St. Jude Supportive Resources

Medical Teams

Clinical staff that are on the medical team include:

- Primary Care Teams consist of an attending physician, a nurse practitioner or physical assistant, and a nurse. Patients may also have a hematology-oncology fellow assigned to help with care.
 Together the care team, the patient, and the family will make decisions about the patient's care together.
- *Pharmacists* can tell families how each of the patient's medicines works. This includes antibiotics, pain medicine, and chemotherapy drugs. A pharmacist is there to make sure the patient's medicines work as well as they can, that the dose is safe for the patient, and that parents and other caregivers understand how to give medicines.
- *Genetic Counselors* work with patients, siblings, and parents to determine if genetic testing is needed. They also explore family histories to determine risks for other family members.
- Clinical Nurse Specialists (CNS) can help teach parents about the patient's treatment and potential symptoms that may occur, how to give IV fluids or medicines outside of the hospital, how to feed through a G-tube, wound and skin care. They can also help support parents and families as they prepare to leave the hospital and plan for successful home treatments.
- Clinical Nutritionists can help the patient get the food and supplements that will best meet the child's needs. A dietitian can teach parents and other caregivers about how to maintain the best nutrition for the patient, keep track of the patient's nutrition intake, create a nutrition plan, etc.
- Respiratory Care staff members offer 24-hour services for patients who have breathing problems. The Respiratory Care team also cares for patients before and after surgery, because surgery can sometimes lead to lung infections.
- The Pain Management Team includes doctors, nurses, psychologists, physical therapists, and pharmacists who are trained to help reduce pain in children, while watching for any side effects of pain medicine.
- The Medicine Room is where your child gets the treatments that their primary clinic doctor orders like Chemotherapy, Blood Products, and other medicines or treatments. The Med Room is open 24/7. After 5pm, the Medicine Room functions as a 'gateway' to other services, whether needed at St. Jude or another facility. Parents can call the Medicine Room with any after-hours problem and be directed accordingly. You can reach the Medicine Room by calling the main hospital number, 901-595-3300. You can also call your primary clinic as phones will be transferred to the Medicine Room after 5pm.

Clinical Trials

Clinical research is scientific research that includes people. Scientists do it to learn more about diseases and treatments. Most clinical research studies have 4 phases.

• Phase I clinical research: for first-time experimental treatments. They can include healthy volunteers or people with a certain disease or condition.

- Phase II clinical research for treatments that have already been tested in Phase I. Scientists want to learn how well the new treatment works for you and others with a certain disease. They might test the new treatment against the regular treatment to see which works better. They might also test different doses (amounts) of the new treatment.
- Phase III clinical research compares the new treatment with the regular treatment in large numbers of people. They also look for side effects of the new drug or treatment. They might compare these to the side effects of the regular drug or treatment.
- Phase IV clinical research done after the US Food and Drug Administration has approved a drug, treatment, or piece of medical equipment for use.

Appointments & Scheduling

- Patient Representatives: Before each outpatient visit, you will check in with a patient representative alerting the clinic that you have arrived for your appointment. Located in every clinic and at the North (Med Room) and South (H Clinic) greeter's desk. They can print appointment schedules, communicate reasons for appointment delays, and can retrieve a blanket or cup of water, etc.
- Schedulers: St. Jude Patient Scheduling is located on the Patient Care Center third floor. Schedulers are available in-person 7 am-7pm every day including weekends and holidays or you can call 901-595-6146 and your call will be directed to the correct scheduler. You can also use the My St. Jude patient portal to check your child's schedule. Many situations affect how a schedule is made age of the patient, urgency of the care needed, certain equipment that might be needed. For last minute changes, the scheduler will call you but the call can be missed, or the change made after you're already en route to St. Jude. Schedules can be mailed to a home address- if changes happen within a certain timeframe before your appointments, a schedule is auto-printed and mailed to permanent address in your child's medical record. You can always talk with your scheduler to confirm your appointments.

Visiting and other Inpatient Guidelines:

- *Friendships:* When a child makes friends, it is ok for them to meet in other areas such as teen room, imagine room or other play areas.
- *Visitors*: Parents and visitors who have received live vaccines should not enter the hospital If they have received the oral polio or smallpox vaccine within 4 weeks; or if they have rashes after receiving the chickenpox (varicella) vaccine. Injectable flu vaccines do not contain live viruses. You can ask each clinic their rules for visitation.

Social Work

For quick access to the Social Work department, patient families can call 901-595-3670 to speak with a social worker.

