Pediatric Patient Handbook

What you and your child need to know during your stay





WELCOME

to St. John's Children's Hospital

St. John's Children's Hospital is a special place for children and their families. We provide care designed to meet the needs of your child and family.

If you have any questions or concerns, please ask us. We want you to feel at home.

As the parent or guardian, you are part of your child's health care team. You can help by:

- Giving correct and complete facts about your child's health
- Easing your child's fears
- Telling your nurse when you don't understand something or have a concern
- Learning what you need to do to care for your child when he or she goes home
- Taking care of yourself

Please read about the services we provide. It will make your stay at St. John's Children's Hospital a little easier.

OUR STAFF

It takes a hospital team to care for your child.

At St. John's Children's Hospital, all staff members wear hospital identification badges. Each staff member is specially trained to work with children of all ages.

The medical team includes:

- The attending doctor who will oversee your child's care.
- Residents and medical students from Southern Illinois University (SIU) School of Medicine.
- Nurses who are assigned to your child. You will have three nurses each day.
- Child life specialists are available for your child and family to help deal with pain, stress and fears. Your child life specialist will stay with your child during procedures, and will help your child understand what is happening.

The child life specialist also has special training to help siblings understand why their brother or sister is being hospitalized and what special treatments they may be receiving to help them get better. Please ask your child life specialist for help with sibling support.

• A Parent Advocate may visit you to address questions or concerns about your hospital stay, or after you go home. St. John's also has a Patient Advocate who can help you with issues you have during your child's hospital stay. To reach the Patient Advocate,

call ext. 44098. (From outside the hospital, dial (217) 544-6464, then the extension when prompted.) If you have a question or concern, talk to your nurse or the parent/patient advocate first. They will be able to help you more quickly. We want you and your child to feel comfortable and satisfied with your care.

- Other people may be involved in caring for your child. For example, physical therapists help children participate in physical activity and achieve their highest level of physical function. Occupational therapists help children learn daily living skills. Speech therapists help with language and eating. Respiratory therapists treat children who have breathing problems. Dietitians provide nutritional counseling and recommend meals for patients. People from the laboratory, radiology and other areas of the hospital also may be involved in your child's care.
- Chaplains are available 24 hours a day to provide spiritual support to patients and their families. Social workers are available to counsel you with social, emotional and financial issues related to your child's illness.

You are encouraged to discuss your child's needs with any staff member. Do not hesitate to ask questions or to request detailed answers. Writing down questions will help you remember them.

RIGHTS & RESPONSIBILITIES

Patient/Family Rights

You and your child have the right to:

- quality health care.
- have your spiritual, cultural and social needs respected.
- receive care and support that meets his or her age and needs.
- make decisions about the care of your child.
- receive complete information that you can understand about your child's condition, tests, procedures and treatments.
- refuse consent for treatment to the extent permitted by law. You also have the right to be told what will happen if you refuse treatment.
- know the names of those who care for your child.
- talk about any ethical issues that may arise during your child's care.
- know about any research or educational project affecting your child's care or treatment. You have the right to say you don't want to join in these projects.

You and your child have the right to privacy. Information about you and your child will not be shared with anyone who is not caring for your child. When calling St. John's Pediatrics to ask about your child, you will be asked to provide a code. No one without this code will be given phone condition reports.

You have the right to transfer your child to another hospital if we cannot meet your child's needs for treatment or service.

You have the right to make an advance directive if you are 18 years of age or older. This means you have the right to choose someone to make health decisions for you if you no longer are able to make your own decisions.

You have the right to complain to the hospital staff and/or outside representatives of your choice, and you have the right to be free from restraint, interference, coercion, discrimination or reprisal when voicing a complaint.

Patient/Family Responsibilities

You and your child are responsible for:

- providing correct and complete information about your child's health.
- telling your child's doctor or nurse if you do not understand any part of your child's treatment.
- telling us how much you want to be involved in your child's care.
- paying for your child's care.
- respecting the rights of other patients, families and hospital staff.
- respecting rules about visitors to the hospital.
- bring to the attention of the appropriate staff those occasions when your rights as a patient are not being respected.

