We created the Decision Guide as a companion piece highlighting the key principles to managing the cancer decision-making process. In it, you will find helpful tools designed to present you with an informative, insightful review of one approach you as a patient or caregiver may choose to adopt and incorporate in your own search for the best cancer treatment available.

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

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

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

At the very least, the Decision Guide contains useful information about hospitals, treatment options and questions you may use to assess the doctors and hospitals you visit throughout this experience. Good luck!
Today, more than ever, patients have access to an array of treatment options. The sheer number of available options makes understanding the basic treatments an extremely important component of a patient’s decision-making process. Exploring this wide range of treatment options requires a general understanding of three traditional treatment modalities—surgery, radiation therapy and chemotherapy. New, emerging therapies constitute a fourth group of therapies patients may examine prior to selecting a treatment option.

**Treatment Differentiation**

Here is some basic information about the four treatment categories.

- **Surgery** – Surgery is the oldest and, perhaps, the most widely practiced form of cancer treatment. Nearly sixty percent of patients undergo some form of surgical treatment. *Surgical Oncologists*—doctors who specialize in cancer surgery—perform a variety of surgical procedures to cut cancerous tumors out of the body. Surgery is often used in conjunction with radiation therapy and/or chemotherapy. Before pursuing surgical treatment, patients should always obtain a second medical opinion from a different surgical oncologist. Patients may seek additional opinions from a radiation oncologist and/or a medical oncologist to compare, contrast and choose the best possible option from this comprehensive array of opinions. Surgery is permanent—therefore it is critical that thorough laboratory and diagnostic work have been conducted to ensure the cancer is confined to the surgical area.

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

  Recent technological advances in diagnostic imaging machinery allow *Radiation Oncologists*—doctors who specialize in the planning and delivery of radiation therapy—to map a cancerous site and deliver precise beams of radiation right where the patient needs it most. Differences do exist in the quality of radiation equipment; therefore, patients should always look for a treatment facility with the latest diagnostic equipment and radiation machinery. Radiation therapy is often used in conjunction with surgery and/or chemotherapy; however, radiation may sometimes serve as a more effective, less invasive primary treatment that, in some cases, replaces surgery.
• **Chemotherapy** – Chemotherapy is a broad term relating to a group of medications designed to damage a cancer cell’s ability to grow. *Medical Oncologists*—doctors who specialize in treating cancer with different types of drugs and chemotherapy—overlook this aspect of cancer treatment. Patients receive chemotherapy orally or through an intravenous (IV) administration. Unlike radiation therapy, conventional chemotherapy is a *systemic* treatment carried throughout the body by the bloodstream. New medications help to control side effects and, with the proper comprehensive team of experts, the side effects can often be managed and minimized. Chemotherapy is often used in conjunction with surgery and/or radiation therapy.

• **Emerging Therapies** – In the hands of a skilled physician, emerging therapies represent promising new treatment options available in select hospitals across the country. Immunotherapy, bone marrow transplant, hormonal therapy, photodynamic therapy, hyperthermia and arterial embolization illustrate some of the more prominent emerging therapies available to patients. Typically, patients and physicians turn to emerging therapies in three different situations: after exhausting all surgical, radiation and/or chemotherapy options; when the physician determines traditional therapies will no longer improve the patient’s condition; or when the patient may benefit from an emerging therapy used in conjunction with other conventional treatments.

**Special Services**
Apart from the four main treatment modalities, patients must also consider pain management and *palliative care* services.

• **Palliative Care** – Palliative Care is a specialized form of medicine focused upon alleviating pain, nausea or any number of other side-effects patients may experience during treatment. Few hospitals offer a dedicated Palliative Care Department—but regardless of this trend, effectively managing a cancer patient’s pain is necessary for optimal treatment. Unmanaged pain may interfere with a patient’s sleep patterns, appetite and treatment schedules. Patients should inquire about the Palliative Care or Pain Management programs available in their hospitals.
QUESTIONS TO ASK YOUR DOCTOR

Establishing an open dialogue with a doctor provides patients with the opportunity to learn specific information regarding the staging and diagnosis of their cancer, their treatment options and, most importantly, their physician’s credentials and experience. Before meeting with a doctor, it’s important to know the basics.