The social worker can discuss services available to help the patient and family adjust to the illness and treatment. On occasion, there are certain scenarios that a referral to social work may be helpful, such as

financial issues, parents feeling overwhelmed, a change in a custody agreement, or a change in a patient's medical plan.

Some of the Social Work department services include:

- Counseling parents or guardians about dealing with the stress that illness can place on them, their work, their marriage, and their families
- Providing details about any current patient or parent support groups
- Helping families find information about current financial resources in the community, including wish granting groups
- Finding community agencies to address specific needs that the patient and family identify

Spiritual Care Services

To reach a chaplain, patient families can call 901-595-3672 or the hospital operator.

There may be times during the patient's illness when the patient or parents have spiritual questions. At other times, they may just need someone to listen to them or pray with them. During these times, they can call upon the staff in Chaplain Services. The chaplains are here to help patient families as spiritual friends, whatever their needs. Services offered include providing religious Sacraments, support, counseling, education, options for worship. They can also help connect you with a faith community in the Memphis area, arrange for faith leaders like clergy to visit your child, and providing several worship opportunities while at the hospital like Godly Play, Catholic prayer, and Muslim service. St. Jude has a chapel on the first floor of the Patient Care Center. It is always open and is a quiet place to pray or meditate.

Child Life

For more information about Child Life or to contact a specific Child Life Specialist, patient families can call 901-595-3020.

Child Life can help patients and young family members cope with this new experience in ways that make sense to them. Child life specialists often use play, art, and other fun activities as therapy. Using knowledge of the patient's culture, environment, language, and background, our child life specialists will develop a therapeutic plan. A child life specialist can also help the patient's brothers and sisters cope with their feelings. They can support parents and guardians in talking with the patient and brothers and sisters about serious illness and death.

Child life specialists work with the care team and family to meet the patient's needs including:

- Emotional needs
- Child development
- Education needs related to diagnosis and treatment
- Distraction, play, and relaxation.

Other resources provided by Child Life:

- Music therapy: The use of music to treat a range of medical and non-medical conditions
- The music therapist sees about 4-7 children/day, spending about 30-60 minutes with each child. Helps to cope with pain, boosts self-confidence, and prompts children to move their arms and other muscles; stimulates the brain to regulate emotions. [REFERAL REQUIRED?]
- *Mock Scanner:* Can be used to help with normalization for your child's scans. They can simulate the experience and help your child prepare for certain imaging tests. They can also encourage imaging without use of sedation/anesthesia.
- *St. Jude Passport Program:* encourages patients to set goals and celebrate their accomplishments. In addition, the St. Jude Patient Passport Program is a unique way for staff members to participate in and celebrate these achievements with patients.
- Legacy Bead program: provides ways for patients and families to document their journeys and create lasting memories of their experiences.

Psychology Department

For more information about the Psychology staff and the services they provide, patient families can call 901-595-3581 to speak with a staff member.

Dealing with the effects of disease can take its toll on a patient's emotions and those of the entire family. At times it may be hard to cope. St. Jude psychologists are here to help. The Psychology department can help patients and family members manage stress, manage discipline, and behavior issues, resolve conflicts in parent-child relationships, and deal with feelings of anxiety, anger, depression, fear, or grief.

The Psychology Department also provides:

- Therapy
- Psychological testing
- Neuropsychological testing

School Program

To learn more about the School Program and the services they provide, patient families can call 901-595-3346 or they can stop by room BP099 in the hospital.

The St. Jude School Program allows patients to continue normal educational activities and provides reentry services to ease patients back to their community schools. The program offers several services to assist patients with their academic progress. The school program also has resources for teachers to help their students returning to school after treatment.

Services that the School Program provides:

- Home-Bound Services
- Hospital-Bound Services
- English as a Second Language Services
- Tutoring

- ACT and SAT Exams
- School Reintegration Services and Advocacy
- Early Childhood Clinic. For patients under the age of 3

Rehabilitation Services

If patient families are interested in learning more about Rehabilitation Services, they will need to ask the patient's primary clinic staff for a referral.

Rehabilitation Services at St. Jude include audiology, occupational therapy, physical therapy, and speech-language pathology. These services can help the patient feel more comfortable and function better. A Rehabilitation Service therapist can also help the patient become more physically active, recover quicker from surgery and other procedures, communicate by using special equipment, and become more comfortable.

Volunteer Services

Helping Hands: Helping Hands volunteers go wherever they are needed in the hospital and offer the valuable service of sitting with children whose parents need a break. Families can use this service if parents need to speak with staff members in private, siblings need care while patients are being treated, parents or guardians need a brief break, etc. If patient families are interested in the Helping Hands service, they should ask a staff member to contact Family, Guest, and Volunteer Services.