If your child is in isolation, you, your family and guests are responsible for following the infection control rules to keep your child, other patients and visitors safe.

INFECTION CONTROL

Preventing germs from spreading

Hand washing

Hand washing is the best thing you can do to prevent germs from spreading. It is important to cleanse your hands after feeding or helping your child in the bathroom, after you have eaten and after you have used the bathroom.

You can use soap and water, and there is also anti-bacterial gel available in patient rooms and throughout the hospital.

Isolation

The purpose of isolation is to help prevent the spread of germs among patients, visitors and hospital staff. The type of isolation depends on how the germ causing the illness spreads. Germs can enter the body through the air you breathe or from stool, blood or other body fluids, such as wound drainage. If your child is in isolation, please ask your child's nurse for more information.

Patient safety

Do not pick up, hold, feed or play with any child in the hospital but your own. You can cause harm to other patients or to yourself. These guidelines will help protect you and your children at home from illness and protect other children in the hospital.

If any family member has a cold or other infectious disease, please do not allow that person to visit your child in the hospital. If any family members have been exposed to measles or chicken pox within the past 21 days, and has not had these diseases before, please do not allow them to visit. Be sure all children visiting are up-to-date on their immunizations.

PATIENT INFORMATION

Educational needs/ Kohl's Technology Center

Your child's educational needs are important to us while he or she is in the hospital. The Kohl's Technology Center is available for computer learning use as well as games and internet access. The pediatric social worker can help you communicate with your child's school regarding a tutor.

Resource materials, including books, patient education materials and magazines, are available to all families of patients. Topics include: wellness; illness; growth and development; parenting; nutrition; and death. Please contact your nurse if you would like any of these materials.

Infant stimulation materials

Crib mobiles, mirrors, music boxes, rattles and other infant stimulation materials are available for children during their stay. Please call your child life specialist at ext. 30594 or your child's nurse.

Language assistance

Interpreters are available to non-English speaking families and families with a hearing impaired member. The following services are available upon request: telecommunication devices for the deaf (TDD); telephone amplifiers; closed caption television and video player equipment; printed language aids; readers for the visually impaired; sign language interpreters; and foreign language interpreters. To request these services, please ask your nurse, the Information Desk on your child's floor or the hopsital operator.

Nursing assistance

Call for nursing assistance by pressing the nurse call button near the bed. A nurse call button is also located in the bathroom.

Play areas

Pediatric Healing Garden

The pediatric Healing Garden is located on the 5th Floor of St. John's Children's Hospital. It is for all pediatric patients. To visit the Healing Garden, please ask your nurse.

Teen Lounge

The Teen Lounge is available for patients ages 10 to 20 and their visitors. To access the Teen Lounge, please contact the child life specialist at ext. 30594.

Children's Playroom

The Children's Playroom is located on the 5th Floor of the Children's Hospital. It is for patients and their visitors (ages infant to 10 years old).

All children must be supervised by a responsible adult when in a play area. Play area rules are posted in each area. Please follow these rules to keep the hospital safe and clean. If your child is unable to go to the play areas because of his/her medical status, please ask your child life specialist or nurse to help you find appropriate bedside activities.

Receiving telephone calls

To receive phone calls in your room, tell people to dial (217) 544-6464 and then your extension when prompted. (You will find your extension on the phone.) Incoming telephone calls are blocked from 10 p.m. – 7 a.m.

Room service

Room service is available 24 hours a day by calling ext. 63257. Menus are in the room. Please allow 45 minutes for food to arrive.

Please talk with your nurse before ordering from the menu. He or she can tell you what your child is allowed to eat. If a special meal, is needed, such as vegetarian or kosher, your doctor must approve. Please do not give your child any food without asking your child's nurse.

Parents/guardians of pediatric patients are allowed to order a meal three times per day. Guest trays are charged \$8.50.

Television and DVD players

Each patient room has a television set. DVD players and a variety of movies are available as well. Please request these items through your child's nurse or the child life specialist. You also may bring your child's favorite DVDs from home.

