

6

TREATMENT OPTIONS



Learning About Treatment Options. After your child is diagnosed with a blood cancer, you will work with members of the healthcare team to determine the best treatment plan. Treatment options vary for the different types of blood cancer. The treatment plan may include a clinical trial. Your child's treatment options depend on their specific diagnosis; age; genetic testing; overall health and other factors. Childhood blood cancers are often treated aggressively, and children tend to tolerate treatment better than adults.

Your child's treatment plan may include:

- Chemotherapy
- Targeted therapy
- Immunotherapy
- Radiation therapy
- Stem cell transplantation
- Palliative (supportive) care
- A combination of any of the above

The treatment plan may also include any of the above treatments as part of a clinical trial.

Surgery can be, but usually isn't, part of the treatment for cancers that involve the blood and bone marrow. However, children may undergo various procedures or tests to diagnosis, monitor or assist in the treatment of blood cancers. These may include:

- Lymph node biopsy
 - Surgical removal of all or part of a lymph node to test for cancer cells
- Bone marrow aspiration and biopsy
 - Removal of a sample of bone marrow or bone from the hip bone (using a hollow needle) to assess blood cell production
- Central line and/or port placement (see **Methods of Administering Drugs** on page 9.)

Drug therapies, such as chemotherapy, can be given in a few different ways. See **Methods of Administering Drugs** on page 9.

FACT

“Palliative care” or “supportive care” is not just end-of-life care. Palliative care is also used alongside curative treatment to help manage side effects and improve your child's well-being.



Once the treatment plan is decided, note the details in **Your Child's Treatment Plan** on page 13.



Visit www.LLS.org/3D to view an interactive 3D image of bone marrow biopsy and aspiration.

Genetic Testing. Genetic tests are used to identify, examine and measure chromosomes and genes. These tests are an important part of diagnosing and treating childhood blood cancer. Some examples of tests used include cytogenetic analysis, which examines the chromosomes of the cancer cells, and fluorescence in situ hybridization (FISH), which looks at the genes or chromosomes in cells and tissues.

Generic and Biosimilar Drugs. Your child’s treatment plan may include the use of a generic or biosimilar drug. Both generic and biosimilar drugs are approved by the United States Food and Drug Administration (FDA) and may offer a more affordable treatment option for patients.

How Generics Are Made. A generic drug is the same as a brand-name drug in dosage, safety, strength, how it is taken, quality, performance, and intended use. Before approving a generic drug product, the FDA requires many rigorous tests and procedures to assure that the generic drug can be substituted for the brand-name drug.

How Biosimilar Drugs Are Made. Many drugs developed are called biological products (known as “biologics,” also known as “the reference product”) because biological products are produced through biotechnology and use living systems, such as a microorganism or a plant cell. Monoclonal antibodies and vaccines are some examples of biologic products. Because the makeup of biologics is very complex, it is challenging to create imitations of the drugs. Generic drug development is simpler, like following a recipe with standard ingredients. Biosimilars are more challenging because they are made up of living cells, which are very sensitive to their environments and cannot be recreated by a chemical formula. Manufacturers have to create their own, unique process to create an identical outcome to that of an existing treatment.

Biosimilars:

- Are imitations of biologics (the FDA-approved reference product)
- Are very similar to their reference products—this means that the product is analyzed using technology that compares the characteristics of the reference product and the biosimilar.
- Have no meaningful differences from the biologics—this means that the manufacturer of the biosimilar has shown that there are no differences between the reference product and the biosimilar in terms of safety, purity and potency (safety and effectiveness). This is shown by putting the biosimilar through human clinical trials.

Ask your child’s healthcare team if biosimilar drugs will be used in treatment and for additional information.

Researching Treatment Options. Learning about the treatment options available for your child can help you best advocate for their care. Be wary of information found online. Always check to make sure the information is provided by a reliable source.



Call an Information Specialist at **(800) 955-4572** or visit **www.LLS.org/InformationSpecialists** for free materials and services designed to simplify this search for information and support.



Visit **www.LLS.org/booklets** (filter by Children and Young Adults) to learn more about specific treatments.

