Family support

This page is for your notes

Family support

Child Life: Helping your child understand

Our Child Life team is available to provide support to the whole family during your child's transplant stay.

- Child Life will provide toys, games and art activities to help decrease anxiety and boredom and to provide an outlet for the many different emotions your child may be experiencing.
- Your child can also participate in music therapy and creative arts on a regular basis.
- Knowing that children often cope better when they know what to expect, Child Life specialists can assist with providing developmentally appropriate education to your child and their siblings about transplant as well as preparation for medical tests and procedures. Child Life also supports your child and family during stressful times with coping techniques and ideas individualized to your child's needs.

Child Life specialists explain the procedures to children.

- We use special words, toys and games developed for each age group.
- This helps children better understand what is happening during exams and procedures.
- Child Life can also help children to relax and cope by using comforting stories and calming exercises.
- We also provide age-related games and activities to do in the room.

Ideas from Child Life

- Hide some of your child's toys and games:
  Bring them out one at a time. This will keep things new and exciting for a longer period of time.
- Mail is something most children in the hospital enjoy.
  Give family and friends our hospital address:

Child's name

c/o Cook Children's Medical Center
5 Pavilion
801 7th Ave.
Fort Worth, TX 76104

- Surprise your child with recorded voice or video messages from friends and family. You can do this on most cellphones or electronic devices.
- Be kind to yourself and leave your child's room at least once a day to take a break.

Please call the Child Life department if you or your family would like to visit with a Child Life Specialist, or please ask your nurse to call for you.

Family support

School information

Education, in its many forms, is an important part of the life of every child.

The school program at Cook Children's Medical Center is a joint effort of the Fort Worth Independent School District and the medical center to serve any child with frequent or long-term stays.

- The mission of the program is to provide appropriate, individualized instruction for each student.
- The school program can benefit children psychologically and developmentally by providing normalcy, familiarity and academic support.

During hospitalization, your school-aged child will receive four hours of bedside instruction weekly.

- After discharge, your school-aged child is eligible to receive up to three hours of instruction daily in our hospital classroom.
- In order for your child to be enrolled in the hospital program, you will be asked to complete a packet of enrollment forms.
- Our school staff will then call your child's school and request a temporary withdrawal of the student.
- Our hospital teachers will talk to your child's teacher, and together, we will develop the best learning plan. When needed, we will act as coordinator for patients returning to their homes by ensuring appropriate transitions.

Please call the Education department at 682-885-4178 if you have any questions or concerns.

Family support

Case Management

Case Management consists of social workers, nurses and financial specialists who can provide services to help reduce the stress on our families through all the phases of treatment.

Our social workers can help you with the following:

- Explain Social Security benefits, disability benefits, insurance coverage and other government programs.
- Help you apply for government financial aid during treatment.
- Affordable medical care and prescription drug coverage.
- Find information about your child's diagnosis and treatment plans.
- Support groups and educational programs.
- Assistance with obtaining transportation, meals or gas funding for your visits.
- Referrals to community counseling and outside agencies.
- Workplace and school education/consultation, applying for family and medical leave (FMLA) and/or homebound services for children who cannot leave home for school or other activities, etc.).
- Personal support for you and your child through all phases of treatment.

We can teach you how to:

- Talk with your child's treatment team members.
- Talk with children, family and friends about your child's diagnosis and care.
- Cope with emotions you or your child are experiencing — sadness, anger, worry and fears.
- Discuss with your child how to care for themselves and their treatment when they are out of the hospital.

We can help you access:

- Transportation to and from medical care appointments.
- Other community resources that are available to your child with their particular diagnosis.

Your social worker is here to assist you in providing the best care you can for your child. If we can be of assistance to you, please contact at 682-885-7932.

The following resources are commonly utilized while your child receives treatment. There are additional resources available to you that you can speak about with your social worker directly. So as always, please contact your social worker with any questions or concerns.

Need help with insurance?

Please talk to your financial counselor about any concerns you may have. Also, tell us about any financial changes, such as:

- Change of insurance
- Change of address
- Loss of employment
- Loss of benefits

Our financial counselor can help you:

- Plan payment arrangement for out-of-pocket expenses.
- Understand your child's insurance benefits.
- Understand and work with insurance complications.
- Help families apply for government programs.

Pastoral Care

Illness can be stressful for children, their parents and other family members. Chaplains provide families the compassionate help they may need. Chaplains are available without cost to families on a 24-hour basis to provide counseling, spiritual and emotional support and referral guidance. Call 682-885-4030 during business hours, or ask the nurse or hospital operator to page a chaplain. Communications with clergy are confidential under state law.