PARENT/VISITOR INFORMATION

Accommodations

Hotels and motels

The Carpenter Street Hotel is located on the corner of Sixth and Carpenter streets. Phone number is (217) 789-9100 or 1-888-779-9100 (toll free). Transportation to and from the hospital is available on request from 5:30 a.m. – 10 p.m. A free continental breakfast is served from 6 – 10 a.m.

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A discounted room rate is available to patients and their families. For more information on this rate and eligibility requirements, call the Admitting (Pre-access) Department at (217) 544-6464, ext. 45926.

Other hotels in the area offer special rates to families of St. John's Children's Hospital patients; some also offer shuttle service. To receive a special rate, tell the hotel you are with a St. John's patient. You are responsible for making your own arrangements.

Within the hospital

A single sleeper bed is available in most patient rooms. Please inform your child's nurse if you will be spending the night. The hospital will provide linens and a pillow. You will need to bring your own toiletries.

Ronald McDonald House

Overnight accommodations are available for families of children receiving inpatient care or outpatient treatment at Springfield area hospitals. Please contact your nurse or social worker for details and arrangements. If you have stayed at the Ronald McDonald House before, you can call (217) 528-3314 to be placed on their waiting list. The Ronald McDonald House is located at 610 N. Seventh Street.

Ethics committee

You may need to make difficult decisions about your child's care. A special group at the hospital is available to help. It is called the Medical Moral Committee. If you would like to meet with a member of the committee, please tell one of your child's caregivers.

Financial arrangements

Your bill: The bill you will receive will cover many aspects of your child's hospital care — nursing, laundry, lab testing, medications, etc. You will receive a separate bill for physicians' services, including services provided by radiologists and Emergency Department physicians. If you have questions after you receive your bill, please contact a customer service representative at (217) 525-5615.

Christian Care: At St. John's, our mission is to care for the sick and injured, regardless of their ability to pay. Through our Christian Care Program, the hospital provides discounts for patients who are experiencing economic difficulties and who have investigated all other means of assistance. To learn more, call the Business Office at (217) 525-5615.

KidCare: Illinois KidCare is the low-cost and/ or free health care coverage for children and pregnant women. It covers doctor visits, prescriptions, dental care and hospitalization. Many working families qualify for this program. For more information, call the Business Office at (217) 525-5615.

Insurance

Patients with insurance should submit all information, policy numbers and identification cards upon admission. After discharge, the hospital will bill your insurance company. Any balance after the insurance payment is your responsibility and due within 30 days of the insurance payment.

Patients without insurance are responsible for full payment of hospital services received. Payment is required within 30 days of the date of discharge, unless arrangements have been

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made in advance with the Business Office. If you need to make special financial arrangements, please call the Business Office at ext. 44266, 8 a.m. – 4 p.m., Monday – Friday.

For Patients with Medicaid, group health insurance is considered primary (it will be billed first) to Medicaid if either you or your spouse is employed. Also, coverage from liability insurance is always primary to Medicaid. If either situation applies to you, please inform the Billing Office at ext. 44273.

Meals

St. John's Cafeteria

To reach the Cafeteria take the visitor elevators to the 1st Floor. Follow the hallway signs to the cafeteria entrance. All items may be ordered as carry out foods to take to your child's room. Please check with your child's nurse for the hours of St. John's Cafeteria.

Subway®

Located in the Prairie Heart Institute Monday – Friday from 7:30 a.m. – 2:30 p.m. Closed weekends

Jazzman's Café

Located in the main lobby on the 2nd Floor Monday – Friday from 6 a.m. – 6 p.m. Closed weekends

Vending machines

Food and beverage vending machines are accessible 24 hours a day in the cafeteria. Vending machines are also located in the following areas:

- Hallway west of the Children's Hospital lobby
- 3rd Floor lounge, main building near the Mason Street Corridor
- Emergency Department

Parking

Visitor parking is available in the parking ramp on the corner of Ninth and Carpenter streets. Handicap accessible parking is available in designated areas. For Patient-Assisted (valet) parking, please drive your car into the circle drive in front of the Women & Children's Center and see the attendant. Patient-Assisted parking is available Monday through Friday, 8:30 a.m. - 4 p.m. Security officers will provide 24-hour escort services for visitors going to the Ronald McDonald House or any hospital parking area.