Chemotherapy. Chemotherapy (chemo) is the use of strong drugs or chemicals, often given in combinations or administered at intervals, to kill or damage cancer cells. Chemotherapy drugs are often called “anticancer agents.” Chemotherapy can produce long-term remission (no sign of illness) or outright cure for many people, depending on the type of cancer and its stage.

Not all chemotherapy treatments are the same. Certain chemotherapy drugs are used only for certain disease types. All chemotherapy drugs interfere with cancer cells’ ability to grow or multiply, but different groups of drugs harm cancer cells in different ways.

The specific chemotherapy drugs, the dosages, and timing of administration depend on your child's specific diagnosis. For example, a child diagnosed with an acute leukemia typically needs chemotherapy treatment that includes a hospital stay to recover that lasts several weeks. Chemotherapy may also be combined with radiation therapy, targeted therapy, immunotherapy or stem cell transplantation. Ask your child's healthcare team for a road map of the treatment plan.



See **Methods of Administering Drugs** on page 9 to learn more.

Chemotherapy kills cells that are rapidly dividing, both cancer cells and healthy cells. The damage to healthy cells can cause side effects. Side effects of chemotherapy can include:

- Appetite changes
- Nausea and vomiting
- Diarrhea
- Constipation
- Mouth sores
- Hair loss
- Low blood cell counts
- Skin changes
- Fertility issues
- Problems with concentration and focus

Ask members of the healthcare team what to expect and alert them to any new or worsening signs and/or symptoms or side effects.

Maintenance Therapy. Depending on your child's diagnosis, maintenance therapy may be part of the treatment plan. Maintenance therapy is given after remission to help prevent disease relapse. Not all patients will require or benefit from maintenance therapy. Maintenance therapy is most often used in the treatment of acute lymphoblastic leukemia (ALL). Most maintenance drugs are given orally, and typically patients are treated in an outpatient setting. The patient receives lower doses of chemotherapy and tends to have less severe side effects. Maintenance therapy lasts 2 years. Ask your child's healthcare team if the treatment plan will include maintenance therapy.

Targeted Therapy. Targeted therapy is another type of drug therapy used to treat cancer. Unlike the drugs used in chemotherapy, the drugs used in targeted therapy specifically attack cancer cells. They "target" the genetic changes or proteins that contribute to the cancer cells' growth and survival.

Targeted therapies may cause side effects, but these may be either different from or less severe than the side effects caused by chemotherapy. Usually, the drugs used in targeted therapies do not affect healthy cells as much as standard chemotherapy drugs. The types of side effects vary, depending on the specific drug used. Side effects of targeted therapy can include:

- Rashes
- Nausea
- Fatigue
- Diarrhea
- Fever
- Muscle or joint pain

Ask members of the healthcare team for information about what to expect. Alert the healthcare team to any new signs, symptoms or side effects.

Targeted therapies may be used along with chemotherapy or other treatments. Targeted therapy drugs can be administered in a variety of ways. See **Methods of Administering Drugs** on page 9 to learn more.

Immunotherapy. Immunotherapy, also called “biological therapy,” utilizes the patient’s own immune system to fight cancer. The body’s immune system helps protect against disease and infection. In most circumstances, the body’s natural immune system seems unable to identify cancer as a foreign invader. Immunotherapy is based on the concept that immune cells or antibodies that can recognize and kill cancer cells can be produced in the laboratory and then given to patients to treat cancer. Several types of immunotherapy are either approved for use by the FDA or are under study in clinical trials to determine their effectiveness in treating various types of cancer.

Immunotherapy treatments and the ways in which the treatments are given vary, as do side effects. Common side effects of immunotherapy include rashes and flulike symptoms, such as fatigue, body aches, nausea and fever. However, other side effects are possible. Ask members of the healthcare team what to expect and alert them to any new signs, symptoms or side effects.



For more information about immunotherapy, visit www.LLS.org/booklets to view **Immunotherapy**.

Chimeric Antigen Receptor (CAR) T-Cell Therapy. Chimeric antigen receptor (CAR) T-cell therapy is a type of immunotherapy that uses a person’s own immune cells (T cells) to identify and attack cancer cells.

