

CHILDREN'S MERCY

# NEW JOURNEYS

A handbook for families  
with children who have  
special health care needs.

Created by the  
FAMILY ADVISORY BOARD



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## WELCOME LETTER FROM THE **FAMILY ADVISORY BOARD**

From the moment your child or teenager is diagnosed with a medical condition your life changes. As parents of these children, we know this firsthand. The purpose of this handbook is to share with you things we have learned along the way and to help you make well-informed decisions while taking part in your child's care. You are an important member of your child's health care team.

This handbook was developed by members of the Family Advisory Board (FAB) who are parents of children who receive services at Children's Mercy. We have gained insight and knowledge through our participation on the FAB, as well as our experience of being a parent of a child or teenager with complex medical needs.

Many parents and family members say they feel overwhelmed when they first come to the hospital. The terminology can be very hard to understand and just finding your way around can be frustrating. We all know what it is like to try to maneuver the system while taking care of a sick child.

This book is for you, from parents to parents. The Family Advisory Board truly hopes this handbook will help you get to know Children's Mercy and will empower you to become a partner on your child's health care team.

Our best wishes,

Children's Mercy Family Advisory Board



## **ABOUT CHILDREN'S MERCY**

Children's Mercy is the only free-standing children's hospital between St. Louis, Mo., and Denver, Colo. It provides comprehensive care for children and teens from birth to 21 years of age. Children's Mercy is consistently ranked among the leading children's hospitals in the nation.

Children's Mercy understands the importance of family members to the health and well-being of your child. They honor, empower and respect the vital role of the family by recognizing them as the constant in their child's life. As parents, you know your child best. You are an essential member of the health care team and may be with your child 24 hours a day.

Children's Mercy is committed to providing patient- and family-centered care. Patient- and family-centered care is a collaborative approach to caregiving and decision-making. The family and staff respect the knowledge, skills and experience that the other brings to health care decisions. The staff will partner with you to provide the best care for your child.



## **FAMILY ADVISORY BOARD**

Started in January 2003, the Family Advisory Board (FAB) is a board of 21 families who are primary caregivers of a child who has been cared for at Children's Mercy. FAB meets once a month and reports to Children's Mercy's executive vice president and co-chief operating officer.

The FAB's goals are to:

- support the mission of Children's Mercy
- promote a relationship in which family members and professionals work together to ensure the best services for children and families
- facilitate open communication for families
- respect confidentiality
- maintain realistic expectations
- work to enhance the Children's Mercy experience for all children and professionals.

Learn more about the Family Advisory Board at [childrensmercy.org/FAB](http://childrensmercy.org/FAB).

Consider becoming a member, or contact the Family Advisory Board with your suggestions on how to improve patient- and family-centered care.



## TEEN ADVISORY BOARD

Formed in March 1999, the Teen Advisory Board (TAB) commits to providing education and support to Children's Mercy patients, families and staff. TAB is a group of teens between the ages of 13 to 19 with experience in a variety of diagnoses.

The purpose of TAB is to provide:

- Children's Mercy with a patient advisory board representing various ages, backgrounds and communities
- an opportunity for a representative group of patients to express concerns, ideas and suggestions
- the TAB Children's Mercy staff representatives who will listen to and advocate for them
- direct patient feedback to the Children's Mercy executive vice president and co-chief operating officer.

Visit the TAB website at [childrensmercy.org/TAB](http://childrensmercy.org/TAB).

## EL CONSEJO DE FAMILIAS LATINAS/HISPANAS

Started in 2008, El Consejo de Familias Latinas/Hispanas is a council of Spanish-speaking families whose children receive services at Children's Mercy. They meet once a month and partner with staff on ways to improve communication and services for non-English speaking families. Visit the Consejo website at [childrensmercy.org/Consejo](http://childrensmercy.org/Consejo).



# PATIENT'S RIGHTS, RESPONSIBILITIES AND RULES

## Our Promises to Our Patients:

You are important to us.

You are part of your health care team.

You may talk freely with your health care team about your care and safety. Your care and safety are our most important goal.

You may ask us as many questions as you would like. You may ask for an interpreter at any time.

You may tell us how you feel.

We will tell you the truth.

We will listen to you.

We will talk with you about your care in a language you understand.

We will help you do what you need to grow and learn.

We will be as gentle as possible when we care for you.

We will keep your body covered as much as we can.

We will ask you if you hurt. We will try to help you feel better as quickly and safely as possible.

We will help you continue to do the things that are important to you, your family and your faith.

We will help you learn how to take care of yourself.

## We will also:

- Tell you who we are.
- Explain what our job is.
- Talk with you about why you are here.
- Explain to you how things may feel.
- Notify your doctor that you are in the hospital.
- Notify a friend or family member that you are in the hospital (18 years or older, upon your request).
- Make you as comfortable as possible.
- Tell you what might help you and what we believe might not help you.
- Give you information you need to make decisions about your care.

**We will take good care of you and respect you no matter:**

- Your gender identity.
- The color of your skin.
- Where you were born.
- What language you speak.
- What your beliefs are.
- What you can and cannot do.
- What you look like.
- Who is in your family.
- Whether you or your family can pay for your care.

**Additional Rights:**

Your family and friends can be with you when the hospital policies say it is okay and when you want them to be with you.

If we offer a research study to you, you may say yes or no. Saying “no” will not change how we care for you.

We will help you make plans if you and your family choose to go home or to a different hospital, unless it harms your health or safety.

You and your parents may see your medical record as permitted by law. We will help you with this.

You and your parents may ask for assistance to pay for your medicine or medical care.

If you are 18 or older and are able to make decisions for yourself, you may create an Advance Directive. An Advance Directive is a written or spoken plan that tells us what treatments you want or do not want. It also tells us who should make decisions for you if you are unable to tell us yourself. If you want, we will help you create an Advance Directive.

If you are 18 or older and are able to make decisions for yourself, you have the right to approve or refuse any part of your medical treatment. If you are younger than 18 and wish to say no to any part of your care, we will discuss this with you and others as needed.

If you are 18 or older and are not able to make decisions for yourself, we will talk with your legal guardian or designated representative to make decisions that are in your best interest.

## Questions or Concerns?

You may ask to talk to a member of the Ethics Committee at any time if you have a problem about treatment decisions.

If you think we have not kept our promises, please tell us so we can try to make things better. If you are still unhappy, please ask to talk to our Patient Advocate, who will listen to you and address your concerns. You may also file a formal complaint with the Patient Advocate.

## YOUR RESPONSIBILITIES AS A PATIENT

There are things only you can tell us. So that we can give you good and safe care, it is important that you tell us:

- why you are here.
- how you feel.
- if you have pain and where.
- what others have done to help you feel better.
- what you and your family do at home to help you feel better.
- if you don't understand something.
- if you have concerns about your care.
- if there is something on your mind.
- if you need help following your plan of care or keeping your appointments.

## HOSPITAL RULES

These rules are for everyone (staff, patients, families and visitors) who enters Children's Mercy.

1. Keep the hospital a safe and restful place.
2. Privacy and confidentiality must be protected at all times.
3. Never use foul or mean language.
4. Never use physical or emotional abuse.
5. Weapons are not allowed in our facilities or on our grounds.
6. Tobacco, e-cigarettes, alcohol or illegal drug use is not allowed.
7. Do not steal or damage hospital property or the possessions of others.
8. Hospital-owned medical equipment must be operated only by authorized individuals.
9. Follow our visiting rules.
10. Do not go into restricted areas.

## **VISITOR GUIDELINES**

Parents and legal guardians are not considered visitors and are encouraged to stay with their child. Parents and guardians of inpatients will receive an orange wristband that will allow access to the inpatient units without stopping at security.

Children's Mercy understands that visits with family and special friends help patients feel better.