1. **Bring someone with you:** Bringing a friend or loved one to the consultation can help patients manage their nerves and ensure they ask all of the necessary questions.

2. **Take notes:** Logging the doctor’s responses to questions will help patients keep track of the information the doctor provides and serve as a useful reference after the consultation ends.

3. **Prepare written questions and thoughts BEFORE the consultation:** Time is usually limited during a consultation; therefore, writing a list of questions before the consultation allows patients to fully utilize the time they have with the doctor.

Patients may consider incorporating some of these general questions into their own lists.

**Questions to ask an Oncologist**

- Identifying the *stage* of my cancer (i.e. Stage I, II, III or IV) is critical to selecting the appropriate treatment. What laboratory and diagnostic testing will you use to definitively stage my cancer and how can you assure me of the accuracy of your diagnosis and staging?
- What treatment options do you normally recommend for people with my type and stage of cancer? What results do you expect?
- Why do you recommend this treatment over others?
- What additional tests would you recommend and what additional information would the tests provide?
- What are all of the possible treatment options that I should know about? What are the advantages and disadvantages of each and why do you recommend the option you are suggesting?
- How long will this suggested treatment last?
- How often will I have this treatment?
- Will I have to change my normal activities? If so, for how long?
- How will we work together on securing second medical opinions and second pathological and laboratory test reviews?
- Would you please tell me about your training, qualifications and experience in treating people with my type and stage of cancer?
- What is your view of working cooperatively with other professionals who will care for me in other areas of physical or emotional need that may arise during the course of my treatment (E.g. psychologists, nutritionists, physical therapists)?
**Experience Matters**
Research studies conducted by National Cancer Institute hospitals illustrate the correlation between the numbers of specific surgical procedures a surgeon performs and the surgeon’s success rate with that same procedure. Diagnosing, staging and treating specific forms of cancer equips physicians with a certain focus and a level of specialization that can have a very real, positive impact on the patient’s treatment process. But assessing the experience of a surgeon, a hospital or even a radiation oncologist requires the patient to ask questions.

**Interviewing a Surgeon**
Nearly sixty percent of cancer patients will undergo some sort of surgery during treatment. Patients electing to pursue surgical treatment may utilize some of these questions during their consultation.

- Are there any non-surgical ways to treat this condition?
- How long is the recovery period after surgery and how soon after surgery may I start therapy (if necessary)?
- What are the risks of this surgery?
- How many of these specific surgical procedures have you performed in the past year?
- What is the surgeon’s success rate for this surgery?
- What are the potential complications associated with this surgery? How common are these complications and what can be done if they occur?
- Who will perform the operation? Will a surgical intern perform the operation?
- What other specialists should be or are planning to be present during the surgery?

**Evaluating the Information**
Patients, along with supporting friends or loved ones, should review their consultation notes soon after the meeting’s end. Information gathered from the doctor’s responses to these questions increases a patient’s knowledge base and provides a deeper understanding of the disease, the treatment options and the doctor’s approach to delivering care. But more than the doctor’s treatment approach, a face-to-face consultation allows patients the opportunity to gauge the doctor’s personality. Patients should ask these questions after meeting a doctor:

- Am I comfortable talking with this physician?
- Does this physician seem to have the time to talk with me?
- Does this physician genuinely listen to my concerns and offer meaningful feedback?

Patients require the care and sensitivity of a physician whose focus rests upon listening to the patient’s needs, incorporating those needs into a sound medical treatment plan and adhering to that plan with the flexibility to allow for change.

