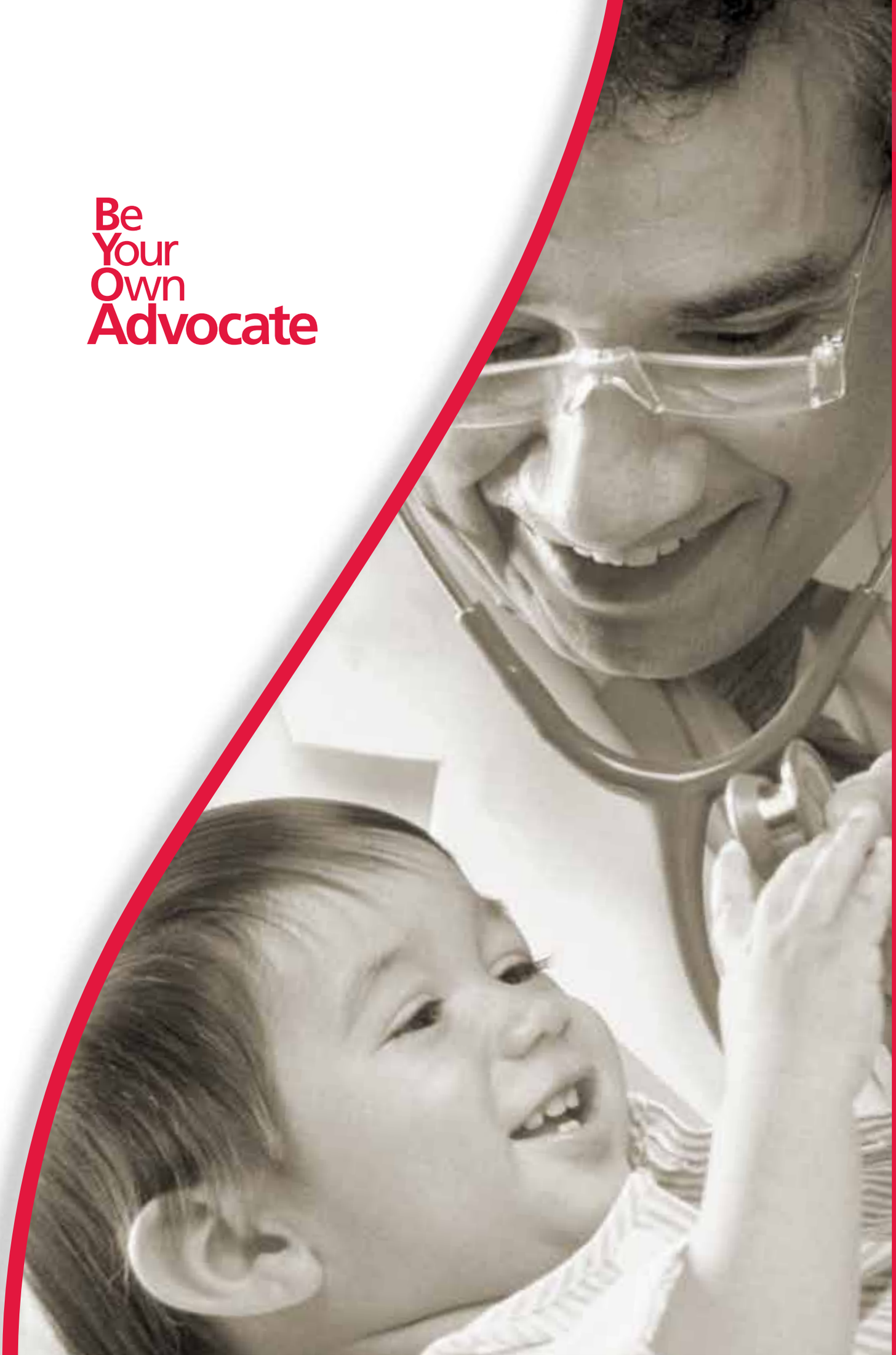
Be Your Own Advocate



Your Healthcare Team & Treatment

Healthcare Team Members: Who are they and what are their roles?