- Parents/legal guardians may stay with their child 24 hours a day.
- Patients may have other visitors from 9 a.m. to 9 p.m.
- Visiting privileges in PICU, ICN and for patients in isolation may be different because of the special needs of the children. At certain times, no visitors will be allowed.
- The number of visitors is not restricted by policy. However, visits may be limited by the nurse manager or the parent/guardian.
- Visitors may only visit the patient they came to see.
- Visitors may only use playrooms when with the patient. An adult will stay with children in the playroom at all times.
- All visitors under the age of 16 must be with an adult.
- Patients cannot leave the patient care unit without permission of the patient's nurse.
- Visitors must be free of illness (runny nose, sore throat, diarrhea, vomiting) or exposure to communicable disease. A nurse will check all visitors under 18 years of age for signs and symptoms of "infection." All visitors should wash their hands before entering the patient's room.
- Only two parents or authorized adults may stay overnight in the patient's room, unless approved by the nurse manager or nurse in charge.
- Alcoholic drinks, drugs and weapons will not be allowed in the hospital. Anyone suspected of having these items will be told to leave the hospital immediately.
- Disruptive behavior will not be allowed. Disruptive visitors will be told to leave the hospital.

If you do not follow these rules, you may not be allowed to visit.

## QUICK TIPS FOR VISITORS

- **Call ahead:** Families quickly lose a sense of privacy when staying in a hospital. Check with the family for the best times to visit. It shows respect for the family and you won't miss the patient if tests, therapy or surgeries are scheduled.
- **Excuse yourself:** Step out of the room to let the patient carry out private tasks, or when doctors or nurses enter the room.
- **Never bring food or drink** unless you check with the family first. Many patients are not allowed to eat or drink for long periods of time.
- **Keep young visitors in your control:** Respect the condition of the patient you are visiting and the other patients—supervise visiting children. Children must always be with an adult, whether in the patient room or playroom.
- **Limit the visit:** Patients are glad to have visitors, but long visits and too many visitors can be tiring to both the patient and family.

## WHEN PEOPLE WANT TO HELP

Friends, family and neighbors may want to help, but don't know what you need. Accept their help! It will make them feel better and can give you some relief, but you may have to suggest what will help you most. Consider suggestions like these:

- **Run errands.** Get groceries to keep the perishables in date, take siblings to day care, school or after-school activities, take pets to the vet, pick up dry cleaning, etc.
- **Provide child care** for siblings at home or give "care packages" and special outings to the patient's brothers and sisters.
- **Prepare meals** for the freezer or for quick fixes for the family at home.
- **Help with household chores** such as watering plants, mowing the lawn, cleaning house, walking dogs, collecting mail and doing laundry.
- **Keep info-phone-chain**, if requested. Help keep the patient's extended family and friends up to date on the patient's condition so the family gets a break from too many phone calls. Be the family contact person.
- **Offer a shoulder and an ear**—but not advice unless requested.
- **Help with seasonal activities** such as holiday shopping, birthday shopping, present wrapping, card sending.
- **Give parents/caretakers a "time-out."** Offer to sit with the patient so parents can step out and have lunch, time alone, or time to clear their minds.

Helpful gift suggestions: soft pillow or blanket, slippers, books, magazines, healthy snacks, gum, mints, toothbrush, activity books, journal, or organizer for hospital papers.

### **INFECTION CONTROL: GUIDELINES FOR VISITORS**

- Visitors under 18 years of age must be checked before visiting patients in the hospital.
- Adult visitors will be asked if they or their children have had any infectious diseases lately, such as a cold or the flu.
- The nurse or other hospital staff may also check the visitor for any obvious infectious-type symptoms such as runny nose, watery eyes, cold, rash or fever.
- Visitors with obvious symptoms, recent exposures or disease will not be allowed to visit.
- After the nursing staff okays the child to visit a patient, the nursing staff will sign his or her name and the date on a “visitor apple” sticker. The “visitor apple” sticker will then be placed on the child to wear during the hospital visit. The child will be checked again and get a new sticker for each visit.
- People who see a child on an inpatient unit without a name bracelet or “visitor apple” should tell a nurse.
- All visitors should wash their hands before entering the patient’s room.



# GETTING AROUND CHILDREN'S MERCY

## FINDING YOUR WAY

The signs at Children's Mercy Hospital are based on color zones and universal symbols to help guide you to the right locations. Maps are available at the information desk on the ground floor. You may also stop any staff person and ask for directions.

The hospital is divided into color zones of purple, pink, green, blue and yellow. There are signs throughout the hospital to help you find the appropriate color zone. In each color zone, there are directories with universal symbols and the color zone is shown on the bottom of every sign.

## CHILDREN'S MERCY ADELE HALL CAMPUS PLACES TO EAT

**Cafeteria/Orbits Diner** — On the ground floor next to the Castle elevators, open every day at these times:

<b>6 a.m. – 10 a.m.</b>	<b>Breakfast</b>
<b>11 a.m. – 2 p.m.</b>	<b>Lunch</b>
<b>2 p.m. – 4 p.m.</b>	<b>Grill Open</b>
<b>4 p.m. – 8 p.m.</b>	<b>Dinner</b>

### **Classics Express Café**

<b>6:30 a.m. – 10:30 a.m.</b>	<b>Breakfast</b>
<b>10:30 a.m. – 2 p.m.</b>	<b>Lunch</b>
<b>7:30 p.m. – 2:30 a.m.</b>	<b>Late Night</b>

The Diner and Café accept cash, MasterCard, Visa or Discover credit or debit cards. Contact your social worker if you cannot pay for food.

### **Subway**

On the first floor of the hospital in the Sombart Lobby.

Open **7 days a week from 7 a.m. to 11 p.m.**

### **Oasis Vending Machine Area**

Vending machines with drinks and snacks are available on the first floor of the hospital, west of the Snack Shop. The Oasis is always open and has tables and chairs, a microwave oven and a \$1 bill changer for your convenience. Note the miniature train overhead.

### **ATM**

There are two ATMs at Children's Mercy, one in the Sombart Lobby (first floor) by the Snack Shop and one located on the ground floor by the security check-in.

### **MAIL DROP**

The mail drop is located in the Sombart Lobby (first floor) by the Snack Shop, next to the ATM. Mail is picked up Monday through Friday at 2 p.m.

## **GIFT SHOP**

Our Gift Shop is open Monday through Friday from 8:30 a.m. to 5:30 p.m. and Saturday from 10 a.m. to 4 p.m. Toys, books, magazines, postage stamps, mylar balloons, candy, aspirin, personal care products and gifts are available in the Gift Shop.

## **SECURITY**

The Security department helps to provide a safe environment, and watches the buildings, parking lots and grounds. Security will ask you to show a picture ID and will give you a visitor sticker that you must wear in an easily visible location at all times. Parents of inpatients will receive an orange wristband that will allow access to the inpatient units.

The main Security Office is located on the first floor in the Green Zone, next to the Oasis vending machine area. You can report lost items, ask for escorts to or from hospital parking, and report other security concerns in person or by calling (816) 234-3340. Firearms, alcohol, tobacco and illegal drugs are not permitted on hospital grounds.

## **CHAPEL**

The entrance to the Lisa Barth Interfaith Chapel and garden is near the cafeteria on the ground floor. The chapel and garden are open 24 hours a day, seven days a week.

The interfaith chapel has many uses. It is available for prayer, reflection and meditation. There are regularly scheduled interfaith and faith-specific worship services. Families of patients can use the chapel for baptisms, anointings and blessings. It also offers a calm, private area for sensitive consultations and intimate family conversations.

## **RONALD MCDONALD FAMILY ROOM**

The Family Room is a special place within Children's Mercy where inpatient families can rest and still be close to their child. The Family Room offers a comfortable home-like setting including a living room area with a television, fully equipped kitchen, and a quiet room for conversation and phone calls. The Family Room also has seven bedrooms for napping, showers and a laundry facility. Overnight accommodations are available to families with a child in the PICU or NICU.

The Family Room is located on the second floor of the West Tower in the Green Zone. When there are meals provided it is usually announced on the inpatient units.