Services and resources:

- Spiritual and emotional support of patients, family and staff
- Ethics consultations
- Counseling, referral, information and assistance
- Bereavement support, literature and referral
- Patient and family advocacy
- Liaison to churches and other faith groups
- Chapel
- Prayer garden

Volunteers

Cook Children's adult volunteers undergo additional training in order to work in the Stem Cell Transplant Unit. When possible, one volunteer will be assigned to a family for the duration of their stay so that the patient and family can build a trusting relationship that helps caregivers feel more comfortable taking a break when they need it. The training is about two hours long and goes over appropriate boundaries, guidelines for the Stem Cell Transplant Unit and what patients experience during the transplant process so that volunteers are prepared for the intensity.

Ronald McDonald House®

The Ronald McDonald House serves families who meet the following criteria for admission to the house:

- The Ronald McDonald House serves families with ill children 21 years old or younger.
- Both new and returning families must be referred by a hospital social worker.
- All overnight guests 18 years of age and older must complete and pass a background check. Upon passing the background check, the family will be placed on the wait list for the desired check-in date. The cost of a background check for up to four adults will be paid by Ronald McDonald House of Fort Worth. Any additional background checks will be $10 each at the family's expense.
- If it has been more than one year since your last visit, all overnight guests 18 years of age and older must complete and pass a background check (see above statement).
- Check-in/check-out times are from 8:30 a.m. to 8 p.m. unless prior arrangements have been made with the director of house operations or the resident manager. Office is closed from noon to 1 p.m. daily.
- Please call 817-870-4942 for room availability on the day you wish to check in.
- Each adult staying at the Ronald McDonald House must present a photo ID upon check in.
- After 45 days of stay (90 days for bone marrow patients and premature babies), a family must leave the house for a period of two weeks before reapplication can be made for another stay.

- Rooms can only be occupied by immediate family members and those extended family members who are directly involved in the care of the patient. No more than five persons per room.
- A donation of $20/night is requested from each family.
- A family can be asked to leave at the discretion of house staff.
- If any family member has been diagnosed with a communicable disease while staying at the house or if any visitor is believed to have exposed residents at the house to such a disease, it is most important to notify one of the staff members immediately. At the discretion of our Physician's Advisory Board and/or house staff, it may become necessary for the family to leave the Ronald McDonald House.
- All patients under 18 years old who stay at the Ronald McDonald House must be accompanied by an adult or guardian at all times.
- If both parents are under 18 years old and unmarried, only one parent may stay and must be accompanied by their parent/guardian.
- If either or both parents are under 18 years old and married, proof of marriage is required to stay.

Glossary

This page is for your notes

Words we may use

Absolute neutrophil count (ANC)
Neutrophils are a type of white blood cell that help protect the body from infection. Numbers of neutrophils in the patient's blood are used to show when engraftment starts after transplant, or recovery after chemotherapy.

Acute lymphoblastic leukemia (ALL)
A fast-growing cancer of the lyphoblasts, a type of white blood cell. Also known as acute lymphocytic leukemia.

Acute myelogenous leukemia (AML)
A fast-growing cancer of the myeloblasts, a type of white blood cell. Also known as acute non-lymphocytic leukemia.

Allele
A piece of DNA representing a gene inherited from each parent. Alleles are part of the human leukocyte antigen (HLA) tissue type used to match patients and donors.

Allogeneic bone marrow or stem cell transplant
Any bone marrow or blood stem cell transplant that uses cells from a person other than the patient. The donated cells can come from a family member or a donor who is not related to the patient.

Anemia
The condition of having fewer than the normal number of red blood cells or less than the normal amount of hemoglobin in the red blood cells. This condition decreases the blood's ability to carry oxygen.

Antigens
Proteins found in most cells of the body and capable of activating the immune system. A mismatched antigen from a donor can cause the recipient's immune system to be more active.

Apheresis
A procedure where blood is taken from a person's arm and passed through a machine. The machine separates and collects certain cells, such as blood-forming cells, white blood cells or platelets. The rest of the blood is returned through the other arm.

Aplastic anemia/severe aplastic anemia (SAA)
A condition where the bone marrow does not make enough white blood cells, red blood cells and platelets.

Autologous marrow or blood stem cell transplant
A transplant using marrow or blood cells collected from the patient.

Blast cells
Immature blood cells that will never completely develop to mature or normal cells. Another term for leukemic cells.

Blast phase
The advanced stage of chronic myelogenous leukemia, when the number of abnormal white blood cells in the bone marrow and blood is very high. Also called blast crisis.