In CAR T-cell therapy, T cells are taken from a patient’s blood and sent to a laboratory. There, technologies are used to change the genetic makeup of cells. These genetically modified T cells will express a specific receptor that allows them to identify and attack cells that have the target antigen. In the laboratory, the number of engineered T cells is then multiplied and the modified cells are eventually re-infused into the patient.

Serious side effects are associated with CAR T-cell therapy, some of which can be life threatening. Diligent monitoring of a patient’s condition after CAR T-cell infusion is critical to minimize the risk of serious side effects. Most side effects associated with CAR T-cell therapy can be managed. Ask members of your child’s healthcare team what to expect.



For more information about CAR T-cell therapy, visit www.LLS.org/booklets to view **Chimeric Antigen Receptor (CAR) T-Cell Therapy**.

Radiation Therapy. Radiation therapy, also known as “radiotherapy,” uses high energy x-rays (beams of photons) or other types of radiation to kill cancer cells. Although the radiation is directed at cancer cells, it can also damage healthy cells, but current methods minimize the damage done to nearby tissues.

When radiation therapy is used for blood cancer treatment, it’s usually part of a treatment plan that includes drug therapy. Radiation therapy is sometimes given to prepare a patient for a stem cell transplantation. It can also be used to relieve bone pain and pain or discomfort caused by an enlarged liver, lymph node(s) or spleen.

External Beam Radiation. External beam radiation is the type of radiation therapy used most often to treat blood cancers. A focused radiation beam is delivered from outside the body by a machine.

Proton Beam Radiation. At some cancer centers, proton beam radiation may be an option. This type of radiation uses proton beams instead of photon beams (x-rays). Protons are particles with a positive charge. Proton beam radiation can be more targeted than photon beam radiation. This helps to minimize damage to healthy tissues and organs and may decrease the risk of long-term and late effects. This type of radiation therapy is newer and requires a special machine.

Discuss with your child's healthcare team which type of radiation therapy is the best treatment option for your child.

Receiving External Beam Radiation Therapy. To ensure that the radiation is aimed at the same part of the body during each treatment session, a member of the healthcare team may mark your child's skin with small dots of semipermanent ink. During the radiation treatment, your child will lie on a table in the same position every time. Receiving treatment is similar to having an x-ray, but the radiation is stronger. Radiation treatments are typically done every weekday for a period of 2 to 4 weeks. Treatments are usually quick. Your child will likely spend 20 to 30 minutes in the treatment area, even though actual radiation exposure lasts only a few minutes. You will not be allowed in the room while the radiation exposure takes place.

If your child receives radiation therapy to prepare for a stem cell transplantation, small doses of radiation are delivered to the entire body to destroy cancer cells throughout the body. This is called "total body irradiation (TBI)." Treatment is administered in several divided daily doses to minimize side effects. Treatments are usually given one to three times a day over 2 to 4 days immediately before transplantation.

If your child receives external beam radiation, you and other people in contact with your child will not be exposed to any radiation.

Typically, radiation causes fewer side effects during treatment than chemotherapy; however, fatigue is a common side effect. Radiation can also cause the skin in the treated area to become red and irritated and occasionally it will blister (similar, in some ways, to a sunburn). Do not use skincare products on the area without first checking with a member of the healthcare team.

Due to damage of nearby tissues, patients who receive radiation treatment may be at risk for side effects later in life, such as secondary cancers and organ damage. The risk depends on the area treated and the type and dose of radiation used.

Stem Cell Transplantation. Stem cell transplantation, sometimes referred to as "bone marrow transplantation," is a procedure that replaces unhealthy stem cells with healthy blood-forming stem cells.

First, the patient receives a regimen of high-dose chemotherapy and/or radiation therapy which kills the patient's stem cells. This increases the chance of eliminating the blood cancer in the bone marrow and makes room for the new stem cells to grow. This is called a "preparative regimen" or a "conditioning treatment." See **Chemotherapy** on page 2 and **Radiation Therapy** on page 4.

After the conditioning treatment, the patient receives the stem cell transplant. Stem cells are transfused into the patient's blood. The transfusion is similar to a blood transfusion. The stem cells are infused through a central line and the transfusion can last several hours. The transplanted stem cells go from the patient's bloodstream to the bone marrow. The new cells grow and provide a supply of red blood cells, white blood cells (including immune cells) and platelets.

