your concerns.

Occasionally, well-intentioned efforts to resolve conflicts or concerns fail to bring about an acceptable compromise. In such circumstances, you may want to consider working with another doctor. It is your right to change doctors if you wish to do so. Changing doctors does not mean there is something wrong with you or your doctor. Your doctor should be willing to give you a referral to another physician if you request it. You can also get referrals from other health care professionals or other people living with lung cancer. You may need to repeat some of the same steps you went through in finding your current doctor, including consulting with your health insurance company. Your current doctor will continue to provide care until you find another doctor to take over. You will not be left without care.

Over the course of your illness, your doctor will make many recommendations. While you may be generally satisfied with your doctor and your care, you may not be comfortable with a specific recommendation. In such a situation, you may want to get a second opinion. Your doctor can give you the names of other doctors who can provide a second opinion, or you may want to find a doctor on your own. The resources listed in the previous section *Choosing Your Doctor* can be used to find someone to provide a second opinion. Some managed care plans require you to pay for a second opinion. You may be able to appeal this provision. The customer service staff at your health insurance company can give you information about how to submit an appeal.

CHOOSING TREATMENT FACILITIES

Your choice of treatment facilities is often influenced by outside factors. People are frequently referred to a specific treatment facility because their doctor practices there. Your facility choices may be dictated by your insurance plan, especially if you are enrolled in a managed care plan. People living in rural communities may have a limited number of choices within reasonable traveling distance. Despite outside limitations, finding a quality health care facility can enhance your treatment experience.

Types of Cancer Care Facilities

Cancer care can be provided at a community hospital, university-affiliated teaching hospital, or cancer center. Cancer treatments are also frequently provided in outpatient oncology clinics. Some treatments can even be provided in your home.

Local community hospitals offer many benefits for people undergoing treatment for cancer. Advantages include familiar surroundings, the nearby support of family and friends, a smaller environment that can be more personalized and less overwhelming than larger care centers, and less time, energy, and money spent on travel. There are potential disadvantages to community hospital care, which may or may not be applicable to your local hospital. Local hospitals may not have as much experience with certain procedures because they treat fewer patients than larger facilities. They also may not have all the latest medical equipment. There may or may not be access to clinical trials.

Teaching hospitals or university-affiliated hospitals are facilities associated with a medical school. These facilities are usually quite large and treat many thousands of people each year. They generally offer the advantages of extensive cancer care experience, state-of-the-art equipment, and staff that are up-to-date with the latest medical knowledge. These facilities usually offer excellent cancer care. Nonetheless, there are potential disadvantages to these facilities that may or may not be important to you. The size of these facilities can be overwhelming; it may be hard to find your way around when you first visit. You may need to travel a significant distance to reach your nearest teaching hospital. Friends and family members may not be able to visit as often as they would like because of this distance. Travel can also be costly.

Part of the mission of teaching facilities is to train new doctors, nurses, and other health care professionals. As a result, you may be examined or cared for by many people at different stages of their professional training. Several students or professionals in training may be observing your treatments and procedures, which can feel like an intrusion on your privacy. Some people do not mind this aspect of being cared for at a teaching facility, but others find it can be trying at times.

If you live in a large city, you may be near an NCI supported cancer center. The NCI Cancer Centers Program is comprised of more than 50 NCI-designated cancer centers engaged in research to reduce the occurrence of cancer, and cancer-related illness and death. Two types of cancer centers are supported through NCI Cancer Center Program grants.

- **Comprehensive Cancer Centers** – conduct basic science (laboratory-based), clinical (patient-based), and prevention and control research; these centers also have community outreach and cancer education programs
- **Clinical Cancer Centers** – conduct clinical (patient-based) research and may have other research programs

Facilities designated as NCI cancer centers offer complete cancer care and accessibility to clinical trials. Because NCI cancer centers are involved in research, they are well informed about the most current cancer treatments. You can call NCI at 800-4-CANCER to find the NCI cancer center nearest you.

Community cancer care centers and oncology outpatient facilities offer specialty cancer care in a local setting. The level of care provided by these facilities is often very good. Many of these facilities participate in community-based clinical trial groups. If you are interested in participating in a clinical trial, talk with your doctor or the facility director to find out if they are part of a clinical trial group. The director of the facility can also provide you with information about the qualifications of the staff, quality reports about the facility, and patient satisfaction survey results. Support group members may be able to share their experiences at facilities where they have received care.

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) is an independent organization that inspects hospitals and other health care facilities to ensure they meet JCAHO quality standards. JCAHO accreditation is not required for a facility to operate. However, JCAHO accreditation provides an indicator of both the facility operator's interest in quality and the assurance that the facility meets the quality standards outlined by JCAHO. For information about JCAHO accreditation of outpatient care facilities, check the JCAHO Internet site at www.jcaho.org/accredited+organizations/ambulatory+care/index.htm.