Blood-forming cells
Unspecialized cells that have the ability to grow into red blood cells, white blood cells and platelets. Also called hematopoietic cells.

Bone marrow
The soft, blood-forming tissue inside of bones. Marrow makes blood-forming cells, white blood cells, red blood cells and platelets.

Bone marrow transplant (BMT)
The process of giving healthy marrow to patients whose marrow is damaged or diseased.

Central line, venous catheter
A thin, flexible, spaghetti-sized tube that is inserted into a large vein in the body, usually in the chest. It is used to take blood samples and to give drugs and blood products.

Chemotherapy
A drug treatment that kills cancer cells. Used to treat cancer and prepare patients for a marrow or blood cell transplant.

Chronic myelogenous leukemia (CML)
A cancer characterized by a life-threatening increase in myeloid cells; a type of white blood cell made in the bone marrow.

Clinical trial
A series of carefully controlled scientific studies using a limited number of patients.

Conditioning
The process used to prepare a patient to receive a marrow or blood cell transplant by first destroying the diseased cells and the cells from the patient's immune system. Chemotherapy with or without radiation therapy is often used. Also known as preparative regimen.

Confirmatory human leukocyte antigen (HLA) testing (also called CT)
Repeating a donor's HLA tests.

Confirmatory typing
To make sure that a potential donor is the best match for a patient, they are asked to give another blood sample for additional testing. Confirmatory typing refers to both confirmatory HLA typing and testing for infectious diseases. The donor being considered also completes a health history to help determine if donating would pose any special risks for either the patient or the donor.

Cord blood
The blood collected from the umbilical cord and placenta after a baby is born. Cord blood contains high numbers of blood-forming cells in a small amount of blood that can be used in transplantation.

Cytomegalovirus (CMV)
A virus that can cause diseases and infections like pneumonia.

Discharge planning
The decisions and arrangements made for a patient's treatment needs after they leave an inpatient hospital, clinic or facility.

Deoxyribonucleic acid (DNA)
The molecule that contains a person's genetic information, or characteristics or traits that are passed down from one's parents.

Donor workup
The process that a potential donor who closely matches the patient goes through to make sure they are healthy and ready to donate marrow or blood cells.

Embryonic stem cells
Stem cells that come from human embryos.

Engraftment
The stage when the transplanted blood-forming cells start to grow and make healthy new blood cells.

Fanconi anemia (FA)
A rare, inherited type of aplastic anemia. Found most often in young children and characterized by a high rate of cancer and leukemia.

Figrastim (G-CSF)
A man-made version of a normal human protein that increases the number of blood-forming cells in the body.

Gene
The basic unit of inheritance, or of characteristics passed on from one's parents, made up of DNA.

Graft-versus-host disease (GVHD)
A condition where the transplanted marrow or blood cells react against the patient's tissues. It is caused when the donor's T-cells attack a recipient's organs.

Haploidentical
A donor who is a half-match which is usually a mom, a dad or a sibling. Parents are always a half-match for their children. Siblings (brothers or sisters) have a 50% chance of being a half-match for each other.

Hematopoietic cells
Early-stage cells found in the blood that can grow into red blood cells, white blood cells or platelets. Also called blood-forming cells or progenitor cells.

Hemoglobin
The part of a red blood cell that carries oxygen.

Hereditary
Physical characteristics that a person inherits from their biological parents.

Histiocytosis
A rare but possibly life-threatening disorder similar to cancer, in which histiocytes (immune system cells) start to multiply and attack the person's own tissues and organs.

Histocompatibility
Refers to how well the tissue matches between two persons.

Human leukocyte antigen (HLA)
Refers to proteins found in almost all cells of the body and making up the main part of each person's tissue type. HLA testing is used to match patients and donors for stem cell and organ transplants.

HLA typing
The test by which HLA antigens and alleles are identified.

Hodgkin disease
A lymphoma that can usually be cured. However, when standard chemotherapy fails, Hodgkin disease may be treated with an autologous marrow or blood stem cell transplant.

Immune system
The body's system of defenses against disease.

Leukemia
A group of cancers of the white blood cells. It can be acute (rapid onset) or chronic (slow onset). A person with leukemia has a very high number of abnormal white cells.

Lymphocyte
A type of white blood cell and an important part of the body's immune system. There are two recognized types of lymphocytes: T cells and B cells. T cells are a kind of lymphocyte that cause graft-versus-host disease. B cells are the cells that help protect us from germs we have been exposed to in the past. After transplant, it takes up to a year for B cells to return to normal.