Combining all of the information gathered from this process equips patients with a more complete overview of the doctor’s approach to treating this disease.
Selecting a treatment hospital may be the most important, and the most difficult decision a person with cancer makes during the treatment process. Community Hospitals, University Hospitals and Private Clinics scatter the healthcare landscape, providing the newly diagnosed and those searching for a second opinion with a variety of choices. Weighing these choices by gauging a hospital’s specific services, relative to the patient’s needs, is one effective way for a person to choose a treatment hospital.

Patients may use the following criteria to assess a treatment facility:

- **Services:** All hospitals are NOT created equal! As patients research hospitals and review the multitude of oncology programs available, one constant thought should always be, “How will this program integrate its services to help me fight my cancer on all fronts?”

- **Staff:** A hospital is nothing more than bricks and mortar without the doctors, nurses, nutritionists, naturopaths, mind-body specialists and pastoral support staff members who make up the care team. Patients may differentiate one hospital from another by noting the approach the staff takes to patient care—do staff members collaborate with patients and advocate patient participation in the decision-making process?

- **Technology:** Recent technological advances in diagnostic imaging, radiation and chemotherapies are changing the face of cancer treatment today; and patients deservedly reap the benefits from the precision mapping and treatment delivery options now available. A hospital with state-of-the-art technology equips doctors with powerful and more exacting means of delivering innovative and expert care, right where the patient needs it most. As patients examine various treatment options with a hospital, ask the question, “Is the diagnostic laboratory and treatment equipment available at this hospital the most advanced of its kind?”

**The Playing Field At-A-Glance**

**Community Hospitals:** The Association of Community Cancer Centers estimates over 80 percent of U.S. cancer patients visit a Community Hospital for treatment. These facilities focus upon delivering patient care. Sometimes, Community Hospital’s lack the financial resources to offer the advanced diagnostic testing and treatment protocols available in larger hospital settings. This is an issue patients should carefully investigate.

**University Hospitals—*Academic and Teaching***: The broad “University Hospital” designation refers to *Academic* and *Teaching* Hospitals—titles reflecting a hospital’s affiliation with either a major university or a medical school, respectively. Featuring broad research/laboratory initiatives as well as a dedicated oncology staff, an *Academic Hospital* provides access to a variety of clinical trials. *Teaching Hospitals* mirror their Academic Hospital counterparts, but lack the full-time laboratory research programs
characteristic in the Academic Hospital setting. Both centers provide advanced diagnostic and treatment protocols, as well as clinical research trials.

**Private Clinics:** Private Clinics provide patient care in a freestanding, non-hospital setting. Like the professional buildings that house both dentists and orthodontists, Private Clinics usually feature a group of oncologists with the same medical expertise practicing one, possibly two, of the three traditional oncology treatment modalities surgery, chemotherapy and radiotherapy. These smaller facilities offer limited diagnostic testing and treatment services compared to those larger treatment hospitals with greater staff sizes and comprehensive treatment protocol.

**Helpful Questions to Ask When Evaluating a Hospital**

- Has this facility been reviewed by any accrediting boards or patient satisfaction surveys? If yes, would you please discuss the results of those reviews/surveys?
- How many patients with my form of cancer does this facility see per year?
- Does this hospital practice an integrated approach to cancer care? If so, please explain.
- How many treatments or surgical procedures specific to my cancer are conducted annually?
- What special hospital services or support services will I require during my stay? How do these services work together?
- Does this hospital participate in clinical trials specific to my cancer?
- Does this hospital provide a palliative-care service to help ease pain or other side effects that might arise during treatment?
- How old or new is the diagnostic and x-ray equipment in this facility?
- Does this hospital have laboratory, imaging and other testing facilities on-site?
- What research facilities focusing upon cancer research are affiliated with this hospital? Are new research findings integrated into the hospital’s listing of treatment protocol?
Everyone has a system for making decisions—many times however, patients lose sight of “their system” when placed in a situation as complex and, at times, as overwhelming as a cancer diagnosis. Our job is to help you regain control of this decision process by making it uniquely yours!