Choosing a Hospital

The Agency for Healthcare Research and Quality (AHRQ) in cooperation with the United States Department of Health and Human Services and other private and public health organizations developed a guide to help people choose a hospital that meets their needs.³ An adaptation of that guide is presented on the following pages.

How can you choose the best quality hospital for the care you need? It is important to consider quality because research shows that some hospitals do a better job than others do. For example, we know hospitals that do a greater number of the same surgeries have better outcomes for their patients.

Quick Check for Hospital Quality

Look for a hospital that:

- is accredited by the JCAHO
- is rated highly by state, consumer, or other groups
- is one where your doctor has privileges (permission to admit patients)
- is covered by your health plan
- has experience with your condition
- has success with your condition
- checks and works to improve its quality of care

Questions to Ask When Considering a Hospital for Your Cancer Care

The following questions can help you make the best hospital choice for your care.

1. Does the hospital meet national quality standards?

Hospitals can choose to be surveyed by JCAHO to make sure they meet certain quality standards. The standards address the quality of the staff and equipment, and the hospital's success in treating and curing patients. If a hospital meets the specified standards, it becomes JCAHO-accredited.

Accredited hospitals are reviewed at least once every three years to be sure

³ *Your Guide to Choosing Quality Health Care; Choosing a Hospital*. Consumer Information, September 2002. Agency for Health Care Policy and Research, Rockville, MD. www.ahrq.gov/consumer/qntool.htm

the hospital continues to meet JCAHO standards. Most hospitals participate in this program.

JCAHO prepares a performance report on each hospital it surveys. The report lists:

- accreditation status
There are six accreditation levels ranging from the lowest (not accredited) to the highest (accredited with commendation).
- date of the survey
- evaluation of the key areas reviewed during the survey
- results of any follow-up activity
- areas needing improvement
- comparison with national results

You can order JCAHO's performance reports free of charge by calling 630-792-5800. Alternatively, check JCAHO's Internet site at www.jcaho.org for a hospital's performance report and accreditation status.

The American College of Surgeons (ACOS) accredits cancer programs at hospitals and other treatment centers. There are over 1,400 ACOS accredited cancer programs in the United States. ACOS provides a searchable database of these programs on their Internet site at web.facs.org/cpm/default.htm. You can also telephone ACOS at 312-202-5000 to find accredited programs near your home.

2. How does the hospital compare with others in my area?

One important way to learn about hospital quality is to look at hospital report cards developed by state and consumer groups. A recent study about such reports found that in addition to helping consumers make informed choices, they also encourage hospitals to improve their quality of care. This is a very good reason to look for and use consumer information about hospitals.

Resources for reports on hospitals include:

- Some states (for example Pennsylvania, California, and Ohio) have laws requiring hospitals to report data on the quality of their care. The information is shared with the public so consumers can compare hospitals.
- Some groups gather information on how well hospitals perform and how satisfied their patients are. An example is the Cleveland Health Quality Choice Program, which is made up of businesses, doctors, and hospitals.
- Consumer groups publish guides to hospitals and other health care choices in various cities. Find out what kind of information is available where you live by calling your state department of health, health care council, or hospital association. Also, ask your doctor what he or she thinks about the hospital.

3. Does my doctor have privileges (permission to admit patients) at the hospital?

If your doctor does not have privileges at the hospital, you would need to be under the care of another doctor while at that hospital.

4. Does my health plan cover care at the hospital?

If your plan does not normally cover care at a hospital you are interested in, hospital case managers and/or business office personnel may be able to contact your insurance company and negotiate an agreement to pay for your care. If your insurance company refuses to work out a payment agreement, you would need another way to pay for your care at that hospital. This is not an option for many people because hospital care is very expensive.

5. Does the hospital have experience with lung cancer?

General hospitals handle a wide range of routine conditions, such as hernia repairs, gall bladder problems, and pneumonia. Specialty hospitals have a lot of experience with specific conditions (such as cancer) or certain groups of patients (such as children). University-affiliated teaching hospitals usually handle all aspects of medical care. You may want to ask if the hospital you are considering has a special team of cancer care professionals.

6. Has the hospital had success treating lung cancer?

Research shows hospitals that do many of the same types of procedures tend to have better success with them. In other words, ‘practice makes perfect.’ When considering a facility for a specific procedure, ask your doctor or the hospital if there is information on:

- how often the procedure is done there
- how often the doctor does the procedure
- patient outcomes for the procedure (how well the patients do)

Some health departments and other agencies publish reports on patient outcomes for certain procedures. Outcome studies can help you compare which hospitals and surgeons have had the most success with a particular procedure.