Helping Hands volunteers are available:

Mondays and Fridays, 6 p.m.–9 p.m. Tuesdays, Wednesdays, and Thursdays, 9 a.m.–6 p.m. Saturdays and Sundays, noon–8 p.m.

Kay Kafe Companion: Look for folks in yellow smocks. Kay Kafe Companion volunteers assist the patients and families by helping them through the hospital's cafeteria, the Kay Kafe, acting as a host/greeter. The Kafe is a busy place during lunch and the companion volunteers serve a vital role for families. Volunteers might also help carry items from stations to the cashier and/or dining room tables, offer highchairs, napkins, condiments, etc.).

Kay Kafe Companion volunteers are available:

Monday – Friday, 10:45 am - 1:45 pm

Ready Runner: Look for folks in red smocks. Volunteers assist staff and families by being a family assistant, general lobby helper, and wagon/wheelchair rounder. To ensure patient safety/infection control, this volunteer will assist in keeping the lobby and all outpatient areas neat and will round up stray wagons and wheelchairs, as well as assist patients and families by escorting them to different areas throughout the hospital.

Ready Runner volunteers are available:

Monday – Friday, 8 am - 5 pm

Doggy Daze: A chance for patients to visit with dogs and their owners. Owners are volunteer trained and dogs are trained. Patients should have permission from their doctor to attend.

The typical schedule is as follows:

1st and 4th Tuesdays in outpatient areas: 9:30 am - 10:30 am 1st and 3rd Thursdays on inpatient units: 9:30 am - 10:30 am

Note: This schedule is not guaranteed. Overhead announcements will be made before each event.

Happy Cart: Volunteers provide crafts, activities and distractions to the patients of St. Jude via a cart.

The typical schedule is as follows:

Tuesdays and Thursdays: 5:30 pm - 7:30 pm

Saturdays: 11:00 am – 1:00 pm

Beverage Cart: Volunteers deliver hot chocolate and coffee to patients and families on all inpatient units and the medicine room each night as volunteers are available.

Quality of Life Service

If patient families are interested in Quality of Life Services, they will need to ask their child's primary clinic staff for a referral.

A patient's doctor may ask the St. Jude Quality of Life Service to help with treatment. This team includes doctors and nurse practitioners who have specialized training in pain and symptom management, communication, decision making, coordination of care, hospice care, and bereavement.

The Quality of Life Service staff can:

- Support families in the process of making difficult medical choices
- Help coordinate care with the patient's St. Jude primary medical team and outside resources
- Assist in the development of a plan of care that fits the family's goals, values, and beliefs
- Assess and manage pain and other symptoms
- Address emotional, social, and spiritual suffering related to serious illness.
- Provide bereavement support and coordination

Housing and Patient Services

Patient families who are looking for more information about housing can call 901-595-4501.

The St. Jude **patient housing program** is made possible by generous donors. Each facility is set up for patients and designed to be like a home for out of town families. Housing assignments are based on how long a patient family will be staying in Memphis and what kind of care their needs. The program is

designed to accommodate a family of four, which includes the patient. The St. Jude patient housing staff will work with the patient's care team to help meet that child's needs. If a patient has special needs, the parents or guardians should talk with the housing social worker or the patient's assigned social worker.

Housing Facilities include:

- Tri Delta Place
 - On-campus housing that is reserved for St. Jude patients and families who need lodging for the first 1-7 days
 - o Hotel-style lodging with two queen beds in each room.
- Ronald McDonald House
 - o Off-campus housing that is reserved for St. Jude patients and families who need lodging for 8-90 days
 - o Mid-term lodging facility with two queen beds in each room, with a shared communal-style kitchen and living room areas
- Target House
 - Off-campus housing that is for St. Jude patients and families who need housing for 90 days or more
 - o Long term housing facility; each apartment has two bedrooms, a living room, and a kitchen
- Parcels at Concourse
 - o Off-campus housing for St. Jude patients and families who need extended stay housing
 - o Each apartment has two bedrooms, a living room, and a kitchen

Local transportation is offered to patients and their families. Hospital shuttle buses will take patients and their families between St. Jude and the Ronald McDonald House, Target House, Tri Delta House, or their hotel. There is no charge for this service.