The team of healthcare providers who will provide your treatment is sometimes called a "multidisciplinary" team in that they are professionals from across different specialties and departments within the hospital. This dedicated group of professionals works in concert to provide you the best treatment plan. Because they are instrumental to your care, it can be helpful to know more about their specific roles. If you have any questions, don't hesitate to ask members of your healthcare team about their role or the specific care they are providing. Below is a list of various care providers and their roles:

Physicians

Primary care, general practitioner or **internal medicine physicians** provide general healthcare. They are usually the doctors who refer patients to hematologists/oncologists for treatment of blood cancers. Following completion of your treatment, you will continue to see this physician for general healthcare needs.

Physicians receive training at a university or teaching hospital. If you are being treated at one of these facilities, you might encounter the following types of doctors: attending physicians have medical degrees and have completed residency training; fellows are doing further training in a specialty after having completed medical school and residency training; residents work with attending physicians to become certified in a particular specialty after having graduated from medical school and completed an internship; interns must be supervised by a senior physician while they train in a general area of medicine following medical school graduation; medical students have completed two to three years of medical school and work in hospitals under the supervision of attending physicians.

Anesthesiologists administer drugs or other treatments for pain management, most often during and after surgery, as well as other procedures.

Hematologists, medical oncologists and **radiation oncologists** are physicians specializing in cancer treatment.

Physiatrists are certified in physical medicine and rehabilitation and work with patients dealing with physical impairment and the loss of function.

Physician's Assistants (PAs) are licensed to practice specific aspects of medicine under the supervision of a physician.

Pathologists study cells and tissues, and interpret lab test results to confirm a patient's diagnosis.

Surgeons or **surgical oncologists** can operate and usually specialize in the surgical removal of cancer.

Nurses

Registered nurses (RNs) have completed a specific amount of training and have a nursing degree. RNs provide care under the order of a physician, nurse practitioner or a physician's assistant. Many RNs are certified in caring for patients in a particular specialty, such as oncology.

Nurse practitioners (NPs) or **advanced practice nurses (APNs)** are registered nurses who have completed graduate-level studies in nursing and have advanced training in a specific field, such as oncology. NPs and APNs work closely with physicians, and can prescribe medications, as well as diagnose, treat and manage a patient's care.

Certified nursing assistants (CNAs) have completed a specific amount of training and are supervised by nurses or other medical staff. CNAs provide practical care, such as assistance with bathing.

Other Healthcare Team Members

Case managers or **care managers** guide patients from diagnosis through treatment, providing cohesion to other professionals on your healthcare team.

Chaplains provide spiritual support to patients and families. Most hospitals employ chaplains from a variety of faith backgrounds and denominations.

Child Life Specialists use their knowledge of child development to help prepare and support children and their families through various components of diagnosis and treatment. They promote the involvement of parents or other family members as partners with the child's healthcare team.

Dietitians or **nutritionists** are food and nutrition experts who help guide and counsel patients on nutritional eating.

Occupational therapists (OTs) are trained to help people return to or improve upon activities that are important to everyday living, such as dressing, bathing or working.

Patient navigators support and guide patients through the many components of care from diagnosis through treatment, which can include setting up appointments, referring patients to support services and helping with paperwork. Patient navigators also maintain communication between the patient and other members of his or her healthcare team.

Physical therapists (PTs) provide services to help patients regain function, improve mobility, relieve pain and prevent or limit permanent physical impairment.

Psychiatrists, psychotherapists and **psychologists** assist patients with mental or emotional challenges that arise from being diagnosed with cancer. Psychiatrists are medical doctors who can prescribe medications.

Social workers provide psychosocial support to patients and their families. They help plan for patients' needs after discharge from hospitals, and may help arrange for at-home services.

Specialty Pharmacies carry more types of prescriptions than chain or neighborhood pharmacies. Some cancer prescriptions can only be filled at these specialty pharmacies. Ask your healthcare team where your prescriptions can be filled.

Talk to your doctor about any clinical trials for which you might qualify, and find out if your doctor recommends them for you. Participants in clinical trials can play a more active role in their own health care, gain access to new research treatments before they are widely available, and help others by contributing to medical research.

Hospital _____

Phone _____

Email _____

Medical Lab _____

Phone _____

Email _____

Medical Contacts:

Primary Care Physician _____

Phone _____

Email _____

Nurse _____

Phone _____

Email _____

Primary Oncologist _____

Phone _____

Email _____

Oncology Nurse _____

Phone _____

Email _____

Radiation Oncologist _____

Phone _____

Email _____

Surgeon _____

Phone _____

Email _____

Pharmacy _____

Phone _____

Email _____

Social Worker _____

Phone _____

Email _____

Psychologist _____

Phone _____

Email _____

Your Healthcare Team & Treatment

Working with Your Healthcare Team

Your care and treatment for blood cancer is very much a team effort, and you are the most important member. When you are being treated for cancer, circumstances may seem beyond your control. However, you play an integral part in developing your care plan, along with your physicians and other members of your care team.