## **CHILDREN'S MERCY HOSPITAL KANSAS**

**Ocean Side Café:** 7 a.m. to 8 p.m. every day

**Gift Shop:** 9 a.m. to 5 p.m. Monday through Friday

## **HOSPITAL SERVICES**

At Children's Mercy, we want to do whatever we can to prepare your child and help her/him feel at ease. We created "Story Book Tours" to help prepare kids for their experience. We have Web story books for overnight stays, exam room visits and same-day surgeries. To see these, go to [childrensmercy.org/storybooktours/](http://childrensmercy.org/storybooktours/).

### **INPATIENT**

When your child stays overnight in the hospital he or she is an inpatient. You can pre-register for scheduled admissions online if you wish, at [childrensmercy.org/preregistration](http://childrensmercy.org/preregistration).

- See the Tips for Parents section for tips on how to prepare for your hospital stay and what to bring with you.
- There will be "The Handbook" in each inpatient room.

There are inpatient beds at the Children's Mercy Adele Hall Campus and Children's Mercy Hospital Kansas locations. Children's Mercy East, Northland and West do not have inpatient units. Children's Mercy Hospital Kansas does not have Intensive Care Units.

Parent rooms are available on many inpatient units. They provide a quiet space for parents to step away from the bedside, have private conversations or have a snack.

### **ICN**

The Intensive Care Nursery, also known as the NICU, is for very sick newborns and infants. It provides the most advanced technology in the region to care for critically ill newborns. Children's Mercy is the region's only Level IV NICU and has more than 70 beds. To see a video about the ICN go to [childrensmercy.org/nicu](http://childrensmercy.org/nicu).

### **PICU**

The Pediatric Intensive Care Unit is for very ill or severely injured children and teens. The Benjamin E. Twyman Parent and Family Room is designated for parents and family members to provide a quiet space away from the bedside, have a private conversation or eat a snack.

### **OUTPATIENT**

When your child comes to a clinic for a doctor's appointment, your child is an outpatient. Children's Mercy has many clinics around the greater Kansas City area. There are also outreach clinics available in several locations in Kansas and western Missouri.

- If you have an appointment with a clinic, you can pre-register and update your information online if you wish, at [childrensmercy.org/preregistration](http://childrensmercy.org/preregistration).
- You can prepare your young child for a visit to the doctor with an online storybook called "Mercy Bear's Adventure Exam Room Visit" at [childrensmercy.org/StoryBookTours](http://childrensmercy.org/StoryBookTours). It is very important to arrive on

time for your clinic appointment. Remember to bring a diaper bag or backpack with the items your child may need during the visit.



**TIP FROM A PARENT:** “We always have a bag filled with snacks, toys and books to take with us to clinic visits.”

## **EMERGENCY ROOM**

The Emergency Room (ER) should be used for emergencies. There is an Emergency Room at Children’s Mercy Adele Hall Campus and at Children’s Mercy Hospital Kansas. These are full-service, pediatric emergency departments, treating all levels of injury and illness, with access to pediatric medical and surgical subspecialties. Children’s Mercy Adele Hall Campus offers a Pediatric Level I Trauma Center, the only one between St. Louis, Mo., and Denver, Colo. The Trauma Center is specially equipped for children and offers immediate access to a wide variety of highly trained and certified doctors, surgeons, nurses and other personnel, and equipment 24 hours a day. There is a separate parking lot at the south end of the medical campus, with an entry off Holmes.

The Tom Watson Emergency Department at Children’s Mercy Hospital Kansas is the only pediatric emergency service provider in the southern half of metropolitan Kansas City, with pediatric physicians, nurses and support staff available 24/7. It is not a designated trauma center.

If you must bring your child to the ER, bring your child’s medical information, medications and insurance information with you. The doctor will ask you about your child’s medical history and care.

## **URGENT CARE**

Urgent Care Centers provide medical treatment by a doctor for patients who need prompt care when their usual doctors are not available. If your child has a true emergency, go directly to the ER or call 911 for ambulance service. There is an Urgent Care Center for children at Children’s Mercy Blue Valley, East and Northland.

## **SAME DAY SURGERY**

Also referred to as outpatient surgery, this service is for children who are expected to have an operation and go home the same day. For example, if your child is having ear tube surgery, your child may have outpatient surgery at Children’s Mercy Hospital Kansas or at Children’s Mercy Adele Hall Campus.

- You can pre-register for a scheduled surgery or update your information online if you wish, at [childrensmercy.org/Preregistration](https://childrensmercy.org/Preregistration).
- You can prepare your child for surgery by visiting our website at [childrensmercy.org/PreOp](https://childrensmercy.org/PreOp). You can view an online video about surgery and read other resources.

## **OPERATING ROOM**

Surgery is performed in the operating room. A child may be admitted to the hospital as an inpatient before more difficult or complicated operations. A surgery book can be found online at [childrensmercy.org/PreOp](http://childrensmercy.org/PreOp).

## **RADIOLOGY**

Radiology is where your child gets X-rays, CT or CAT scans, MRIs, ultrasound tests, fluoroscopy, and nuclear medicine procedures. These are all ways to take pictures of the inside of your child's body. It is important that your child lie still while taking these tests, so your child may be sedated (given medicine to feel relaxed and sleepy). Some tests require special preparation. You can learn ways to help your child cope at [childrensmercy.org/helpingcope](http://childrensmercy.org/helpingcope).

## **INTEGRATIVE PAIN MANAGEMENT**

There are many ways to help children cope with pain. The Integrative Pain Management team helps children deal with pain using massage, hypnosis, guided imagery, or acupuncture. Their efforts help the child feel less pain, and use less pain medicine. This can lower costs and reduce side effects of medicine. Ask for a referral, or call (816) 983-6750 to make an appointment.

## **MEDICAL RECORDS or HEALTH INFORMATION MANAGEMENT**

You may request a copy of your child's medical records. The Health Information Management (HIM) department is located on the ground floor in the Pink Zone. Hours are Monday through Friday 8 a.m. to 5 p.m.

## **OUTPATIENT PHARMACY AND LAB**

The Outpatient Pharmacy and lab is located on the ground floor of the Hall Family Outpatient Center, near the main entrance to both the hospital and the clinics at 2401 Gillham Road. It is open daily from 7 a.m. to 7 p.m.

The pharmacy accepts Kansas or Missouri Medicaid, most major prescription plans and cash. Call (816) 234-3055 to find out if the pharmacy accepts your plan. For more information, you can go to [childrensmercy.org/Pharmacy](http://childrensmercy.org/Pharmacy).

## **PATIENT PORTAL**

The patient portal, known as MyChildrensMercy, provides access to your child's medical records anywhere you have internet service. You will be able to find information about your child's allergies, immunizations, current medications and lab results. You can also view documents from your child's visits, and make requests to schedule and cancel appointments. To enroll in the Children's Mercy Patient Portal, ask an access representative in a clinic or at the Admissions desk.

# SUPPORT SERVICES

Learn more about support services at [childrensmercy.org/Patients\\_and\\_Families/Support\\_and\\_Services](https://childrensmercy.org/Patients_and_Families/Support_and_Services).

## CHAPLAINCY SERVICES

Hospital chaplains offer spiritual support and counseling to all patients, of all faiths. They can provide religious services or help your own religious leader provide services in the hospital. Chaplains also help when families have to make end-of-life decisions, and provide grief support when a child has an injury, illness, disability or death. Call (816) 234-3317. Tip: if you wish to create a “sacred space” in your child’s room, the chaplain will help you to arrange this and to explain your needs to the hospital staff.

## CHILD LIFE AND MUSIC THERAPY

Child life specialists and music therapists provide services to make the hospital experience easier and more comfortable for patients and families. They try to reduce the stress and worry that may come with being in the hospital or from being ill. They provide health care play, planned music tasks, preparation, procedure support and playgroups. They match these activities to the patient’s age and development. For more information, call (816) 234-3757 or visit the Child Life website at [childrensmercy.org/child-life](https://childrensmercy.org/child-life).

## HOME CARE SERVICES

You will always receive instructions to help you care for your child at home. If specialized care is needed, you may be taught to give that care, such as tube feedings or home dialysis. To help you with some specialized care, nurses and therapists from Children’s Mercy Home Care may visit your home, and will answer your questions by phone any time of day or night.