Telephones

You may use patient or in-house phones to call hospital departments listed in this handbook. Just dial the five-digit extension number. (See insert for important numbers.)

You may dial out on this phone at any time; dial 9 first. To place a long distance call using AT&T, dial 9 + 0 + the number. You can reach other long distance carriers from the telephone in your room by dialing the access code provided by that carrier.

Cell phones and wireless communication devices may not be used in the Neonatal ICU and Pediatric ICU. Cell phones may be used throughout the rest of the facility.

Visiting hours

Parents, grandparents and legal guardians may visit and be at the bedside at any time. Only two adults (over the age of 18) may spend the night in the patient's room. Siblings and other visitors may visit during visiting hours. All children must be accompanied by an adult. Visiting hours are from 11 a.m. to 8 p.m. In special care areas (Pediatric ICU) you may be asked to limit the number of visitors. Please check with your child's nurse before inviting visitors.

HOSPITAL SERVICES

In alphabetical order

Asthma education

Through the Huff and Puff Program, children and their families receive valuable instruction on coping with this respiratory disease. Call ext. 50343 for more information.

ATM

Available on the 1st Floor near the Cafeteria.

Breastfeeding moms

If you are a breastfeeding mom, please see your nurse for support and information regarding feeding your baby.

Car seat safety

If you have any questions regarding your child's current car seat or fitting your new infant properly in a car seat, please see your child's nurse. A certified child passenger safety technician may be available to assist you with these concerns.

Gift Shop

St. John's has two gift shops, in the lobby of the Carol Jo Vecchie Women & Children's Center and in the main lobby of the hospital. Both are open 9 a.m. – 7 p.m., Monday thru Friday and 10 a.m. – 4 p.m. every Saturday. The main lobby's gift shop is open from 10 a.m. – 4 p.m. on Sundays and the Carol Jo Vecchie Gift Shop is open Sunday from noon – 4 p.m. Items for sale include gifts and toys for all ages, fresh and artificial flower arrangements, magazines (main gift shop only), greeting cards, candy, snacks, mylar balloons and much more. The Gift Shops are staffed by St. John's Samaritans (volunteers).

Home Health Services

If your child needs additional care, therapy or assistance with medication, your doctor may prescribe home care services. This will be provided by the home health service preferred by your insurance company.

Among the services available to you through St. John's Hospital Home Health Services are nursing, physical therapy, speech therapy, occupational therapy, dietary planning, counseling or pastoral care and home health aides to assist in providing your child's care. These services are available to patients who live within a 50-mile radius of Springfield. Home Health also has an office in Decatur to serve patients from that area. Our Case Management (Social Work Services) Department is also available to help you arrange for any additional services you may need or to assist you in obtaining the proper care you need at home.

Laundry facilities

A washer and dryer are available in the Family Lounge located on the 5th Floor. Please ask your nurse for detergent. To be fair to other families, please remember to remove laundry promptly. St. John's Children's Hospital is not responsible for lost or stolen laundry.

Massage therapy

A massage therapist, funded by the the Friends of St. John's Hospital, is available to massage your child while in the hospital. Please contact the child life specialist at ext. 30594 for more information.

Parent Help Line

Parent Help Line is a phone line that offers support, information and referrals to parents of children ages 0-19 throughout Illinois. Call for information about a free monthly news letter, educational materials and a weekly television program (Springfield 1 p.m., Channel 4). The Parent Help Line can be reached at ext. 45808 or 1-888-727-5889. Parent Help Line is also available at *www.parenthelpline.org*.

Pastoral Care services

Chaplains are available 24 hours a day. At your request, chaplains will contact your priest, minister or rabbi.

The Chapel is located on the second floor of St. John's Hospital and is open 24 hours a day. Mass and Holy Communion schedules can be obtained by contacting Pastoral Care. Contact Pastoral Care Services through your child's nurse or by calling ext. 55675 on your hospital phone.