7. How well does the hospital check and improve on its own quality of care?

Increasing numbers of hospitals are trying to improve their quality of care. One way to do this is to keep track of patient outcomes for certain procedures. Another way is to keep track of patient injuries and infections that occur in the hospital. By finding out what works and what does not, the hospital can improve the way it treats patients.

Ask the hospital quality management department how it monitors and improves the hospital's quality of care. Also, ask for the results of any patient satisfaction surveys the hospital has done. These will tell you how other patients have rated their quality of care.

YOUR HOSPITAL EXPERIENCE

Most people with lung cancer become familiar with one or more hospitals during their experience with the disease. A hospital is its own little world with unique customs and language. The hospital is just an everyday workplace for the staff. But for you, the hospital is likely to be full of strange objects, words, and routines.

Being in the hospital can be challenging. Hospital staffs can have a tendency to focus on your medical needs rather than responding to your feelings. There may be times when hospital personnel refer to you by your disorder rather than your name, such as “the lung cancer in room 912.” This can leave you feeling as if you are being treated like an object rather than a person. In addition, hospitals have routines they must follow in order to function smoothly. Patients are expected to fit into these routines regardless of their personal preferences. These situations can be very trying and leave you feeling somewhat helpless.

It is important to do what you can to feel a sense of control about your hospital care. It may help to visit the hospital before a planned stay to become familiar with the surroundings and routines. Many hospitals have patient services departments with social workers on staff who can direct you toward a variety of resources. Some hospitals also have case managers (nurses or social workers) who coordinate your care with the various departments that will be involved in your treatment. You may want to meet with one of these professionals to ask any questions you may have before being admitted for treatment. In addition, many hospitals have patient education centers. You may want to visit your local patient education center and utilize some of their services.

Every hospital patient deserves quality care. At the same time, hospital personnel are usually very busy. As a hospital patient, you will have to balance these two realities. It is important to speak up if your needs are not being met. It is also important to be courteous and reasonable in what you ask of the staff. Let the staff members know if something about your care seems amiss. A tone that is polite, respectful, and clear is usually best. Avoid behavior that may appear rude, demanding, or disrespectful. Your goal is to get your needs met. Treating the hospital staff with respect and consideration increases the likelihood that they will respond positively and do what they can to accommodate your requests. You can discuss unresolved concerns or problems with someone in the patient services department.

Tips you may find helpful for making your hospital experience run smoothly include:

- Be sure you understand ahead of time what doctor will be supervising your care. Find out how to reach this person before and during your hospital stay. You may want to ask the supervising doctor who else will be involved in your care (other doctors, residents, medical students, etc.).
- Ask people to visit regularly during your hospital stay. They can help look out for your welfare, bring items from home, and follow-up on any concerns you may encounter.
- Build a positive relationship with hospital staff. Express appreciation for the things they do for you. This fosters a good working relationship. People who feel appreciated are generally receptive to requests for assistance.
- Feel free to ask questions. If you are confused about something, ask for an explanation. If something is upsetting you, talk to someone who can help resolve the problem. It helps if you approach problems in a friendly way. In general, hospital staff will go out of their way to be helpful. Family or friends can follow-up on your concerns or questions if you are not up to handling things on your own.
- Friendly humor can help to reduce tension and build positive connections with hospital staff.

When you are ready to be discharged from the hospital, your doctor and case manager (if you have one) will do discharge planning. This involves:

- making arrangements for any in-home care you may need
- providing you with instructions about how to care for yourself at home
- advising you about activities to avoid and for what length of time
- specific instructions about signs or symptoms to be aware of that may indicate a need for urgent medical attention
- follow-up appointments with your doctor, physical therapists, or other health care professionals
- prescriptions for any medications you will need to take at home

Be sure you understand all your discharge instructions before leaving the hospital. It is often helpful to have someone with you when these instructions are explained so he or she can help you recall them once you get home. A written list of instructions should be provided for your reference. The list should have the name and telephone number of at least one person to contact if you have questions or problems once you get home.

SUPPLEMENTAL CARE SERVICES

A variety of health care and other supportive services are available to people with lung cancer. This section briefly reviews some of these services. Your oncology social worker or nurse can help you find additional information about these services if you are interested in pursuing any of them.

Home Health Care

Increasing numbers of people with cancer are choosing home health care. Home health care offers many of the services that used to be available only in a hospital or outpatient facility. Services that may be available include:

- intravenous (IV) therapy including chemotherapy infusions, heparin therapy (for blood clots), supplemental fluids, and antibiotics

- blood drawing for laboratory tests
- nursing care
- physical therapy
- respiratory therapy
- medical social work
- home health aides
- personal care assistants
- homemaker and housekeeping services
- home medical equipment such as supplemental oxygen, respiratory equipment, wheelchairs, hospital beds, etc.

Nurses, home health aides, and personal care assistants can be scheduled according to your needs. Homemakers perform such tasks as cooking meals, doing laundry, and grocery shopping.