Lymphoma
A cancer of the lymph nodes. Lymph is a colorless liquid that takes substances around the body to where they need to go. Hodgkin disease is one type of lymphoma. All others are grouped together and are called non-Hodgkin lymphoma.

Malignant
Cancerous.

Match
In a marrow or blood cell transplant, the match refers to how much alike the donor's and patient's tissue types are.

Marrow
The soft, blood-forming tissue that fills the cavities of bones. Marrow is responsible for making blood-forming cells, white blood cells, red blood cells and platelets.

Multiple myeloma
A cancer of the plasma cells in the blood. Often associated with bone pain and infections.

Myelodysplastic syndrome (MDS)
Also called pre-leukemia. It is a disease of the bone marrow in which too few platelets, red blood cells and white blood cells are made.

Myelofibrosis
A disease that causes scar tissue to form in the bone marrow. As a result of the scar tissue, normal blood cell production is blocked.

Myeloproliferative disorder (MPD)
A group of disorders caused by overproduction of blood cells by the marrow.

Neuroblastoma
A cancerous tumor of early-stage cells that occurs in children. It is sometimes treated by a marrow or blood cell transplant.

Neutrophil
A type of white blood cell that helps protect the body from infection. Numbers of neutrophils in the circulating blood are used as an indicator of engraftment after transplant, or recovery after chemotherapy.

Non-Hodgkin lymphoma (NHL)
A cancer of the lymph tissue.

Non-myeloablative transplant
Also known as reduced intensity regimen. A type of transplant that uses lower doses of chemotherapy and/or radiation to prepare a patient for transplant.

Osteopetrosis
An inherited disease of the bones where the bones get very hard and the marrow cannot grow.

Peripheral blood stem cell (PBSC) donation
Peripheral blood stem cells are collected through the process known as apheresis. The donor's blood is withdrawn through a sterile needle in one arm and passed through a machine that separates the blood-forming cells. The rest of the blood is returned to the donor through the other arm.

Plasma
The liquid portion of unclotted blood.

Platelet
A blood cell that helps control bleeding.

Protocol
A specific plan for treatment of a disease or for a research study.

Radiation therapy
Treatment with high-energy rays to destroy or shrink cancer cells.

Recipient
A patient who receives blood stem cells.

Red blood cell
A cell that carries oxygen to all parts of the body.

Relapse
The return of a disease following remission.

Remission
When signs and symptoms of disease are gone after treatment.

Sarcoma
A cancer of the supporting tissues of the body, such as cartilage, fat, muscle, blood vessels, tendons or ligaments.

Serologic testing
A method used to determine an individual's HLA antigens.

Severe combined immunodeficiency disease
A genetic disease in which the immune system cannot produce antibodies or T cells to protect a person's body. It is often treated with a marrow or blood stem cell transplant.

Sickle cell anemia
A genetic condition caused by a change in the hemoglobin gene. Inheriting two sickle genes causes sickle cell anemia. Symptoms include moderately severe anemia and repeated painful experiences. Sickle cell anemia is sometimes treated with a marrow or blood stem cell transplant.

Sickle cell trait
A person who has one gene for sickle cell anemia. Sickle cell trait cannot change to become sickle cell disease. A person will develop sickle cell anemia only if both parents pass on the trait (gene) to them.

Stem cells
Any of the cells in the body that can grow into other kinds of cells. Blood stem cells grow into white blood cells, red blood cells and platelets. In a blood stem cell transplant, blood stem cells are given to patients after they are treated for a disease of the blood.

Stem cell transplant (SCT)
Refers to the use of blood stem cells as a treatment for cancer or other diseases.

Syngeneic transplant
A marrow or blood cell transplant using cells donated from the patient's identical twin.

T cell
A type of white blood cell that plays an important part in the immune system.

Thalassemia
A group of genetic (inherited) disorders, all of which involve not making enough hemoglobin, resulting in anemia.

Tissue
Materials from your body, including skin, hair, nails, blood and urine.

Tumor
Any abnormal growth of cells. Tumors can be caused by cancer cells or noncancer cells.

Umbilical cord blood (UBC)
The blood collected from the umbilical cord and placenta after a baby is born. Cord blood contains a large number of blood-forming cells.