Security services/Lost and Found

Security officers will provide 24-hour escort services for visitors going to the Ronald Mc-Donald House or any hospital parking area. The Security Department also offers a free jump-start service for visitors with car trouble. To reach Security, call ext. 44020.

If you lose something while at St. John's Children's Hospital, please call the Security Department at ext. 44019 (8 a.m. - 4:30 p.m. Monday – Friday).

Social Work Services/Discharge planning

Social workers are available to assist you and your family with social, emotional and financial issues related to your child's illness. They may be helpful in referring you to services, as well as in coordinating services.

PAIN MANAGEMENT

Pediatric Procedure Room

If your child requires a procedure that may cause pain or anxiety, it will take place in our childfriendly Pediatric Procedure Room.

Your child will have the chance to play with a variety of distraction toys before, during and after the procedure. The room has low lighting, music and a water panel, and our nursing staff is trained to perform child-friendly procedures.

When possible, we encourage parents to be present for all procedures. After the procedure, your child will be rewarded with something from the pediatric treasure chest. Please ask your child's nurse or child life specialist if you have any further questions about our procedure room.

Patient Rights for Pain Management

As a patient at St. John's Children's Hospital, you and your child can expect:

- Information about pain and pain relief measures.
- A concerned staff committed to pain prevention and management.
- Health professionals who respond quickly to reports of pain.
- Your reports of pain will be believed.
- Up-to-date pain management.

Patient Responsibilities for Pain Management

As the parent of a patient at St. John's Children's Hospital, we expect that you will:

- Ask your doctor or nurse what to expect regarding pain and pain management.
- Talk to doctors and nurses about choices for pain relief.
- Work with your doctor and nurse to develop a plan for managing pain.
- Ask for pain relief when pain first begins.
- Tell your doctor or nurse if your pain does not stop or get better.
- Tell your doctor or nurse about any worries you have about taking medicine for pain.
- Help your doctor or nurse measure your child's pain.

When Your Child is Experiencing Pain

- Tell the nurse, doctor, therapist or child life specialist.
- Work with the professionals treating your child to manage the pain.

Measuring Pain

- While your child is in the hospital, he or she will be asked to rate the level of pain on a scale of 0-5. Zero means there is no pain at all. Five means it's the worst pain imaginable.
- If your child is an infant or nonverbal, the nurse will use a special scale to score your child's pain.
- Never assume doctors or nurses know your child is in pain. Help your child talk about how he or she feels. Tell us right away!

PAIN MANAGEMENT METHODS

Non-pharmacological (without medicine)

We will tell you what is going to happen. If you have questions, or need us to repeat anything, we will be glad to help. Parents and patients are encouraged to ask questions and express feelings.

Giving a child some control or input can help to reduce pain.

We ask parents to stay with their child. Children feel more secure when their parents are with them.

Cuddling is nature's own pain remedy.

Distraction is a great way to ease pain. Some forms of distraction are talking, video games, movies, pop-up books, TV, music and being read to. See your child life specialist for other ideas for distraction.

When in the hospital, it is important for children to continue doing normal activities as much as possible.

Pharmacological (with medicine)

Your child will receive pain medication and/or a PCA (Patient Controlled Analgesia).

Let the nurse know when your child needs pain medication.

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How parents can ease fear and pain

- Find out what is going to happen and learn about the tests or procedures.
- Be honest and calm when you talk to your child. If you are upset, your child will be upset.
- Encourage your child to ask questions and talk about feelings.
- Tell your child that the doctors and nurses are trying to help him or her get better.
- Choose positive words such as "feel better" and "brave." Avoid words like "afraid" and "hurt." For example, instead of asking "Are you afraid?" ask "How can we be brave?"
- Listen to your child.
- Give choices when you can.
- When able, encourage your child to play, draw, or do something he or she enjoys.
- Choose your words carefully when you are talking to others on the phone. Your child hears every word.



800 E. Carpenter Street • Springfield, IL 62769 Phone: (217) 544-6464 • www.st-johns.org