The shuttle buses run a continuous loop on this schedule:

On-call Monday through Friday: 7 pm to 11:30 pm

Sunday through Friday: 6:30 am to 7 pm

Saturday: 8 am to 5 pm

Valet Parking is offered free of charge, Monday –Friday from 6:30 am to 6:30 pm. (No tipping allowed). Patient/family caregivers whose car was parked by a valet and needs to stay later than 6:30 pm can obtain their keys at the PCC front desk from Security. If your child goes inpatient from outpatient, your car can stay parked until a family member can check with valet services. There is no specific timeframe in which you have to move the vehicle if the patient goes inpatient. After inpatient arrangements are made, you can check with the attendant, obtain your keys and relocate to a more appropriate area.

Food services are offered to help with the cost of meals for the patient and one parent by issuing a St.Jude Meal Card or a grocery store gift card. A free grocery delivery service called Shipt is also available to families.

• <u>Meal cards</u> can be programmed for up to seven days in a row and for a specific dollar amounts and time periods. These amounts and times depend on meals request – breakfast, lunch, or dinner.

You can use the meal card at the hospital cafeteria for all meals. St. Jude meal cards cannot be used off campus.

- <u>Grocery store gift cards</u> are offered to patient families staying in Ronald McDonald House or Target House. Local patients and those staying in short-term lodging are not eligible for grocery store gift cards. Parents can request gift cards weekly in Patient Services, Monday through Friday from 9:00 am 3:30 pm.
- <u>Shipt</u> is a national grocery delivery service that offers free annual grocery delivery memberships to St. Jude families. Shipt offers same-day grocery delivery from Kroger. Shipt grocery prices are a little higher than regular in-store prices due to the convenience of delivery. For more information, ask for a Shipt postcard in Patient Services.
- <u>Snack bags</u> are offered free for outpatients while at St. Jude for treatment. Each snack bag contains three snack items and a beverage. A snack bag ticket can be picked up in the Patient Services office upon arrival.
- *Room Service:* When your child is admitted to one of the hospital's inpatient floors, you will be given a room service menu based on your child's ordered diet. To order a meal, just choose something for your child from the menu, and call extension 3000 with your request. Your child's meal should arrive within 45 minutes of your call. *Room service is for the patient's meal only.*

Monday through Friday, 7 a.m.–9 p.m. Saturdays, Sundays and holidays, 7:30 a.m.–9 p.m.

- *Nutrition rooms*: located on each of the inpatient units. Parents have access to some food and the rooms are open 24 hours/day. The nutrition room refrigerator is only for items stocked by Food Service.
- <u>Family lounges</u>: on each inpatient floor with a microwave, refrigerator and seating. Any outside food of patients needing a refrigerator must use the fridge in the Family Lounge. (Not the nutrition center)
- Guest Tray: If a caregiver cannot leave the room (special circumstance), they may request for a guest tray to by ordered by a nurse. Guest trays will be charged to the meal card and delivered to the room by Room Service.
- Food Trucks: Outside of the Marlo Thomas Center, different food trucks are stationed daily and feature a variety of food choices available for patients, families, and staff. While meal cards can be used at the hospital cafeteria, St. Jude meal cards cannot be used for food trucks.

Note: We understand that families are coming to St. Jude from all over the world, and there may be certain foods that would help families feel more at home during their stay at St. Jude. Families may request foods native to their culture, and food services will do its best to try to provide these foods for families.

Security:

Security officers are the first people you encounter when arriving on campus and the last people you see as you exit the gates. Roving officers are also seen throughout the campus. The Memphis Police Department will accompany security calls; a Memphis City Police Officer will respond with a St. Jude security guard whenever you call for help. Security is able to assist if you have car trouble, feel sick, see something suspicious or need a lift to a building, or for any reason you need to reach a security officer.

Reaching Security:

- Call 901-595-4444 anytime to reach the Security department
- Use one of the six Call Stations located in the parking areas throughout the campus.

Call Station Locations:

- Near the Chili's Care Center, Tri Delta Place, and the Kmart St. Jude Life Center as well as on every floor of all three parking garages
- When you push the button for help, the call is connected directly to the Security Control room which is staffed 24/7.
- The security control officer will send an officer to assist the call station user.
- This button can be used for anyone who needs help, and it does not have to be an emergency.

Other services managed by security

- Lost and Found can be accessed at the lobby desk in the Patient Care Center.
- Security also locks up luggage.

Interpreter Services

To request an interpreter, patient families can call 901-595-2983

St. Jude offers 24-hour access to qualified interpreter services. During difficult times, a medical interpreter can relieve family members of the added stress of interpreting for their limited-English-speaking loved ones. St. Jude provides medical interpreters at no cost to the family. Qualified face-to-face interpreters in Spanish, French, and Portuguese are available in the hospital from 8 a.m. to 5 p.m., Monday through Friday. If other languages are needed, or whenever a face-to-face interpreter is not available, our 24-hour telephone service has trained over-the-phone interpreters in more than 150 languages.