Types of Stem Cell Transplantation. There are four types of stem cell transplantation. The three most common are:

- Autologous transplantation: The stem cells are collected from the patient's own body, before they receive conditioning treatment.
- Allogeneic transplantation: The stem cells come from a different healthy person (the donor).
- Reduced-intensity stem cell transplantation: As in an allogeneic transplant, the stem cells come from a healthy person (the donor), but the conditioning chemotherapy is less intensive.

A fourth type of stem cell transplantation, syngeneic transplantation, is an option for patients who have an identical twin with whom the patient has identical genetic makeup and tissue type.

Finding a Donor. For an allogeneic stem cell transplant, your child will need a bone marrow donor. To determine if a potential donor is a match for a patient, a lab technician examines samples of tissue cells from the patient and the potential donor and compares the proteins on the outer part of the cells. These proteins are called "human leukocyte

antigens (HLAs).” If the HLAs on the donor cells are either identical to or similar to those of the patient, the transplant is more likely to be successful.

In some cases, the HLA match is a sibling, but since this is not guaranteed, the healthcare team will search for matched unrelated donors (MUDs) through stem cell donor banks or registries. Matches can also come from haploidentical donors and cord blood. See **Other Sources of Donor Stem Cells** below.

If a matched person refuses to be a donor, ask the healthcare team to work with all parties to understand everyone’s point of view and to correct any potential misunderstandings of the process. It may also be helpful to speak to a mental health professional.

Considerations for Sibling Donors. If an allogeneic stem cell transplantation is recommended for your child, the healthcare team will likely look to siblings first as potential healthy donors. There is a one in four chance that any sibling will be an HLA match. While your focus may be on your child with the cancer diagnosis, it is important to consider how being a potential donor may affect your other child(ren). The healthcare team will use a blood test to check if siblings are an HLA match. The healthcare team will also need to evaluate siblings’ medical history and overall health.

Keep these thoughts in mind and address the feelings and concerns of potential sibling donors.

- Ask members of the healthcare team and a child-life specialist to explain the entire testing and donation process to your child who is a potential donor. Explain to your child that if their cells match those of their sick sibling, they may be able to help by donating stem cells.
- If your child is hesitant about being a donor for their sibling, do not be angry. Work with the healthcare team to understand your child’s fears and to address them. Your child has seen their sibling go through cancer treatment, and it is understandable for them to be afraid of medical procedures.
- Your child may feel anxious about going through the testing process to determine if they are an HLA match for their ill sibling. A younger child may be scared of the actual blood test. All children may feel conflicting emotions about the possible outcome of the test. If the sibling is not a match, they may feel guilty for not being able to be a donor.
- A sibling who is a match may be scared about the stem cell collection process. Work with members of the healthcare team to explain the stem cell collection process and answer your child’s questions.
- If the transplant is unsuccessful or if there are complications, the child who donated their cells may not only feel upset but feel guilty as well. It is important to remind them that the outcome of the treatment is not their fault.



For more information about the stem cell collection process, visit www.LLS.org/booklets to view **Blood and Marrow Stem Cell Transplantation.**

The National Bone Marrow Transplant Link ([nbmtlink](http://nbmtlink.org)) helps patients, caregivers, and families cope with the social and emotional challenges of bone marrow/stem cell transplant from diagnosis through survivorship by providing vital information and personalized support services. Visit www.nbmtlink.org or call **(800) LINK-BMT [(800) 546-5268]** for more.

Other Sources of Donor Stem Cells

Haploidentical Donor. To increase the number of potential donors, some transplant centers have begun to perform half-match (haploidentical) transplants for patients who cannot find a closely matched HLA donor. Since a child receives half of their HLA markers from a parent, a biological child and their parent will always be a half match, while there is a 50 percent chance of a sibling being a half match. Researchers are studying haploidentical transplantation with the hope that it can become a more available and safer option for patients.

Cord Blood. Stem cells are present in blood from the placenta and umbilical cord of a newborn baby. These stem cells can repopulate the bone marrow of a compatible recipient and produce blood cells. Frozen cord blood is a source of donor stem cells for transplantation to HLA-matched recipients.