Learn more about Children’s Mercy Home Care at [childrensmercy.org/home-care](https://childrensmercy.org/home-care) or call the Missouri office at (816) 701-4300 or the Kansas office at (913) 696-8999.

Before setting up home care services, you may want to find out:

- Does your insurance company pay for home care services? (Does it include personal care, nursing care, social work, therapy services and private duty care? Does it pay for hourly care or an in-home visit?)
- Is there a deductible? How much? What home care company can you use? Does your home care company provide durable medical equipment (DME)? (This is equipment such as central line supplies, wheelchairs, etc.)

## INTERPRETERS/SIGN LANGUAGE

You need to talk with your child’s health care team, and understand what they say. When you make an appointment for a doctor or therapist visit, tell the staff if you need an interpreter for a language other than English. If you come to the ER, ask the staff to get an interpreter for you.

## **KREAMER RESOURCE CENTER FOR FAMILIES**

Located on the ground floor of the Pink Zone on the way to the Orbits Cafeteria, this library has medical information in a language you can understand. There are also books and magazines to read for fun. You can use computers, a copier and a fax machine here. The librarian will answer questions by phone, mail and e-mail. Call (816) 234-3900 or go to [childrensmercy.org/Library](http://childrensmercy.org/Library).

## **NUTRITION SERVICES**

Dietitians will work with your doctors to make sure your child gets good nutrition while in the hospital. Good nutrition helps your child grow and develop, and helps your child heal faster after an illness or injury. Nutrition Services also will work with you to teach you how to feed your chronically ill child. Children with diabetes, food allergies, etc., may need special diets. To make an appointment with a dietitian at the Children's Mercy Adele Hall Campus or Children's Mercy Hospital Kansas, call (816) 234-3468.

## **PATIENT ADVOCATE**

If you have questions, concerns, compliments or complaints about your hospital stay or clinic visit, call the Patient Advocate. Dial 53119 from inside the hospital, or (816) 234-3119 from outside the hospital. A patient advocate will listen to you and will work with you to improve services for you and for all families.

## **PALLIATIVE CARE TEAM**

The Palliative Care Team (PaCT) at Children's Mercy provides support for infants, children and adolescents with life-limiting or life-threatening conditions. The team supports the treatment of underlying illnesses while striving to provide the best quality of life possible for our patients. Your doctor can arrange a meeting with this team.

## **RAPID RESPONSE TEAM**

The Rapid Response Team (RRT) is a group of health care providers who can respond quickly to your child's bedside when there is an unexpected change in your child's condition. You can call the RRT at any time if you have an urgent concern about your child's breathing, heart rate, pain or color. The RRT will come to your child's room within 10 minutes. For more information about the RRT, see the information in your child's inpatient room.

## **RONALD MCDONALD HOUSE**

Families who live more than 35 miles away from the greater Kansas City area may be able to stay in the Ronald McDonald House, if space permits. Contact the Children's Mercy Social Work and Community Services department at (816) 234-3670 to arrange a stay while your child is in the hospital. Families are asked to give \$10/night for lodging, but will not be turned away if they cannot pay.

## **SCHOOL**

Children's Mercy provides qualified teachers during the regular school year to inpatients. Bring your child's current books and assignments if possible. Your child can receive credit for school attendance while in the hospital, and will not fall so far behind in schoolwork if you are able to use this service. Call (816) 234-3390.

## **SOCIAL WORK**

This department helps you get community services, financial aid, rooms in the Ronald McDonald House, interpreters, counseling, transportation and much more. Caring for a chronically ill child can be costly, stressful and complicated. Let the social workers help you find the help you need. Office hours are Monday through Friday, 8:30 a.m. to 5 p.m. Phone (816) 234-3670.

## **VASCULAR ACCESS TEAM**

This team of nurses is specially trained in venous (vein) access. They help the physicians and nurses draw blood and start IVs. If your child is going to have IV therapy for longer than a week, they can put in special IVs that can stay in for longer periods of time. This team changes central line IV dressings and can assess any problems that may occur with these lines. If you know your child has difficulty having blood drawn or difficulty having an IV started, you can request the vascular access team.

## **GETTING TO KNOW CHILDREN'S MERCY**

### **CHILDREN'S MERCY: A TEACHING HOSPITAL**

Teaching hospitals are different from other hospitals in many ways. The biggest difference is the number of people who will be in and out of your room.

### **YOUR PHYSICIAN TEAM**

Parents, caregivers and patients are invited to participate in Family Centered Rounds. The health care teams are formed depending on the needs of each child. Sometimes there are many members of the team. There may be:

- Attending physicians and fellows—These are doctors who supervise the whole team.
- Residents—These are doctors who are in their second or third years of the residency program. They supervise the interns and students.
- Interns—These are doctors who are in their first year of the residency program.
- Medical students—These students are still in medical school. They are here to learn and assist the doctors.
- Other team members such as nurses, social workers, dietitians, pharmacists and therapists may join in Family Centered Rounds.

## **USUAL DAILY SCHEDULE**

Family Centered Rounds are usually between 9 a.m. and noon. The team will spend approximately 10 minutes with each patient and family. The family may choose to meet in the hallway outside the room or at the bedside. During rounds, the team will talk with you about your child's:

- medical history
- plan of care
- plan for discharge.

The medical team will also:

- go over your child's past medical history
- ask you about the events of the night before
- review your child's current medical status
- examine your child
- make a plan for the rest of the day
- update the information on the communication board in your child's room.

You are encouraged to ask questions and make decisions together with the team. If you can't attend or prefer not to attend the Family Centered Rounds, tell your child's nurse. They will make sure a member of the medical team meets with you to discuss your child's care and treatment plan.

They may talk with "specialty" doctors (infectious disease specialists, hematologists, pain specialists, etc.). The "specialty" doctors may examine your child again and help answer questions. The team will use the information from these doctors to make decisions about your child's plan of care.

## **AVAILABILITY**

There is always a doctor in the hospital and available to you. However, if it is not an emergency, please know that it may take some time before a doctor can see you. The team may be working on an admission or emergency.

## **CHANGES IN PLAN**

Your child's plan of care may change during the day. Your team may discuss an initial plan with you, but it could change due to new information or a change in your child's condition. You will always be kept informed about your child's plan of care.

## **DAY OF DISCHARGE**

- A member of the team may tell you early in the morning that your child will be going home that day. This is to help you plan on transportation, social work needs, etc.
- The team will talk with you during Family Centered Rounds.

- After rounds, the resident will complete the discharge paperwork, write the prescriptions, discuss any home health care needs and schedule follow-up visits.
- The doctors will try to have your child’s discharge ready as early in the day as possible.
- Your nurse will review the discharge instructions with you before you go home.

## **OTHER PEOPLE WHO MAY BE ON YOUR HEALTH CARE TEAM**

- When your child is in the hospital, emergency department or clinic you might see several doctors. There are many different kinds of doctors. Sometimes, doctors are very specialized and only practice in a specific area. For example, some doctors work on medical problems with bones (orthopedic doctors or orthopedists), hearts (cardiac doctors or cardiologists), or kidneys (renal doctors or nephrologists).
- A medical doctor also is called a physician.
- Sometimes doctors have a more general practice (primary care physician) and help coordinate the specialty care that your child might need. Primary care physicians are usually in an office setting that can be in or next to the hospital, or in a building not connected to a hospital. A pediatrician is a medical doctor who specializes in the care of babies, children and teens, and is often a child’s primary care physician.
- In addition to doctors, your health care team could include many types of nurses, therapists and other health care professionals. Some health care professionals are listed here:
  - » **ALLERGIST**—a medical doctor who treats allergies.
  - » **ANESTHESIOLOGIST**—a medical doctor who gives the patient medicine to keep part or all of the body from feeling pain or other sensation, especially during surgery.
  - » **ATTENDING PHYSICIAN**—the medical doctor who supervises your child’s care and leads the team of health care workers in the hospital.
  - » **AUDIOLOGIST**—a person trained to test hearing and to provide treatment, such as hearing aids, for hearing disorders.
  - » **BOARD-CERTIFIED PHYSICIAN**—a medical doctor is “board certified” if he or she has passed an exam in a medical specialty, usually after several years of study beyond the medical degree.
  - » **CARDIOLOGIST**—a medical doctor who specializes in heart disorders, or the cardiovascular system (heart and blood vessels).