Depending on the details of your health insurance, you may have some choice as to which hospital you seek treatment. Your oncologist will lead your treatment team. It is important for you to feel comfortable with your oncologist and members of your healthcare team. You should talk freely and in detail about your symptoms, pain and any other changes you notice in your body. Ask any and all questions that you have regarding any aspect of your treatment.

If you are not feeling well at any of your appointments, or you feel having someone else with you at appointments would be helpful, enlist the help of a trusted family member, friend or social worker to accompany you to tests and appointments.

It is also important to feel like you have a rapport with your healthcare team. If at any time you feel like your personal style is not a good fit with a member of your team, share your concerns with someone you trust. Try to discuss your concerns directly with your healthcare team member. This could be another opportunity to enlist the help of a family member or friend to help you. Many hospitals have patient advocates whose role is to solve problems between patients and healthcare staff.

Familiarize Yourself with Policies and Procedures

Equally important to getting to know your healthcare team is learning of various policies and procedures important to the various components of your treatment.

Familiarize yourself with what to do in the following situations:

Reaching your physician You will have needs and concerns that occur outside of regular appointments, so ask what are the best ways to reach your doctor in these situations, such as a phone call, email, answering service or paging system. Find out how your physician handles emergencies if he or she is not available. Most physician offices recommend patients go to the hospital emergency room or dial 911.

Obtaining Test Results Waiting for test results can be anxiety provoking. Find out how you should obtain test results. In most instances, your physician will want to discuss the results with you or have a nurse from the office contact you. Physician offices vary as to whether they contact you with the results or ask that you call into the office to receive test results. You should always feel free to ask questions until you feel comfortable with understanding the results. Be sure to reference the *Understanding Lab and Imaging Tests* booklet in the pockets at the end of this guidebook.

Confidentiality Healthcare providers are required to protect the privacy of patients under the Health Insurance Portability and Accountability Act (HIPAA). You will be asked to read and sign a HIPAA form prior to your treatment. You will be asked to provide the names of people with whom your healthcare information can be shared. Ask questions before signing the forms and find out who else will have access to your information, such as your insurance provider.

Preparing for Appointments

Preparing in advance for doctor appointments can be beneficial to both you and your healthcare team. Later in this book we provide a list of questions to ask your physician, as well as questions to ask about medications prescribed to you and their side effects. It is also important to write down notes about your concerns and anything that might impact your treatment to share with your doctor at your appointment. These can include:

- General concerns about your treatment as well as any emotional concerns, such as depression
- Pain, new symptoms or any new side effects you have noticed
- Any other treatments you have had, including a massage or acupuncture
- Current medications and dosages (including prescriptions, over-the-counter drugs, vitamins and nutritional supplements)

Suggested Items to Bring to Appointments

Your course of treatment will include many appointments for tests, to see your doctor or for treatment. To make efficient use of your time as well as stay comfortable during these visits, we have created these individual checklists to help you make the most of your appointments, including suggestions on what to bring and what to leave at home.

What to Bring to the Hospital Checklist

- ☐ Photo ID (drivers license or state identification card)
- ☐ Insurance card and information
- ☐ Pajamas, nightgown and robe, if you wish
- ☐ Personal toiletries, such as shampoo, toothbrush, toothpaste, lotion (hospital rooms tend to be dry)
- ☐ Comfortable clothes to wear home
- ☐ Money (including change) to purchase newspapers, magazines, etc.
- ☐ Assistive devices such as walkers, crutches, canes, hearing aids or magnifying glasses labeled clearly with your name
- ☐ A list of prescription medications, dosages and schedule—ask your physician beforehand if you should bring any of your medications to the hospital (a page to list medications is included on pages 1.5 and 1.6)
- ☐ Names and phone numbers of family members or friends to contact in an emergency
- ☐ Written list of past hospitalizations, illnesses, surgeries and allergies
- ☐ A copy of your Advance Directives, including the Living Will or Durable Power of Attorney for Health Care, if you have such documents

Discharge Checklist

The following is designed to help you prepare to leave the hospital:

- ☐ Review with your physician, nurse or pharmacist all information about the medications and care you will need at home.
- ☐ Pick up any prescriptions that you need from the Professional Building pharmacy.
- ☐ Check your room for any belongings you may have left in the drawers or closet.
- ☐ Pick up any valuables you may have left with the Admitting/Registration Department.
- ☐ Check with a billing/financial counseling representative to ensure that all the proper forms have been completed.
- ☐ Confirm that you have transportation home and that you will be picked up at the appropriate entrance.