Our Oncology Information Specialists and physicians constantly look for a better way to help patients learn what questions to ask when selecting a hospital and a physician. This worksheet is our way to help you learn what resources you need to make the best possible decisions about your care. To simplify this process, we broke the Decision Manual into four basic steps:

- **Component One** helps you review your treatment history, asks you to identify key decision-shapers who influence your decisions and points to any additional roadblocks you may encounter during your search for the best cancer care available.

- **Component Two** asks you to develop a list of criteria you will use to assess treatment facilities and physicians.

- **Component Three** is your opportunity to list the treatment facilities and the physicians with whom you wish to focus your search.

- **Component Four** walks you through an analysis of both treatment facilities and physicians you plan to visit and provides you with an opportunity to review the facility where you currently receive care.

**HOW DO I USE THE DECISION MANUAL?**

There is no right or wrong way to use the Decision Manual, so it’s helpful if you do not judge the answers to your questions this way! Your answers are yours, the Decision Manual simply asks you to begin organizing your thoughts and experiences dealing with cancer. We do this by presenting you with a series of questions designed to draw out some very honest responses.

As you begin reading this worksheet, you may choose to write your responses to these questions directly onto this sheet of paper. We provided spaces for your answers. Or, if you would like, ask a friend or loved one to sit with you and, together, openly discuss your thoughts.

The central goal of this entire worksheet is for you to use your answers from the questions on the following pages to measure treatment facilities and physicians against a set of criteria you develop.
COMPONENT ONE: ASSESS YOUR CURRENT SITUATION

- Think about your current situation. Whether you are newly diagnosed, just finishing treatment or seeking a second opinion, it’s sometimes helpful to review where you stand at the present moment. As you think about your situation, focus upon the events leading up to and immediately following your cancer diagnosis and/or your latest treatment. This may take some time, but analyzing the past events leading up to your current situation will help you engage your mind as you begin this exercise. You may wish to use the lines below to make some notes of your thoughts.

_____________________________________________________________________
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_____________________________________________________________________
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_____________________________________________________________________

- After revisiting all of the different steps and the various emotions that carried you to this point today, is there anything you feel that is missing from this scenario? You may feel nothing is missing from your present treatment process, if so, that’s great. It’s also possible that after reviewing past events, pinpointing an exact “what’s missing” from your situation is not as easy as the question first appears. That’s OK too. You may not uncover an answer instantaneously, but by asking yourself, “what’s missing” you begin to think critically about the level of care you currently receive compared to the level of care you feel you deserve to receive. Finding a match between the care you currently receive and the care you deserve to receive is the goal of this exercise.

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
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- If you experience some difficulty trying to recognize “what’s missing,” you may find it easier to first identify your goals or expectations for the treatment process. What expectations do you bring to the treatment process? Whether you expect complete remission from your cancer or you desire an improved quality-of-life, it is important to address what you are looking to accomplish—your goals—before pursuing treatment. You may also use your goals to shine light on what may or may not be missing from your current situation. What are your goals?
Recognizing your treatment goals and “what’s missing” are two key components to controlling the decision-making process. You may also find it helpful to point out any “roadblocks” or obstacles possibly preventing you from achieving your goals. Identifying these obstacles now allows you to take appropriate action in the future in two ways: 1) it allows you to address the problem directly or 2) it permits you to work around the problem to reach the end goal. What obstacles may prevent you from reaching your goals?

Influential people in your life play an important role in shaping your decisions. Consulting with these key decision-shapers before you decide upon a course of treatment provides you with the opportunity to review your decision with a group of people who impacted your decisions in the past and who may help guide your decisions in the future. Who is involved in this decision-making process besides you (a spouse, a sibling or a friend)?

COMPONENT TWO: ESTABLISH CRITERIA (standards)

Often, establishing some simple “standards” around the decision-making process assists decision-makers in creating a basic framework of principles, allowing decision makers to qualify any potential solutions they may uncover without compromising their beliefs and preferences. This document calls the “standards” you establish “criteria.” At this point, write down the criteria you will impose on any decision you face relative to your care.