- » **CARDIOVASCULAR SURGEON**—the surgeon who operates on the heart and its blood vessels.
- » **CHAPLAIN**—a hospital chaplain provides spiritual or religious support to hospital patients and their families.
- » **CHILD LIFE SPECIALIST**—a person trained in child development, who prepares children for medical experiences, and helps children play and develop skills while in medical care.
- » **DENTIST**—a health care provider who specializes in the care of teeth and gums. Some dentists or physicians have advanced training in oromaxillary (mouth and jaw) surgery.
- » **DERMATOLOGIST**—a medical doctor who treats skin disorders.
- » **DIETITIAN**—a registered dietitian is specially trained in nutrition and the management of diets. All dietitians at Children’s Mercy are licensed in the states of Kansas and Missouri.
- » **EMERGENCY MEDICINE PHYSICIAN**—a medical doctor who provides emergency care of patients for sudden or severe illness and injury.
- » **ENDOCRINOLOGIST**—a medical doctor who treats disorders of the endocrine system (ductless glands and hormones) such as diabetes, growth disorders, thyroid disorders and sex disorders.
- » **FAMILY PRACTICE PHYSICIAN**—a medical doctor who provides total health care of one person or the whole family, and is trained to care for patients of all ages. They are typically primary care physicians for whole families.
- » **FELLOW**—a medical doctor who is training in a medical specialty.
- » **GASTROENTEROLOGIST**—a medical doctor who treats disorders of the digestive system (stomach, intestines, etc.)
- » **GENETICIST**—a medical doctor who studies genetic or inherited disorders.
- » **HEMATOLOGIST**—a medical doctor who specializes in blood disorders.
- » **HOSPITALIST**—a medical doctor who specializes in the care of hospitalized patients only.
- » **IMMUNOLOGIST**—a medical doctor who treats immune system disorders. The immune system protects the body from infections.

- » **INFECTIOUS DISEASE SPECIALIST**—a medical doctor who treats diseases that are spread from human to human or animal to human.
- » **INTERNAL MEDICINE PHYSICIAN**—a medical doctor who provides care in the office and the hospital for both common and complex illnesses of teens, adults and the elderly. They are also primary care physicians for many patients.
- » **LABORATORY MEDICINE PHYSICIANS, TECHNOLOGISTS AND TECHNICIANS**—in laboratory medicine, substances (blood, tissue, sputum, etc.) from the body are examined outside the patient, usually in a lab. Areas of laboratory medicine include chemistry, cytology, hematology, histology and pathology. Technicians and technologists are trained to do lab tests. Chemists, physicians and other people with advanced training may also work in laboratory medicine.
- » **LIBRARIAN, MEDICAL**—a librarian with special training in collecting, organizing and providing information on medical science and medical care.
- » **MUSIC THERAPIST**—a person trained to use music to lessen fear and discomfort, and to help patients heal.
- » **NEONATOLOGIST**—a medical doctor who specializes in ill newborn and premature babies.
- » **NEPHROLOGIST**—a medical doctor who specializes in kidney disorders.
- » **NEUROLOGIST**—a medical doctor who specializes in the treatment of the nervous system (brain, spinal cord, and nerves throughout the body).
- » **NURSE PRACTITIONER**—a registered nurse with advanced training and skills, also called advanced practice nurses (APN). In some states they can provide primary health care and can prescribe medicines.
- » **NURSE, REGISTERED**—an **RN** is a graduate of a state-approved school of nursing who has passed the NCLEX-RN exam.
- » **NURSE, LICENSED PRACTICAL**—an **LPN** is trained in basic nursing care of patients under the supervision of a registered nurse.

- » **NUTRITIONIST**—person trained in foods and nutrition. All nutritionists at Children’s Mercy are registered dietitians licensed in Kansas and Missouri with special training in children’s nutrition.
- » **OBSTETRICIAN-GYNECOLOGIST**—an **OB/GYN** is a medical doctor who gives medical and surgical care for women. This doctor may be a primary care physician for female patients.
- » **OCCUPATIONAL THERAPIST**—a health care provider who uses activities to treat patients, to promote development, recovery or rehabilitation. For example, teaching disabled children how to feed themselves.
- » **ONCOLOGIST**—a medical doctor who specializes in the treatment of tumors, especially cancer.
- » **OPHTHALMOLOGIST**—a medical doctor who specializes in care of the eyes and vision.
- » **ORTHOPEDIST**—a medical doctor who treats the bones (skeleton) and connective tissues (joints, ligaments, tendons).
- » **OTOLARYNGOLOGIST**—an ENT or ear-nose-throat doctor.
- » **PATHOLOGIST**—a medical doctor who specializes in the study of disease, usually in lab samples like blood, tissue biopsies, sputum, etc. Some pathologists specialize in autopsies (examination of dead bodies).
- » **PATIENT ADVOCATE**—a person who will speak up on behalf of patients and their families with the hospital staff, who will work to improve patient satisfaction with hospital services, and who will help to resolve problems.
- » **PEDIATRICIAN**—a doctor specially trained in the care of babies, children and teenagers.
- » **PHARMACIST**—a person who prepares medicines prescribed by doctors and counsels patients on their use.
- » **PHARMACOLOGIST**—a specialist in the preparation and uses of drugs or medicines.
- » **PHLEBOTOMIST**—a person trained to draw blood.
- » **PHYSICAL THERAPIST**—also called a physiotherapist, is a health care provider who uses physical and mechanical means (exercise, massage, water therapy, electric current therapy, etc.) for recovery and rehabilitation (for better movement).

- » **PHYSICIAN**—any medical doctor who cares for people who are sick in the hospital, clinic or community setting. A medical doctor may have an MD (medical degree in allopathic medicine) or a DO (doctorate of osteopathic medicine) degree.
- » **PLASTIC AND RECONSTRUCTIVE SURGEON**—a medical doctor who repairs or improves the shape and appearance of body structures. For example, a plastic surgeon may operate on a baby with a cleft lip, or may do skin grafts to replace skin damaged by burns.
- » **PRIMARY CARE PHYSICIAN**—a medical doctor who manages a person’s health care over time. A primary care doctor is able to give a wide range of care, including prevention and treatment, and can refer a patient to a specialist. This is your child’s “main” doctor.
- » **PSYCHIATRIST**—a medical doctor who specializes in mental, addictive and emotional disorders. A psychiatrist is qualified to order lab tests and to prescribe medications, evaluate and treat psychological and interpersonal problems, and work with families who are coping with stress, crises and other problems in living.
- » **PSYCHOLOGIST**—a care provider who has advanced training in the study of the mind and behavior.
- » **PULMONOLOGIST**—a medical doctor who specializes in the respiratory (breathing) system, who treats lung problems.
- » **RADIOLOGIST**—a medical doctor who specializes in the use of radioactive substances to diagnose or treat patients. A radiologist uses diagnostic imaging tests such as an X-ray, MRI or CT scan to see pictures of the inside of the body. A radiologist may use radiation to treat the body or even place radioactive materials inside the body (for example, to shrink tumors). These treatments are called therapeutic radiology or nuclear medicine.
- » **RESIDENT OR RESIDENT PHYSICIAN**—a medical doctor at any level in a graduate medical education program, including subspecialty programs. Other terms used to refer to these doctors include interns, house officers, house staff, trainees or fellows. A “fellow” is a physician receiving advanced training in a subspecialty. Residency is the period of training in a specific medical specialty. It occurs after graduation from medical school, and it lasts from three to seven years, depending upon the specialty.