Recovery. After the stem cell transplant, your child will spend 30 or more days in the hospital. Children who receive an allogeneic stem cell transplant often need to stay longer than children who receive an autologous stem cell transplant. If you do not live near the hospital, the healthcare team may require that you find somewhere close by to stay after your child's discharge in case there are any serious complications. Some treatment centers offer special housing for children and their parents undergoing a stem cell transplant. However, cost can be an issue. Discuss options with your child's treatment team.

After a stem cell transplant, it takes the immune system 6 to 12 months to recover and for blood cell counts to return to near-normal levels. Recovery time may be less for an autologous stem cell transplant, which is about 3 to 12 months. During this time, your child will be more at risk for illness and infections. It is very important to take steps to protect your child's immune system and to go to all the scheduled follow-up visits with the treatment team.



To help explain the stem cell transplantation process to your child, visit www.LLS.org/booklets to print or order **The Stem Cell Transplant Coloring Book**, or visit www.LLS.org/ColoringApp to download the *LLS Coloring for Kids™* app which includes a digital version of the coloring book.

Ronald McDonald House Charities and American Cancer Society's Hope Lodge offer places for families traveling for medical reasons a place to stay.

Visit www.rmhc.org and www.cancer.org/hopelodge to learn more.

Or, visit www.joeshouse.org for a searchable database of discounted lodging facilities near treatment centers, such as hospitality houses and hotels that offer medical rates.

Graft-Versus-Host Disease (GVHD). Graft-versus-host disease develops after an allogeneic transplantation when the donor's immune cells mistakenly attack the patient's normal cells. This reaction can be mild, moderate or severe—even life threatening. Its signs and/or symptoms can include:

- Rashes
- Blistering
- Nausea, vomiting, abdominal cramps, diarrhea and loss of appetite
- Jaundice (yellowing of the skin), which indicates liver damage
- Excessive dryness of the mouth and throat, leading to ulcers
- Dryness of the eyes, lungs, vagina and other surfaces

Graft-versus-host disease can be either acute or chronic. Its severity depends on the differences in tissue type between patient and donor. The older the patient, the more frequent and serious the reaction may be.

One to two days before the stem cell infusion, the healthcare team will give the patient a regimen of drugs to help prevent the onset of GVHD. These regimens suppress the immune system. The patient may need to continue to take these drugs for many months after transplantation. These drugs, in addition to early detection and advances in understanding the disease, have resulted in a significant reduction in serious or fatal outcomes from GVHD. However, GVHD doesn't always respond to these treatments. It can still have a fatal outcome. Many deaths related to GVHD occur because of infections that develop in patients who have suppressed immune systems.



Read the **Chemotherapy** and **Radiation Therapy** sections on pages 2 and 4 to learn more about each of these treatments.



For more information on GVHD, visit www.LLS.org/booklets to view **Graft-Versus-Host Disease**.

Clinical Trials. Taking part in a clinical trial is a treatment option that many blood cancer patients consider at some point in their journey. A clinical trial may be the best treatment choice for some blood cancer patients.

How Do Clinical Trials Work? A cancer clinical trial is a controlled research study conducted by doctors to test a new treatment, new combinations of treatments, or new dosages. A treatment that's proven safe and effective in a cancer clinical trial may be approved by the FDA for use as a standard treatment. Virtually all of today's standard treatments for cancer are based on the outcomes of previous clinical trials. The purpose of blood cancer clinical trials is to improve treatment options by:

- Increasing survival
- Decreasing the side effects of treatment

Who Can Participate? Each clinical trial has a "road map" or protocol that includes information about which patients are eligible to enroll in the trial and which will be excluded from participation. These inclusion and exclusion criteria are very specific and usually cannot be changed. Eligibility for any given clinical trial depends on many factors, such as:

- Diagnosis
- Stage of the disease
- Physical condition
- Other medical problems
- Prior treatments and responses to those treatments
- Presence or absence of certain genetic mutations
- Age

Clinical trials are carefully designed studies that put the health and safety of the patients first. Placebos are not used in cancer clinical trials unless they are given along with an active drug. No one can be forced to take part in a study. Participation in a clinical trial is always voluntary, and you can withdraw your child from the study at any time.

