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THE HEALTHCARE TEAM AND TREATMENT CENTER



Members of the Healthcare Team. Your child’s team of doctors, nurses, social workers and child-life specialists can offer crucial support and encouragement as your child goes through cancer treatment. Your relationship with the members of the healthcare team can make navigating the challenges of cancer treatment easier.

Who Makes Up the Healthcare Team? After a cancer diagnosis, a number of healthcare professionals will be involved with your child’s care. Based on your child’s needs, the pediatric healthcare team may include

Doctors

- Pediatrician—a doctor who provides primary medical care for children
- Pediatric hematologist-oncologist—a doctor who is specially trained to diagnose and treat children, adolescents and young adults who have blood cancers and other blood disorders
- Pediatric oncologist—a doctor who is specially trained to diagnose and treat children, adolescents and young adults who have cancer
- Radiation oncologist—a doctor who uses radiation therapy to treat patients who have cancer
- Radiologist—a doctor who is trained to read and interpret imaging studies, such as x-rays, a computed tomography (CT) scan or a magnetic resonance imaging (MRI) scan
- Pathologist—a doctor who uses microscopes and different techniques to study cells and tissues in order to identify diseases
- Hematopathologist—a doctor-pathologist who is board-certified in both anatomical and clinical pathology and who examines blood, bone marrow and tissue samples
- Pediatric general surgeon—a pediatric surgeon who performs procedures, such as lymph node biopsies and other tissue biopsies
- Gastroenterologist—a doctor who specializes in treating patients who have digestive tract diseases
- Nephrologist—a doctor who specializes in treating patients who have kidney diseases
- Cardiologist—a doctor who specializes in treating patients who have heart disease
- Neurologist—a doctor who specializes in treating patients who have disorders that affect the brain, spinal cord and nerves
- Endocrinologist—a doctor who specializes in treating patients who have diseases related to the glands of the endocrine system, including the thyroid, pancreas and adrenal glands
- Psychiatrist—a doctor who can prescribe medication to patients to help with mental health conditions

TIP:

Ask the healthcare team to designate a team member as your main contact person. He or she will then be the best person for you to approach with your concerns and the important questions that will probably come up between appointments. Ask how to contact this person and find out how to communicate via phone, email, text and/or an online patient portal (if one is offered by the hospital or treatment center).

Nurses

- Oncology nurse—a nurse who specializes in treating people who have cancer
- Pediatric nurse practitioner—a nurse with advanced training who diagnoses illness, develops and manages treatment plans, and prescribes medications for children, adolescents and young adults
- Oncology nurse navigator—a nurse who specializes in cancer care and treatment and helps patients to overcome barriers to care and find resources

Additional Members of the Pediatric Healthcare Team

- Physician assistant—a medical professional who diagnoses illness, develops and manages treatment plans, prescribes medications, and may serve as a patient’s primary healthcare provider outside of oncology
- Radiology technician—a professional who takes images of the patient’s body
- Phlebotomist—a professional who is trained to draw blood from a patient for medical purposes
- Psychologist—a professional who is trained to help patients, siblings and their families cope with emotional and mental health conditions
- Social worker—a professional who is trained to talk with patients, siblings and family members about their emotional or practical needs and to find them support services
- Child-life specialist—a healthcare professional who can help children and their families cope with serious illnesses, such as cancer
- Education (school) liaison—a professional who acts as an advocate to help a child who has a serious illness continue his or her education, including arranging for educational services in the hospital or at home and assisting with the child’s return to school
- Hospital-based teacher—a teacher at a hospital or treatment center who provides instruction for children with a serious illness who are unable to attend school
- Financial counselor—a professional at the hospital or treatment center who can help people with hospital bills and insurance claims, as well as work with individuals who are unable to pay their bills
- Registered dietitian—a healthcare professional who specializes in food and nutrition

Make sure you record and keep track of the contact information for each member of the healthcare team. You can ask for a business card and take a picture of it with your mobile phone. Not all patients will need support from every type of healthcare professional mentioned in this list. The healthcare professionals who make up your child’s healthcare team will be those who meet his or her needs. If your child has to see a new specialist, ask for a referral to a provider who specializes in treating children with cancer.



Use **Worksheet 4: Healthcare Team Contact List** to record important contact information.

Communicating With Members of the Healthcare Team. Clear communication with members of the healthcare team is very important to make sure your child receives the best care. Talking to healthcare professionals may feel intimidating at first, but with practice, you will begin to feel more comfortable asking questions and expressing your concerns. The following strategies can help improve communication with members of the healthcare team:

- Write down your questions before appointments. Number your concerns in order of importance, asking the most important questions first. Let the doctor know you have a list so that he or she can set some time aside during the appointment to respond to your questions.