- » **RESPIRATORY THERAPIST**—a person specially trained to treat the respiratory tract to improve breathing.
  - » **RHEUMATOLOGIST**—a medical doctor who specializes in the treatment of connective tissue disorders.
  - » **SOCIAL WORKER**—a member of the hospital staff who counsels patients and their families under stress, helps them deal with financial concerns related to medical care, use of hospital and community resources (such as interpreters, transportation, etc.), and prepares for discharge (going home from the hospital).
  - » **SPEECH-LANGUAGE PATHOLOGIST**—a person specially trained to diagnose and treat speech and language disorders.
  - » **SURGEON**—a medical doctor who repairs or removes part of the body that is injured or diseased. A surgeon performs operations. There are many specialized surgeons. For example, a neurosurgeon operates on the brain and nerves. An orthopedic surgeon operates on bones, joints, muscles, tendons and ligaments.
  - » **SPECIALIST**—all doctors must have residency training in a particular medical specialty, and many go on to advanced training in a particular area of medicine. There are many specialty areas in fields of neonatal (newborn), pediatric (childhood) and adult medicine.
  - » **UROLOGIST**—a medical doctor who treats the urinary tract in males and females, and the male genital tract.
- For more information about what other kinds of health professionals do, and what their qualifications are, see the Occupational Outlook Handbook at [bls.gov/oco](http://bls.gov/oco) or ask your librarian.

## **HEALTH CARE PAPERWORK**

If your child needs to be admitted to the hospital:

- give a current copy of your insurance/Medicaid card to the Admitting department or call (816) 234-3567
- sign the consent for treatment during each admission or visit to an outpatient clinic
- speak to the social worker or financial counselor if you don't have medical insurance or Medicaid.

What you should know about your insurance:

- Find the name, address and telephone number of your insurance company.
- Check the type of coverage you have: HMO, PPO, EPO, POS and indemnity (your insurance company can explain the type of insurance you have).
- What is the deductible you will have to pay?
- Is that deductible for each visit to the inpatient (IP) unit or totaled annually for all IP visits?
- Is that deductible for each visit to the outpatient (OP) area or totaled annually for all OP visits?
- What out-of-pocket money will you be responsible for?
- Do you have to pay a co-payment?
- Is there a lifetime dollar amount that your insurance company will pay for each person? What is that amount?
- Who is your primary care physician (PCP)?
- Do you need a referral from your PCP to see a specialist for inpatient admissions?
- If you have questions regarding your insurance contract, you may contact your employer or call the 1-800 telephone number on the back of your insurance card.



**TIP FOR PARENTS:** You may need copies of custody or guardianship papers to prove that you can give consent for medical care. It will take time and effort to keep all your health care paperwork organized!

## PHARMACY

- What pharmacies (drug stores) can you use?
- Is Children's Mercy an approved pharmacy for your insurance company?
- What is the telephone number of the pharmacy you will use?
- Does that pharmacy have the medications that your child will need? (You will need to call them and tell them the medication your child will be taking at home.)
- Will you have to pay a co-payment for medications? If so, how much?



**TIP FOR PARENTS:** Find out where the 24-hour pharmacy nearest your home is, and if it will take your insurance plan.

## **ABOUT YOUR HOSPITAL BILL**

Customer Service Representatives are available to help you over the phone with any questions or concerns you may have about your statement. Representatives are available Monday through Friday, 8:30 a.m. to 4:30 p.m. Call (816) 701-5100 or toll-free at (866) 572-0157.

- You will receive statements throughout the billing process to keep you informed on the status of your account(s).
- You may receive more than one statement for the same hospital stay. The visits to Children’s Mercy are on a blue statement. The inpatient admissions, surgery, anesthesia and observation physician charges are on a green statement. Home care charges are on a pink statement.
- You are responsible for your bill at the time you receive services. If you have insurance, we will submit a bill to the insurance company for you. You are responsible for any non-covered charges, co-pays, co-insurance, deductible and any other amount not paid by your insurance.
- You can log on to the patient billing website at [childrensmercy.org/PFS](http://childrensmercy.org/PFS) to:
  - » make online payments
  - » set up payment arrangements
  - » look at your account information
  - » tell us about any changes to your address, phone number and insurance information
  - » obtain information about financial assistance.
- You can also pay at the time of service:
  - » in the clinic
  - » at the Outpatient Pharmacy
  - » at the Cashier’s office.
- You can pay by mail.

### **MAKE YOUR CHECK OR MONEY ORDER PAYABLE TO:**

CHILDREN’S MERCY HOSPITAL

### **MAIL TO:**

CHILDREN’S MERCY HOSPITAL P.O. BOX 804435 KANSAS CITY, MO 64108-4435

## **MONEY MATTERS**

Caring for a chronically ill child can be expensive! Get to know your health insurance plan and what it covers. If your insurance plan denies your claim for payment, you can appeal the decision. To contest or argue a denial, refer to your insurance plan. For example, say “according to paragraph two, laboratory costs are covered. So you should pay for my child’s blood tests.”

Your doctor may be able to help with a letter that explains why the tests, procedures or other medical care were needed.

Contesting a denied claim can take time and energy and many phone calls and letters. Large employers may have a benefits specialist who helps employees talk with the health insurer. This person may be able to help you with a claim. Check with your employer’s Human Resources department.

For help and advice regarding insurance, keeping your job and managing a debt crisis, you may also contact the Patient Advocate Foundation ([patientadvocate.org](http://patientadvocate.org)) or call (800) 532-5274. Other information about disputing an insurance claim or denial of service can be found in A Consumer Guide to Handling Disputes with Your Employer or Private Health Plan (Kaiser Family Foundation/Consumers Union) at [kff.org/consumerguide/7350.cfm](http://kff.org/consumerguide/7350.cfm).

For more information about Medicaid, see the Centers for Medicare and Medicaid Services at [cms.hhs.gov/home/medicaid.asp](http://cms.hhs.gov/home/medicaid.asp).

Children’s Mercy is committed to serving all children regardless of their family’s ability to pay. We participate in most insurance plans. Please contact your insurance or managed care provider to verify coverage by your specific plan. For families who do not have an insurance or managed care plan, our Admissions Department is available to assist with on-site enrollment for financial assistance. Individuals with limited resources or income may call (816) 234-3567 to find out if they are eligible for public assistance.

The Social Work and Community Services department can also help you find financial assistance and low-cost services for your child. Call (816) 234-3670 to speak with a clinical social worker.

MedlinePlus provides an overview of financial assistance programs at [nlm.nih.gov/medlineplus/financialassistance.html](http://nlm.nih.gov/medlineplus/financialassistance.html).

Medicine can be very expensive. If your health insurance includes a mail order pharmacy service, this may save you money on medicines your child takes often.



**TIP FOR PARENTS:** If you buy prescription medicine or “over-the-counter” (nonprescription) medicine for your child from a pharmacy in your neighborhood, shop around! Prices are not always the same from one pharmacy to another, or from one time to another. Call ahead and ask for prices before you buy; you may save hundreds of dollars a year this way.

“Medical care is really expensive—if I didn’t have Medicaid I couldn’t do anything. Be prepared to spend the time to fill out all the paperwork.”

“Medicaid transportation and gas reimbursement really helps. You have to wait for awhile for transportation to come.”

Patient assistance programs run by drug manufacturers give free medications to qualified patients. You can find a listing of Patient Assistance Programs (PAPs) from state governments and drug companies at [pparx.org/](http://pparx.org/) (also in Spanish at [pparx.org/es](http://pparx.org/es)) or call 1 (888) 477-2669.

## TIPS

### TIPS FOR PARENTS: COPING WITH THE HEALTH CARE EXPERIENCE

- Be honest and talk with your child about what to expect. Children have active imaginations. If they do not have enough information, they will make up a story to fill in the gaps.
- Help your child express his or her feelings. This can be done in a safe way by making up a story, playing pretend or drawing a picture.
- Remember it gives your child comfort to have you there.
- Your touch can offer your child warmth and security. Rocking your infant, and stroking and cuddling children of all ages gives comfort.
- Bring familiar objects from home to the hospital (favorite toy, stuffed animal, pillow, photos of the family or pets, etc.). Maintain normal family rules. Don’t allow too many gifts. Try to keep your usual routines and limits when your child is in the hospital.
- Allow your child to have choices when possible (what to wear, what activity to do, choice of movie to watch or music to listen to, etc.).
- Praise your child for what he or she is doing well. For example, if your child is holding still during a procedure, say what a good job he or she is doing.
- Let your child know that it is all right to cry. Crying helps some children cope.
- Include brothers and sisters as much as possible.
- Gather information from your child’s doctor and health care team. You may want to write questions for your doctor or nurse in a notebook.
- Spend time with your child, but take time for yourself to eat, sleep and relax.
- Remember to let your child know when you are leaving the hospital and when you will come back.