For example:
- I want a doctor who collaborates with other members of my treatment team.
- I want a facility with the most advanced staging and treatment equipment.
- I want a doctor who educates, empowers and respects my opinion.
- I want a hospital with an active pastoral care and counseling department.
- Develop your own list.
COMPONENT THREE: IDENTIFY POTENTIAL OPTIONS

- Please list both the facilities and the doctors you consider as potential options for receiving a second opinion and/or treatment. It is important you identify both the hospitals and the doctors you see as potential options—a hospital is only as strong as its staff of doctors and the level of care a doctor provides may be limited by the hospital’s facilities and technology. Listing the hospitals and doctors you consider visiting will help you visualize your choices so you may begin comparing this list of facilities and physicians with the criteria you listed above in “Component Two.”

Facility’s Name & Doctor’s Name
1. 
2. 
3. 
4. 

COMPONENT FOUR: COMPARE YOUR OPTIONS

Hopefully, the previous three steps helped you identify what you are looking for in a treatment facility and a physician—that is, your needs based upon your current situation and the type of care you expect to receive. Now, how do you distinguish one option from the other—especially in this highly technical field? There are two pieces to assessing the quality of a treatment facility—the facility type and the physicians who work in that facility.

- Assess the “facility type” of each of the hospitals you are considering for treatment and/or for a second opinion. Is it a community hospital, a university hospital or a private, stand-alone clinic? If you have questions about how these facilities differ, please refer to the “Selecting Your Treatment Hospital” section of the Decision Guide for a brief overview of each facility type.

Facility Type
1. 
2. 
3. 
4. 

- Next, evaluate the physician who will be responsible for your care.
  - Is he/she an oncologist—a physician with special training and experience in the medical treatment of cancer?
Is he/she a solo practitioner or does the physician collaborate with other experts to provide you with options and integrated treatments?

Does he/she have access to the latest staging and treatment equipment and how do you know?

How does he/she collaborate and listen to the needs you identified in “Component Two?”

A correlation exists between the number of procedures a physician completes and the physician’s success rate with that same procedure. How many of the same procedures the physician recommends you undergo has he/she performed in the last six months? In the last year? In the last five years?

The questions in this section are very basic, but very important. Assessing a physician’s skill and experience working with and treating patients who have your type of cancer can make an enormous difference in the quality of care you receive. You may have some of your own important questions you developed to evaluate your doctors and we encourage you to use those questions to assess the physicians responsible for your care. If you would like, please use some of the spaces on the next page to help you begin to evaluate your physicians.

**Physician 1**
**Physician’s Name: _________________________**
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

**Physician 2**
**Physician’s Name: _________________________**
________________________________________________________________________
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________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

**Physician 3**
**Physician’s Name: _________________________**
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
WHAT NEXT?

After answering all of these questions, you may find it helpful to review your responses. Analyze your responses by searching for relationships or connections between the answers you provide for Components One, Two, Three and Four.

As you begin identifying “what’s missing” from your current situation, compare your answers to the “what’s missing” question with the list of “roadblocks” you created under “Component One.” Do you see any similarities between the two? You might find the answers you provided to the “what’s missing” question pointing to possible solutions for some of the roadblocks you’ve encountered up to this point.

A second comparison you may wish to examine focuses upon your treatment goals and the list of criteria you create in “Component Two.” Do you see a similarity between the goals you established in “Component One” and the treatment facility and physician criteria you created in “Component Two”? It might be helpful if you think of the criteria you establish as the “bridge” you will “walk” across to reach your goals. Apply those same criteria to the hospitals and physicians you identified in “Component Three” and “Component Four.”

You may find a number of other comparisons as you review your answers. Use the knowledge you gained by completing this exercise to assist your search for the best cancer care available. Our hope is to help you become a more empowered decision-maker.