For more questions to ask the healthcare team, visit www.LLS.org/WhatToAsk or visit www.LLS.org/booklets to view the series **Communicating With Your Healthcare Team**.

- Take notes. Write down the doctor's answers to your questions. Write down any other important information that you need to remember. Notes can include the names of members of the healthcare team, dates and times of future appointments, and instructions for giving prescribed medications to your child. You can also ask the doctor if you can record the conversation so that you can listen to it again later. If your co-parent can't be there with you, you may find it helpful to ask someone else to come with you to appointments and take notes for you so that you can focus on the conversation with the doctor.
- Ask for written or digital information about your child's diagnosis, treatment plan and lab results. Keep everything in one place. This way, nothing gets lost, and you always know where to find the information.
- Share this information with all the healthcare professionals your child sees for any health reason, and encourage the healthcare professionals to talk with each other to ensure the most comprehensive care.
- Ask for written or digital information about any side effects and signs and/or symptoms you should watch for.
- Make sure you understand what signs and/or symptoms require a trip to the emergency room. Ask for a list.
- Make sure that you know whom you should contact in an after-hours or an emergency situation when you need immediate assistance. Find out the best way to reach the emergency contact (for example, a phone number with a direct extension).
- If you have trouble either following or understanding information the doctor is giving you, ask the doctor to slow down or explain things in another way.
- Ask where you can find credible information online or printed resources pertaining to your child's diagnosis or other needs. Call an LLS Information Specialist at **(800) 955-4572** or visit www.LLS.org/InformationSpecialists for information.

TIP:

Today, many treatment centers provide a web-based "patient portal." Ask members of the healthcare team how to access and navigate your child's patient portal. Through the patient portal you may be able to access medical records, schedule appointments, message providers, make payments and more.

TIP:

During appointments, allow your child to talk to members of the healthcare team as well. Encourage your child to ask questions and to explain any side effects, signs and/or symptoms or concerns. Work with a child-life specialist and other members of the healthcare team to help your child understand his or her diagnosis and treatment plan.



Use the following worksheets to keep track of appointments and prepare for meetings with members of the healthcare team:

- **Worksheet 5a: Appointment Calendar, by Month**
- **Worksheet 5b: Appointment Calendar, by Week**
- **Worksheet 5c: Appointment Details**
- **Worksheet 6: Questions for the Healthcare Team**



LLS Pediatric Monthly and Weekly Calendar. Your entire family can use this free magnetic, dry erase calendar to keep up with each other's busy schedules. Call an LLS Information Specialist at **(800) 955-4572**.

Seeking a Second Opinion. Your child may need treatment as soon as possible after diagnosis. If time allows, however, you may want to seek a second opinion. A second opinion may help you feel more confident about the chosen treatment plan. It's okay to let your child's doctor know that you would like to get a second opinion. Most doctors are used to patients seeking multiple opinions, many encourage it and will recommend another specialist. Ask your doctor to send your child's medical records to the doctor who will be providing the second opinion. Insurance companies usually pay for second opinions, but check with your child's health insurance provider to be sure.

Keeping Medical Records. It's important to keep current copies of your child's medical information in an easy-to-find location. You may wish to buy a binder or multiple pocket folder to keep everything in one place or you may wish to use a computer filing system or app. Take these records with you to any appointment, especially to appointments with new doctors who will need to know the details of your child's diagnosis and treatment plan. Information that you should take with you includes

- Your child's medical history, surgical history and information about any allergies
- The family medical history
- A list of current medications, supplements and vitamins
- Immunization records
- Copies of findings from recent imaging or scans
- Lab values
- A list of all the doctors or specialists your child is seeing and their contact information

TIP:

Today, most facilities use electronic medical record (EMR) keeping. Electronic medical records comprise patient history, lab results, treatment plans, imaging studies and other important information. Providers can easily share this data with other providers. If your child will be visiting a new provider or facility, ask your healthcare team to forward his or her EMRs to the new provider before the appointment.



Use the following worksheets to track your child's medical information:

- **Worksheet 7: Medical History**
- **Worksheet 8: Immunization Record**

Designating an Alternate Caregiver. At some point during your child's treatment, another person may need to take your child to an appointment or to the clinic for treatment. Sometimes, you may know this in advance. For example, you may have an important work meeting so a grandparent may volunteer to take your child in for routine blood work. Other times, an unexpected situation may arise and you are not able to take your child to an appointment. For example, if you are sick on the day of your child's treatment, you may not be allowed to go into the clinic (to protect immunosuppressed patients from being exposed to your illness). If the person taking your child to the clinic for treatment is not a parent or a legal guardian, he or she will not be legally allowed to sign a consent form for your child to receive treatment. This is true even for grandparents, older siblings and other family members. Talk to members of the healthcare team to complete necessary paperwork that designates an alternate caregiver for your child. Then the information is in place should either you or your co-parent not be available to accompany your child to an appointment.