What Should You Do if You Are Interested in a Clinical Trial? Ask the healthcare team if a clinical trial is an option for your child. Clinical trials may be an option in many situations including, but not limited to:

- First treatment for newly diagnosed patients
- Patients whose first or subsequent treatment was not effective
- Patients whose disease has come back after a period of remission
- Patients whose current treatment is causing unacceptable side effects
- Patients who desire an alternative to the suggested treatment
- Patients whose disease is in remission and who are interested in possible ways to extend remission
- Patients who have not been able to achieve remission

You do not have to wait until your child's disease is in an advanced state to consider a clinical trial.

Some of the many things you need to consider before enrolling your child in a clinical trial, include:

- The potential side effects of the treatment
- Required tests and procedures
- The number of doctor visits
- The amount of time you and your child may be required to be away from home
- Potential costs involved and which costs are covered by the clinical-trial sponsor, which are covered by the patient and which are covered by the insurance company



Talk to an LLS Information Specialist to learn more about clinical trials. Visit www.LLS.org/InformationSpecialists or call **(800) 955-4572**. LLS offers help in understanding, identifying and accessing clinical trials. Families can work with Clinical Trial Nurse Navigators who will help find clinical trials and personally assist them throughout the entire clinical-trial process. Visit the Clinical Trial Support Center at www.LLS.org/CTSC for more information.



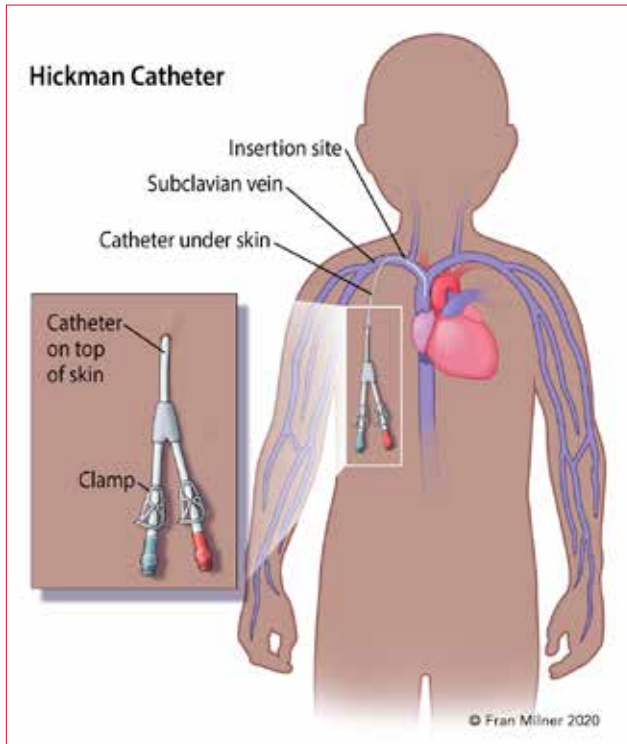
For more information about clinical trials, visit www.LLS.org/ClinicalTrials or visit www.LLS.org/booklets to view *Understanding Clinical Trials for Blood Cancers*.

Methods of Administering Drugs. Drugs can be given in different ways. Commonly used methods of administration include:

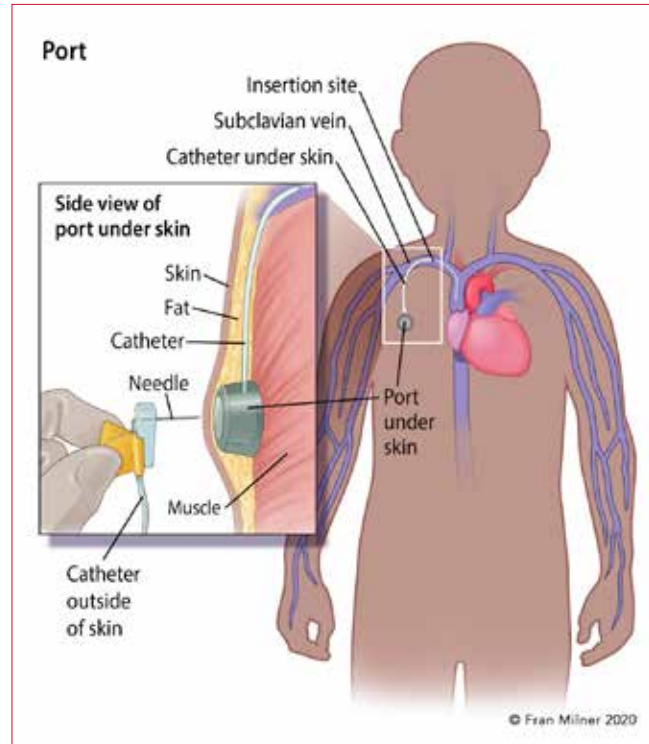
- Intravenous (IV)—into a vein
- Oral (PO)—by mouth as a pill, liquid or capsule
- Intramuscular (IM)—injection into a muscle
- Subcutaneous (SC)—injection under the skin
- Intrathecal—into the cerebrospinal fluid (CSF)