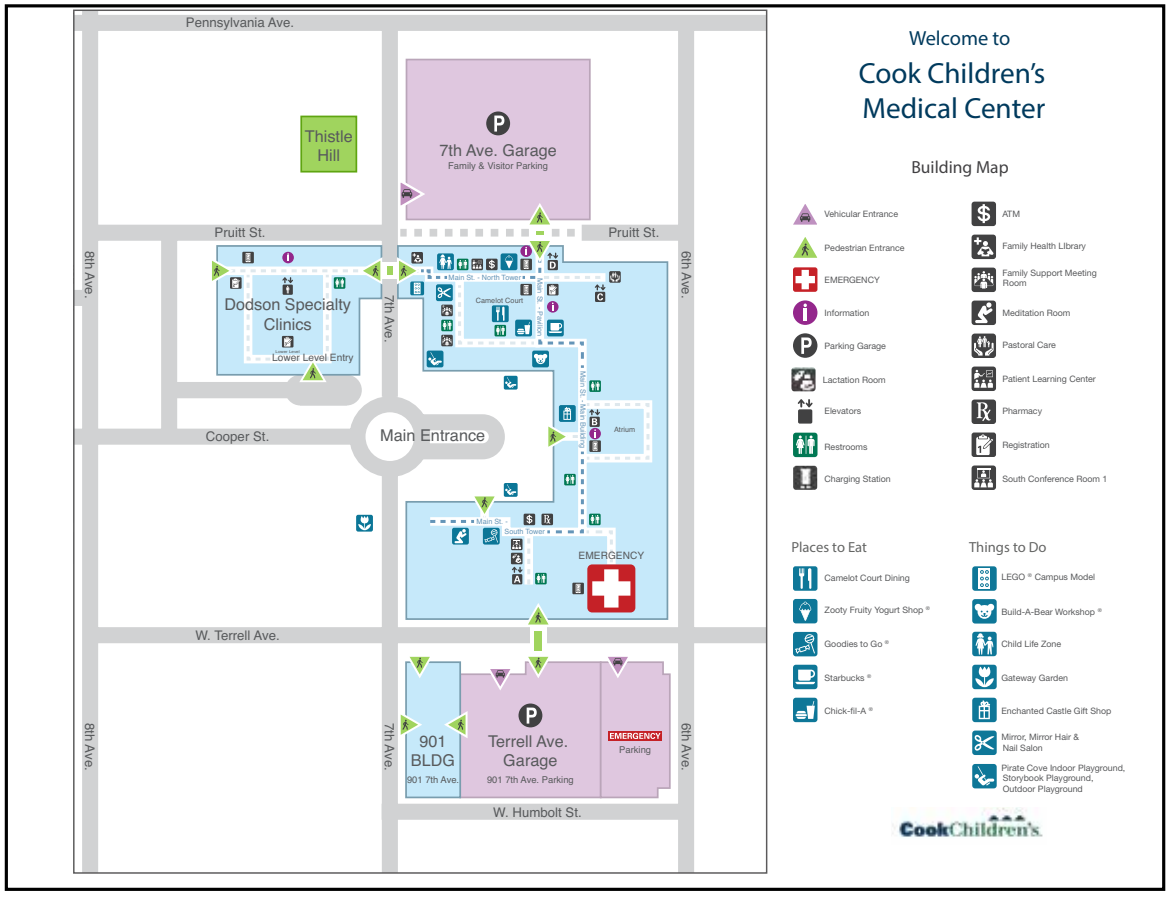
Unrelated bone marrow transplant or blood cell transplant
A marrow of blood cell transplant in which the donor is not related to the patient.

White blood cell
A cell that helps fight infection and is part of the immune system.

Wiskott-Aldrich syndrome
An inherited disease of the immune system where the white blood cells cannot fight infection. It occurs only in boys.

Phone directory and map

Transplant coordinators	682-885-5669
Neuroblastoma coordinator	682-885-4017
Hematology and Oncology Center	682-885-4007
Social workers	682-885-7932
Financial questions	682-885-3986



Cook Children's
801 7th Ave.
Fort Worth, TX 76014
682-885-4007
cookchildrens.org/hematology-oncology

Here are some of the people who are going to care for you and your child while you are in the transplant unit

Team member	Who they are	How to contact them
Transplant doctor		
Transplant pediatric nurse practitioner (PNP)		
Transplant nurses		
Social worker		
Case manager		
Psychologists		
Child Life specialist		
Dietitian		
Schoolteachers		
Pharmacy and pharmacy techs		
Palliative care team		
Physical therapist (PT)		
Occupational therapist (OT)		
Financial counselor		
Patient educator		
Chaplain		
Massage therapist		
Other people you meet		

Cook Children's Hematology and Oncology Center
Bone Marrow and Stem Cell Transplant Program

1500 Cooper St., 5th floor
Fort Worth, TX 76104
682-885-4007

cookchildrens.org

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