Services for Parents:

Laundry, Showers, and Family Lounges: Laundry rooms with washers and dryers are located on inpatient floors – third, fourth, and fifth floors of the Kay Research and Care Center and the second floor of the Chili's Care Center. **These rooms are open 24 hours a day**. St. Jude is not responsible for laundry and other items left unattended. Laundry detergent is provided free of charge. Every parent room connected to a patient room has a private bathroom with shower. St. Jude also offers a Family Lounge with refrigerator, microwave oven, and coffee brewer on the second floor of the Chili's Care Center.

Parent Exercise Room: The Parent Exercise Room is available to parents and caregivers 18 years and older. This room features mats for stretching and floor work, several machines for cardio and weight training, and free weights. Free workout hand towels are also provided! Upon entering the Parent Exercise Room, parents and care givers must complete a liability waiver first. This room is open 24 hours a day and is monitored by security for safety reasons. It is located on the plaza level of the Kay Research and Care Center, room IA-P124.

Massage on the Go: Massage on the GO is a massage service that offers both chair and table massages to adult caregivers and family members of patients at St. Jude. The cost for these massage services is \$1 per minute. There is a 10-minute minimum required. Schedule in advance. You may schedule an appointment through the Massage on the Go website (www.massageonthegomemphis.com), or you may email Samuel Nelson at sam@massageonthegomemphis.com. Offered Wednesdays, 10 am-1 pm; 3rd floor of the Kay Research Care Center (KRCC) in the Family Lounge

ATM/ Credit Union: On a case-by-case basis, the First South Credit Union office on the plaza level of the ALSAC Tower, (Building where Kay Kafe is located) will cash Social Security checks, checks issued by St. Jude and checks issued by cancer-care organizations. First South requires that the name on the check exactly match your personal identification card. You should not sign your check until you get to the credit union or a bank. An automatic teller machine (ATM) for withdrawing cash is located just outside the Kay Kafe near Starbucks.

Charging your Cell Phone: with charging stations in waiting areas with USB electrical outlets.

Charging Station Locations:

Diagnostic Imaging Patient Registration
Radiation Oncology Social Work

Red Frog Hall next to Social Work

Chili's Care Center lobby

D Clinic

South waiting area
Blood Donor Center

E Clinic

North waiting area

Elevator area next to D & E Clinic

PCC Lobby

North waiting area

In the end tables in some waiting areas

Counter seating outside the Kay Kafe

ALSAC Gift Shop: Located outside the hospital next to the Danny Thomas/ALSAC Pavilion. St. Jude logo merchandise can be purchased here.

Open from 8:30 a.m. to 4:30 p.m. Monday through Friday.

St. Jude Hospital Gift Shop: Located next to the Patient Care Center lobby. This shop sells a variety of items for all ages, including toys, balloons, candy, gifts and sundries.

Open from 8:30 a.m. to 4:00 p.m. Monday through Friday.

Mail Services: Post office/mail room on campus located in the Longinotti building. You can mail packages and regular mail, it offers discounted FedEx rates, and you can pay for postage at the mail room but stamps are available in the hospital gift shop.

Concierge Services: BEST Upon Request

If there are any questions about concierge service at St. Jude, please direct patients and their families to call (901) 595-4000.

Using the concierge service can help a family spend more time with their child and other family members. It can also give them more time to take care of activities related to their child's illness and medical care, such as talking with the doctor or learning to care for their child at home. BEST Upon Request can be used for helping with everyday tasks, running errands and shopping, and helping plan events such as a day of sightseeing, a birthday party, or any other occasion.

Patient Education

For more information, call 901-595-4639

St. Jude Parent's Newsletter: Each month, Parent Newsletters are released to provide information to parents about relevant information about patient events.

Patient and Family Recreation Directory: A booklet outlining various services and fun places to visit, offered to St. Jude families free or at a reduced cost, is available in the Family Recourse Center, in every Patient Registration area, as well as the Guest Services information desk in the Patient Care Center or Chili's Care Center lobby.

My St. Jude, website and app: an online site where you can view, but not change, parts of your (your child's) medical health record. You can find the portal by searching "My St. Jude" on the St. Jude website or Google.

https://www.stjude.org/treatment/patient-resources/my-st-jude.html

Together, Website: a new online resource powered by <u>St. Jude Children's Research Hospital</u>. It offers dependable information and a community of support for anyone facing childhood cancer. https://together.stjude.org/en-us/