How Patients Receive IV Treatment. Certain medications irritate the veins and make repeated IV catheter placement difficult. Many patients find that chemotherapy drugs can be given more conveniently and comfortably through a central line (also called a “central venous catheter”) that can stay in place longer than a regular IV catheter.

- **Central Line.** This is a thin tube placed under the skin and threaded into a large vein in the chest or neck. A central line is placed by a doctor. The central line stays firmly in place. It can remain in place for weeks or months. A central line is used for the administration of drugs, blood products, fluids and nutrition and allows for safe and painless blood draws for lab work. See the image of a **Hickman® catheter**, an example of a type of central line, on page 10.
- **Port.** This is a small device attached to a central line. The port is surgically placed, typically under the skin of the chest. After the site heals, no dressings are necessary, and no special home care is needed. To access the line, the nurse inserts a needle through the skin into the port. A numbing cream can be put on the skin before the port is used. See an image of a port on page 10.
- **Peripherally Inserted Central Catheter (PICC) Line.** This type of central line is typically inserted through the skin into a vein in the arm. The doctor or nurse uses a guide wire to thread the PICC line through the vein until it reaches the superior vena cava, a large vein above the heart. Once the PICC line is placed, blood for lab work can be safely and painlessly withdrawn and drugs administered via a capped, self-sealing valve at the end of the catheter.



Hickman® Catheter: An example of a type of central line



Port: A port used with a central line

Caring for a Central Line, Port or PICC. Since these lines and/or a port can stay in place for months, you will need to know how to care for your child's device at home.

If your child has a central line, the site will need to be cleaned and monitored for infection or other issues such as the development of blood clots (thromboses). Hospital or clinic staff will show you how to clean and care for the device. Signs and/or symptoms of infection include:

- Redness
- Pus or drainage
- Warmth to the touch
- A bad smell
- Increased pain
- Fever

Let the healthcare team know immediately if you notice that your child has any of these signs and/or symptoms.

Often blood clots have no signs or symptoms. However, signs and symptoms can include pain, redness and discoloration of the skin. An ache in the shoulder or jaw could also be a symptom of a blood clot. Ask the healthcare team if your child is at risk for a blood clot and what you should do if you suspect a clot.

Long-term devices need to be flushed periodically. You will be shown how to do this and the healthcare team will provide a plan and schedule for flushing the device.

Additional Care and Use of Devices. Depending on your child’s specific treatment plan and needs, you may need to learn how to use the port and central line so that you can administer drugs, fluids or nutrition at home. This may include:

- Learning how to connect and disconnect the lines
- Programming a “pump” to deliver medications or fluids as prescribed
- Flushing lines
- Checking for air bubbles or other issues
- Storing and disposing of medical items properly
- Maintaining a sterile environment to prevent infection

If your child’s care involves the use of a central line or PICC, a member of the healthcare team will teach you how to use and care for the device. In this type of situation, your child will likely receive scheduled at-home visits from a nurse who will draw blood for the lab tests and oversee the care of the line, as well as the administration of drugs, fluids and/or nutrition.

Drug Therapy at a Hospital or Treatment Center. Infusions can last for several hours; some even require hospitalization. You will be able to stay with your child during the infusion.