Infusion and/or Radiation Day Checklist

Infusion therapy and Radiation therapy do not require much preparation on your part. However, there are a few things to keep in mind for your treatment day.

Use this checklist before each appointment to make sure you are ready:

- Talk to your doctor if you have any questions about your treatment regimen.
- Be sure to tell your doctor or nurse about any concerns you have before beginning your infusion or radiation session.
- **Pack something to eat or drink**—Ask your doctor or nurse if there are any special rules about what you should eat or drink before an infusion. You may be at the clinic most of the day, so you may want to bring some snacks or a packed meal. If there are vending machines, you may want to bring change to purchase a snack or beverage.
- **Bring activities**—You may want to bring activities such as crossword puzzles or a book to read to help you pass the time.
- **Arrange transportation**—The medicines to reduce side effects may make you drowsy or dizzy, so it is a good idea to have someone else drive you home after treatments.
- **Ask your doctor or nurse about your medicine**—If you take any other medicines, remind your doctor or nurse. Your doctor may give you special instructions that day.

Please do not bring:

- Valuables such as cash, jewelry, credit cards and checkbooks. Most hospitals are not responsible for your belongings. If you must bring valuables, please ask to have them deposited in the hospital safe.
- Personal electrical appliances such as heating pads, television sets and radios.

Medications Tracker

Through the course of your treatment you may be prescribed a variety of medications, in addition to any you were taking prior to your diagnosis. The medications you are taking and their doses are critically important to your treatment and it is a good idea to have a list of each type and dosage documented. We have provided a couple of pages to help you keep track.

Date Prescribed	Name of Medication	Dosage

Date Prescribed	Name of Medication	Dosage

Questions to Ask to Your Doctor

We've listed some questions that are important for you to ask your physician on each visit. As a suggestion, write down your own questions before your appointment to ensure all your concerns are addressed each time. We also include questions about side effects, and medications at home. The *Each New Day* booklet (at the back pocket of your guidebook) has a questionnaire about treatment and clinical trials. You can also find questions at www.lls.org/whattoask.

Date of visit: _____

Dr. _____

1. What does my blood analysis show?

2. When should I repeat blood work?

3. Can I get a copy of these tests for my records?

4. What other exams should I need and when?

5. I've experienced the following symptoms prior to my visit. What's the reason?

6. What can I do to control these symptoms?

7. How is the progress of my disease?

8. Am I going to have a change in my treatment schedule, dose or medication? Why?

9. What kind of medication do I need to take at home and how often?

10. Why do I have to take them?

11. Is there anything I should avoid? What kind of precautions do I need to take at home?

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Questions About Taking Medications at Home

Asking your healthcare provider questions can help you take an active role in managing your (or your child's) care. If you do not understand any part of the information your healthcare provider gives you, ask him or her to explain it in another way.

Doctor's Name _____

Name of Medication _____

Date of appointment or call _____

1. What if I miss a dose?

2. What if I vomit (throw up) right after I take my medication?

3. Is it okay to drink alcohol during my treatment?

4. When should I take my medication?

5. For how long do I take my medication?

6. How should I store my medication?

7. Do I need to take this medication with food?

Notes

Please write down your own questions and the answers:

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Questions About Treatment Side Effects

Asking your healthcare provider questions can help you take an active role in managing your (or your child's) care. If you do not understand any part of the information your healthcare provider gives you, ask him or her to explain it in another way.

Doctor's name _____

Date of appointment or call _____

1. What are common side effects of this treatment?

2. What are less common side effects of this treatment?

3. When are side effects likely to happen?

4. Are there any side effects I should tell my doctor about right away?

5. What can I do to ease side effects?

6. How will my treatment affect fertility, pregnancy or breastfeeding?

7. What are the long-term and late effects of my treatment?

Notes/additional questions

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