It was defiantly nice to have my physical therapist come to my house. When I had knee surgery a while back, I was in a physical rehabilitation clinic for ten days. This time around was much nicer with my therapist coming to the house. If I didn't feel like getting out of my pajamas, I didn't have to. It was just much nicer at home where I am more comfortable [than in a clinic.]
— Judith, diagnosed with stage IIA NSCLC in 2001 at age 60

Coverage for home health care services varies greatly from one health insurance plan to another. Check with your insurance agent or customer service representative to see what coverage you have for these services. Talk with your oncologist or oncology nurse if you are interested in home health care services. He or she can help you make the necessary arrangements.

Some states provide payments to eligible people who are the primary caregivers of someone with a serious illness such as lung cancer. Call your state Department of Health or the Patient Advocate Foundation at 800-532-5274 to find out if financial support is available in your state. You can also search the state resource guide on the Patient Advocate Foundation Internet site at www.patientadvocate.org/report.php.

Hospice

Hospice care is similar to home health care, but provides services exclusively to people with terminal illnesses who have made the decision to forego further *curative intent* treatment.

Hospice care can be delivered in your home or at a hospice facility. Additional information about hospice care is presented in *Chapter 15: Planning for the Future*.

Eldercare

Eldercare is an umbrella term that refers to a variety of coordinated community, social, financial, and medical services available to people over the age of 60 or 65. Eldercare services are very helpful for older people who live alone or live with someone who is also advanced in years. These services can help you meet the challenges of lung cancer that may otherwise make it difficult for you to continue living on your own. Services available through eldercare agencies include:

- personal care services – assistance with bathing, dressing, and grooming
- home health care services
- financial services – applying for social security, disability or pension benefits, keeping track of and paying bills, submitting insurance claims, negotiating with creditors, etc.
- individual and family counseling
- community service referrals
- transportation services

Counselors evaluate your needs and the needs of your caregiver, and arrange for services. They work with your oncologist to be sure all your medical needs are met. Counselors will also review your health insurance coverage and advise you about what services are covered by your plan. Many services available through eldercare agencies are available to qualified persons free-of-charge or on a sliding scale (fees are based on what you can afford). Talk with your oncology nurse or social worker if you are interested in eldercare services. They may be able to give you referrals and recommendations.

Geriatric Care Managers are professionals charge a fee to provide the same basic services as eldercare agencies. Fees for their services are not reimbursed by most health insurance plans. If you can afford these services, you may want to contact the National Association of Professional Geriatric Care Managers at 520-881-8008, or log onto their Internet site at www.caremanager.org.

Meals On Wheels

Meals On Wheels provides meals for those who want to stay in their homes but are unable to prepare their own meals. This service is available in many communities to people of any income level who are 60 years of age and older. Younger adults may be eligible if they are homebound. Fees for this service vary according to a person's ability to pay. This service can be used on a long or short-term basis. Ask your social worker, nurse, or doctor for information about this program in your community.

Adult Day Care

Adult day care (ADC) centers are community-based programs that provide non-medical care to people in need of personal care services, supervision, and/or assistance with the tasks of daily living. Most facilities are available to anyone 18 years of age or older. ADC centers provide care during the day. Participants return to their homes or the homes of family members in the evening. The types of services typically provided by ADC centers include:

- therapeutic and recreational activities (exercise, crafts, music, etc.)
- health monitoring (but not health care)
- supervision
- personal care assistance
- nutritional meals and snacks
- caregiver support groups or referral to other programs

ADCs are not medical care facilities. Talk with your oncology doctor or nurse about whether an ADC would be appropriate for your situation.

Assisted Living Facilities

Assisted living facilities may be an option for older adults who want to remain as independent as possible, but who need assistance with many of the tasks of daily living.

Assisted living facilities can have from ten to several hundred residents. Different facilities offer their own menu of services that can include:

- basic housing
- meals
- 24-hour emergency monitoring
- supervision and dispensing of medications
- socialization with peers
- assistance with bathing, dressing, grooming, eating, and/or transportation

You can customize the number and type of services you need to fit your particular situation. Cost for this care is variable. Talk with your social worker or oncology nurse about how to obtain additional information about this living arrangement.

SUMMARY

Becoming knowledgeable about lung cancer, the health care system, and your rights as a health care consumer will put you in the best position to find quality health care that suits your needs and preferences. As a health care consumer, you have a right to quality medical care.

Choosing a cancer care team you can work with effectively and comfortably is a key component of quality care. Similarly, a treatment facility that offers services commensurate with your treatment goals and preferences can greatly enhance your sense of satisfaction and comfort.

I hope the information in this chapter contributes to your health and well-being. In addition, I hope your journey through the health care system is smooth and meets your expectations and needs fully.