Questions to Ask Members of the Healthcare Team

Before your child begins **therapy at a hospital or treatment center**, ask the healthcare team the following questions:

- **Is there anything we need to do to prepare for the infusion?**
- **What signs and/or symptoms require medical attention, and what should I do if I notice these signs and/or symptoms?**
- **Whom can I call after hours or in an emergency situation?**
- **Are there any foods, vitamins, medications or supplements that my child needs to avoid because they can interact with the drug?**
- **Are there any precautions I need to take when helping my child once they come home after an infusion?**

Drug Therapy at Home. Treating cancer at home has many advantages. Your child is likely to be more comfortable at home, and you can avoid additional trips to the treatment center. However, when treating cancer at home, there’s a shift in responsibility from the healthcare provider to the parent. “Treatment adherence” means taking medications as prescribed. Treatment adherence is very important. The medication may not work effectively if your child does not take it as prescribed by the doctor. Make sure to give the medication to your child exactly as prescribed.

Even if your child does not receive cancer treatment at home, you may still need to give them other medications at home to help manage side effects or prevent infections.

Tips for Giving Oral Medication to Your Child. Sometimes it can be challenging to get children to take medications. Use the following tips to help your child take medications:

- Explain to your child why taking the medication is important.
- Allow younger children to practice giving medicine to a favorite toy. If you take medication, allow your child to watch or if possible, take your medication at the same time as you give your child their medication. Children often like to mimic their parents.
- Give your child choices. For example, would your child prefer to take the medication in the kitchen or in the living room?
- If your child does better with a liquid, pill, capsule or chewable tablet, ask the healthcare team or pharmacist if the medication comes in your child's preferred form.
- Ask the healthcare team or pharmacist if flavor can be added to liquid medications to make them taste better.
- Ask the doctor if you can break or crush the pill into smaller pieces and mix it with a food such as applesauce, ice cream or syrup. If the pill is a capsule, ask if you can open the capsule and mix the powder with food. Capsules tend to have milder taste than solid pills or tablets. If mixing with food, make sure your child eats the full amount to receive the full dose.
- Give your child a reward, such as a sticker, for taking a medication. Keep a medication log and allow your child to "check off" the medication after they take it.
- Give your child an ice pop or other frozen food before the medicine to numb the taste buds and mask the taste of the medicine.
- Let your child practice swallowing "pills" by swallowing tiny pieces of candy instead.
- Have something sweet on hand, such as fruit juice, to allow your child to wash away the taste of the medicine after swallowing. Grape juice may be a good choice as the strong taste can mask other flavors.
- Make sure your child is upright when taking medication to avoid choking.
- Make sure your child actually swallows the medication. Ask the doctor or pharmacist what to do if your child spits the medication out or vomits minutes after taking the medication.
- Do not use a household spoon to give liquid medication. Use a dosing cup or oral syringe to make sure you measure the right amount of liquid.
- Do not leave children alone with medication. Keep medications in a safe place that are not easily accessible by any children in the home.
- If your child is having difficulty taking medication, ask members of the healthcare team for help.



Use **Worksheet 9: Daily Medication Log** to keep track of your child's medications.



LLS Health Manager™ App. With *LLS Health Manager™*, you can now use your phone to manage your child's daily health by tracking side effects, medication, food and hydration, questions for the doctor, grocery lists and more. You can also set up reminders to take medications and to eat/drink throughout the day. Visit www.LLS.org/HealthManager to download.

In some cases, your child may need to receive medications by an IV infusion at home. See **Additional Care and Use of Devices** on page 10 to learn more.

Questions to Ask Members of the Healthcare Team

- What does the treatment plan include?
- How will the treatment be administered? Will my child be treated in the hospital or at an outpatient treatment center?
- How long will the treatment last?
- Can I be with my child while the treatment is being administered?
- What are the side effects and long-term effects of this treatment?
- Can my child be referred to a palliative (supportive) care specialist for help managing side effects?
- What signs and/or symptoms indicate I should call the healthcare team? Whom can I contact after work hours if I have questions or concerns?
- What signs and/or symptoms indicate a trip to the emergency room is necessary?
- Will my child be able to continue with school and/or extracurricular activities?
- Will my child need to follow a special diet or avoid any specific foods, medications or supplements while receiving this treatment?
- What kind of testing will be done to monitor the disease and treatment? How often will testing needed?
- How will we know if the treatment is effective? What options are available if the treatment is not effective?