Inpatient Considerations. Treatment of children with leukemia and lymphoma usually takes place in either a hospital setting or a clinic. Your child may be admitted to the hospital as soon as the diagnosis is known or suspected. Your child may also need to be hospitalized at other times during the course of treatment. This may be the first time your child has had to stay in a hospital or even stayed away from home for an extended period of time. Rules vary by facility, but keep the following considerations in mind when your child's treatment includes a hospital stay:

- If you know in advance that your child will need to be admitted, ask members of the healthcare team if you and your child can tour the unit before the stay.
- Ask the child-life specialist to help prepare your child for his or her upcoming hospital stay. Talk to your child. Emphasize that the stay is temporary and explain why it is necessary.
- It's likely that you will be able to stay overnight with your child. However, if your child will be in the hospital for several days, make a schedule that includes people your child feels comfortable with (co-parent or another trusted family member) to stay some nights so that you can rest at home.
- Children may be afraid of being left at the hospital. If you need to leave your child's room, let your child know you are leaving and when you will be back. Ask the child to take care of a familiar personal item (for example, a piece of jewelry, a book, a scarf) for you until you get back.
- Remember to take care of your needs too. Take breaks during the day. Go for a walk. Do not forget to eat.
- Keep in mind the needs of your other children. It is hard to be there for everyone; however, the other children in your family need support as well. Ask family members and friends to help. They can keep your other children's schedules running normally, for example. Child-life specialists and nurses can also work with siblings and suggest guidelines for them to visit the hospital.
- Many hospitals have a family lounge that you can visit so that you can get out of the room and socialize for a while.
- All children need time to play, even when hospitalized. Many children's hospitals have a playroom or recreation room with toys, books and activities. Your child may be able to play with other children who are also receiving treatment.
- Ask members of the healthcare team if you can take your child for a walk around the hospital or hospital grounds. If your child has an intravenous (IV) line in place, you may have to roll the IV pole with you. Light exercise and fresh air may help you both feel better.
- Ask if there are free or discounted food options for parents. You and your child may get tired of hospital food. Check to see if there is a cooking facility for families where you can refrigerate and prepare food. You can ask friends and family members to bring meals or you can order food for delivery. Ask members of the healthcare team about any dietary restrictions.
- During the hospital stay, even though nurses are available, your child may want your help with activities such as going to the bathroom or bathing. Allow your child to choose who will help him or her. Some children may feel more comfortable with a parent. Other children and teenagers may prefer nurses. Try not to take it personally if your child asks nurses for help. Your child may be trying to regain a sense of independence or control.

- Learn the rules for visitors and quiet hours. For example, visitors may only be allowed at certain times or only a certain number of visitors may be allowed at a time. There may also be restrictions on what loved ones can send as gifts for your child. For example, live flowers and latex balloons are sometimes not allowed on certain hospital floors where immunosuppressed patients stay. Visitors who have a fever, cough, runny nose, diarrhea, rash or other signs and/or symptoms of illness should not visit your child.

What to Bring to the Hospital. The hospital will supply necessities such as meals, gowns and toiletries, but you and your child may feel more comfortable bringing some of the following items from home:

- Bathrobe, pajamas, socks and slippers
 - If your child has an intravenous (IV) line or a port in place, choose clothing that allows members of the healthcare team easy access for blood draws and administration of medication and fluids.
- A favorite toy, blanket or pillow case
 - If your child is having difficulty with hair loss, use a pillow case that is similar to your child's hair color so the loss of hair is less noticeable on the pillow.
- A book, coloring or activity book, tablet or other items for entertainment
- A charger for a cell phone, tablet or some other electronic device
- Pictures of family members, friends or pets
- Cards, posters or other special items from friends, classmates or teammates
- Preferred toiletries
- Favorite snacks that may not be available at the hospital cafeteria (following dietary restrictions)
- Reusable water bottle

Personal items can make the hospital room feel more like home. However, keep in mind that limiting the number of personal items in the room makes it easier to clean and for members of the healthcare team to care for your child.

Questions to Ask Members of the Healthcare Team About Hospital Stays

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| ■ Before my child is admitted, can we tour the hospital? | ■ What are the visitation rules for family members and friends? |
| ■ What will the daily routine be like while my child is in the hospital? | ■ Will I be able to stay the night with my child in his or her room? |
| ■ How long will my child need to stay in the hospital? | ■ Where can we park when we arrive at the hospital? |
| ■ What do I need to bring to the hospital? Are there any items I should not bring? | ■ Are there parking vouchers or is there discounted parking that is available for parents? |
| ■ Does the hospital have a playroom and/or family lounge? | |