To see pictures of comfort positions, go to [childrensmemory.org/comfortpositions](http://childrensmemory.org/comfortpositions).

## **HELPING YOUR CHILD COPE WITH MEDICAL TESTS**

When your child is in the hospital, he or she may have unfamiliar medical tests and procedures. You and your child's nurse or child life specialist can make these tests and procedures less stressful for your child. The following ideas will help your child cope with procedures. Use these ideas at bedside during blood draws, injections, taking your child's temperature or blood pressure, or any other procedure.

### **INFANTS (0 to 2 YEARS)**

Distract your infant or toddler with bubbles, cause-and-effect toys, pop-up toys, light-up items, toys with different sounds and tones, playing peek-a-boo, use of a bottle or pacifier, or nurse your baby. Relax your child with the use of a rhythmic voice, soft music, gentle touch and massage, and holding your child in your arms or lap during medical tests when you can. Ask about "comfort positions." Prepare your child by pretending to do the procedure on your child's favorite stuffed animal or doll. For example, pretend to take the doll's temperature or blood pressure.

### **PRESCHOOLERS (2 to 5 YEARS)**

To distract your child, you might let him or her blow bubbles or a pinwheel, sing a song, act out a story or talk with you.

Relax your child with storytelling, talking about a favorite activity, listening to music, dimming the lights and holding your child on your lap. Ask about "comfort positions."

Children this age see themselves as the cause of all events. Let your child know that he or she did nothing to "cause" the illness or injury, and that "pokes" or painful procedures are not a punishment for bad behavior.

Give your child a truthful, simple explanation of what is going to happen, so that he or she does not misunderstand or develop unrealistic fears of the procedure.

Visual aids help to teach your child about medical tests and procedures. The Child Life Department has photo teaching books such as radiology (photos of CT and MRI) and surgery (photos of the operating room).

Charts with stickers can help children get used to the routine of getting "pokes" or other procedures that happen often when your child is in the hospital. Give your child choices when you can. Teach him or her that there are no choices about certain medical tests, but he or she can choose whether to sit up or lie down during a blood draw, or can choose which book to read after getting an injection.

### **SCHOOL AGE (5 to 12 YEARS)**

Distract your child with the use of search and find books (I Spy, for example), pop-up books, glitter wands or a favorite music recording.

Help your child relax with deep breathing, blowing bubbles, a pinwheel, a feather or rhythmic breathing.

Encourage your child to ask questions and express feelings about the hospital or diagnosis. Answer questions honestly and help your child work through his or her feelings.

Let your child know that it is okay to feel mad or frustrated, and when your child is frustrated with his or her illness or injury, ask, "What can I do to make today better for you?"

### **TEEN (13 to 19 YEARS)**

Allow your teen to be involved in care and decisions.

Encourage your teen to stay involved with friends and classmates when he or she can.

Help your teen learn to relax during tests and procedures. Your teen can use music, a comfortable place, deep breathing, or imagining a favorite place or activity to feel relaxed.

Tell your teen the reason for procedures and exactly what is going to happen.

Although teens are becoming more independent, they still need your support.



### **TIPS FOR PARENTS:**

#### **WHAT TO BRING TO THE HOSPITAL FOR YOUR CHILD'S OVERNIGHT STAY**

- Favorite blanket or pillow
- Special pictures of family and friends
- Special toy, game, music or videos, stuffed animal
- Pacifier for younger child
- Toothbrush and toothpaste
- Pajamas, robe, slippers and socks
- Books or magazines
- Remember to pack a bag for yourself and bring contact information for friends/family or other people you may need to contact while at the hospital!

### **PREPARING YOUR CHILD FOR THE HOSPITAL**

- Prepare yourself first. Ask your child's doctor any questions or concerns you have about hospitalization.
- You know your child best, so talk with him/her about the hospital in terms he/she will understand and that are non-threatening. Be honest.
- Explain to your child why he/she is coming to the hospital and what will happen there. Younger children should be told no more than three days before they come to the hospital. Older school-age children or teens can be told up to a few weeks before.

- Read books about going to the hospital. Find these books at your local library or in the Kreamer Resource Center for Families.
- Play is a good way to prepare your child for the hospital. Give a younger child a play medical kit. Your child can use medical equipment on a stuffed animal or doll. Ask questions about how your child feels about the equipment so you can clear up any misconceptions.
- Make sure your child knows that being in the hospital is not a punishment and everyone is there to help him/her. Help your child express his/her feelings by talking about what is going on or by answering questions.

### **PREPARING FOR SAME DAY SURGERY**

- If needed, bring medical history, latest physical, X-rays and test results.
- If needed, bring any legal papers about the patient's guardianship.
- Bring a stuffed animal that can be with your child during the surgery or procedure. You may want to bring headphones and music, or handheld games.
- Bring a pacifier, if a pacifier soothes your young child.
- Bring your favorite books or magazines to read while you are waiting.
- Bring a list of your child's medications and information about how much medicine your child takes and how often.
- Make a list of your questions for the nurses, doctors and anesthesiologists.

A nurse will call with dates, times and instructions. The nurse will tell you that your child cannot eat or drink after a certain time.

This call will be made at least one business day before your child's surgery. During that time, feel free to ask any questions you have about the upcoming surgery.

On the day of surgery, there will be several steps to your visit, including:

- You will check in your child and fill out needed paperwork when you arrive at the Same Day Surgery area.
- A nurse will check your child's "vitals," which include height, weight, blood pressure and temperature.
- You and your child will meet with an anesthesiologist.
- While your child is in surgery you will wait in a waiting room.

When your child's surgery is complete, your child will wake up in the recovery room. You will see your child when he/she moves to the post-op area or is transported to an inpatient room.

## **HOW TO KEEP YOUR CHILD CALM AND COMFORTABLE**

- Stay calm and comfortable yourself. If you look scared and anxious, your child will be scared and anxious. Take a few deep breaths to calm yourself. Let your child know you are there to help him/her feel better.
- Focus on what feels good, not on what hurts.  
“I wonder how good it will feel to eat some of your favorite foods.”  
“It feels good to watch your favorite video and laugh.”  
“You can feel better knowing that we are here with you.”
- Read stories or sing songs with your child. Our minds cannot do two things at the same time. If your child is thinking about a favorite place or thing, she cannot focus on pain. If your child is singing a song or reading a story, he is not thinking about how much he hurts. Jokes and funny stories are good—laughter is good medicine!
- Try gentle massage. Rubbing your child’s muscles will help him/her to relax. Holding and cuddling makes your child feel safe and comfortable.
- Practice relaxation techniques together. Learn some basic breathing techniques to help you and your child relax. Then do them together!

## **HELPING YOUR CHILD WITH NEEDLE STICKS**

Tips to help your child with the fear and discomfort of blood draws and IVs:

- Ask if the procedure can be done in the treatment room. This will limit the painful procedures at your child’s bedside.
- Ask if numbing cream or cold spray can be used to numb the area first.
- Let the doctor and/or nurse know if your child has had difficulty with IVs in the past. Ask if the Vascular Access team can be called.
- Ask if a child life specialist can help with your child’s fears.
- Let the nurse know if your child is right or left-handed.
- Be honest with your child and use words your child will understand to explain what is going to happen.

## **HELPING SIBLINGS COPE WITH THE HEALTH CARE EXPERIENCE**

Brothers and sisters of the hospitalized child need information. Although you may want to protect your children, what siblings imagine about their brother or sister could be far more frightening than the reality. You know your children best and how they cope with change. Decide how much you want to tell them. Be honest and allow siblings to ask questions.

Before a sister or brother visits the hospital for the first time, make sure the sibling understands what the hospital is and what nurses and doctors do. Explain what the child might see. Read a storybook about going to the hospital. A child life specialist can help.

When siblings cannot visit the hospital, they can send drawings, letters, photos and home videos.

Maintain a normal routine as much as you can. Send your child to school and other normal activities. Parents and siblings should spend time together away from the hospital.

Siblings have many different feelings when a brother or sister is in the hospital. This is normal. These feelings may include:

- **GUILT**  
Siblings may feel responsible for the hospitalization. They may think that something they did or said caused the illness or injury to happen.
- **FEAR**  
Siblings may worry that their brother's or sister's illness or injury will happen to them.
- **JEALOUSY**  
Siblings may feel left out when the hospitalized child receives more care and attention from other family members.
- **ANGER**  
Siblings may be angry or upset about the changes at home and in their normal daily routine.
- **NEGLECT**  
Siblings may feel that their parent or guardian no longer loves or cares for them when more time is spent with the hospitalized child.



# SAFETY

Children's Mercy wants to provide you the opportunity to share and engage as active members in your child's health care plan. Patients and family members are encouraged to speak up and identify things that aren't working right, which will lead to better and safer care. Here are some tips from Solutions for Patient Safety to help you advocate for your child:

- Ask questions about your child's care.
- Share unique things about your child because you know your child best.
- Wash your hands, your child's hands and remind care providers to wash their hands.
- Learn about the medications your child is taking.
- Know who to contact if you have any questions.

For more information go to the Children's Mercy website at [childrensmercy.org/ChildhoodSafety](http://childrensmercy.org/ChildhoodSafety).

## **YOU CAN HELP PREVENT MEDICAL ERRORS**

Make sure all your child's caregivers (babysitters, grandparents, etc.) know what medicines, vitamins and herbs your child takes, with the correct dose and schedule. Make sure they all know what foods are not allowed and when to call the doctor.

In the hospital, be sure those who care for your child wash their hands. Wash your own hands often. Hand washing prevents the spread of infections!

If your child is having surgery, make sure that you, the doctors and the surgeons all agree on exactly what is to be done.

Speak up if you have questions or concerns. Teach your child to speak up also. If your child usually gets a blue pill, but the nurse or babysitter brings a red pill, your child should tell them about it.

Make sure you know who is in charge of your child's care, especially in the hospital.

Ask why each test or procedure is being done, and ask when test results will be available.

Ask a family member or friend to be your child's advocate if you can't be there. This is someone to keep track of your child's care, check that your child gets the right medicines and ask questions.

Learn all you can about your child's condition. Talk to the doctors and nurses. Visit the Kreamer Resource Center for Families. Be involved in your child's care.

## **KEEPING A SYMPTOMS DIARY**

If your child is having problems, you can help the doctor figure out the cause by keeping a diary. This is just a record of what happens, when it happens, and what happens just before or afterward. After a few days, a pattern may appear.

For example, a child may get “tummy aches” after starting a new medicine, after eating anything with wheat in it, before going to school or right before mealtimes. Once you see the pattern, you may suspect a drug side effect, food intolerance, worries about school or hunger pangs!

Show the diary to your doctor. Figure it out together!

## **ORGANIZING YOUR CHILD’S MEDICAL INFORMATION**

There are many ways to get organized. Choose a way that will help you keep the information you need, when you need it.

The simplest is a notebook with pages where you can list appointments, medications, notes, and questions about your child’s health and behavior. Keep a list of procedures, hospital admissions and surgeries. There should also be a pocket or page with business cards, and contact names and numbers for health services providers and insurance providers.

The Kreamer Resource Center for Families librarian can help you find good articles about your child’s condition, and sample letters to explain your child’s condition to teachers, babysitters, coaches, etc. You can carry this notebook with you every time you visit the doctor, the ER, the hospital, the dentist, etc.

You should carry this notebook in the car when you travel in case you must see a doctor in another city. Take a moment to update this notebook during or just after every doctor visit. You can also ask your doctor or nurse to write down instructions in your notebook.

Over time, you may have several notebooks; one for your child’s first year or two, another for preschool years, another for grade school years, etc. As your child learns to read and write, he/she may want to add notes to this notebook as well. As a teenager, your child may want to take responsibility for updating some pages and keeping track of appointments.

Sample pages can be found at the end of this book.

Some families prefer an electronic record, and keep lists of medications and contact numbers for their doctors in their laptop or computer. Some families may use a secure, online health record. Your child’s medical records are also available through the Children’s Mercy Patient Portal at [childrensmercy.org/PatientPortal](http://childrensmercy.org/PatientPortal).

## **SAFETY TIPS**

- Know what tests are being done, why they are being done and when the results will be ready.
- Ask for reports of all lab and imaging tests, such as CT scans, MRIs and ultrasounds. If you don't understand something in a report, ask for an explanation. Make a note of any follow-up suggested in a report—see that it is followed up!
- Ask that you be sent a copy whenever a specialist communicates with your primary doctor.
- Carry an up-to-date list of all medications and dosages with you at all times. Your list should include the name of the medication, the concentration (100mg/5ml), the dose or amount you are giving, and how often you are giving the medication. You should also know any food or drug allergies when you give this list to your doctor, nurse or pharmacist.



### **TIPS FROM PARENTS:**

"I keep a notebook on my child with appointments, meds, blood pressure, etc. I always carry it."

"Use your phone to take pictures of your medicine bottles so you will always have the correct names and dosages easily available. You can also use the pictures to request refills."

"Keep calendars and list everything (meds, appointments, etc.) or you will forget something. The medication charts I was given really helped. They told when and how much medicine to give him."

### **TIPS:**

Every time you talk to your doctor, nurse, or pharmacist, ask these three questions:

1. What is my child's main problem?
2. What do I need to do?
3. Why is it important for me to do this?

### **MEDICATION SAFETY TIPS:**

- If your child's medication is different from what he received before (different color, size, amount or form) – ask the health care provider or pharmacist to double check the medication.
- Make sure your child's health care provider checks your child's identity (ID hospital bracelet) before giving your child any medication.
- Know the side effects of the medication. Information on medication side effects can be found in the information received with prescriptions,

through the Kreamer Resource Center for Families, or by asking your health care provider or pharmacist.

- Know how to give your child's medication. (See "Important Questions to Ask.")
- Know who to contact with concerns or questions about the medication your child is taking.
- Notify your child's health care provider **IMMEDIATELY** if you think your child is having a reaction to a medication. Do not give your child more medicine until you talk to your child's health care provider.
- Have your child's health care provider update your child's medication list as often as needed. (List reason for taking the medication, the amount, how it needs to be given and how often.)

If you have any questions or concerns, always call your child's health care provider or:

**Children's Mercy Nurse Advice Line:** (816) 234-3188

**Poison Control:** 1 (800) 222-1222

### **IMPORTANT QUESTIONS TO ASK**

Ask both your child's health care provider when the medication is prescribed and the pharmacist when you receive the medication at the pharmacy:

- What is the name of the medication?
- What is the medication for?
- How many times a day is my child supposed to take the medication?
- How many days should my child take this medication?
- What side effects are likely? What do I do if they occur?
- Is this medication safe for my child to take with other medications, herbal products or dietary supplements?
- What food, drink or activities should my child avoid while taking this medication?
- Is the dose of this medication right for my child based on his age and weight?
- What should I do if my child does not improve?

## WEB RESOURCES FOR MORE INFORMATION

[nlm.nih.gov/medlineplus/druginformation.html](http://nlm.nih.gov/medlineplus/druginformation.html)

[kidshealth.org/parent/system/medicine/medication\\_safety.html](http://kidshealth.org/parent/system/medicine/medication_safety.html)

<http://www.fda.gov/ForConsumers/default.htm>

<http://www.healthychildren.org/English/safety-prevention/at-home/medication-safety/Pages/default.aspx>

[ismp.org/newsletters/consumer/default.asp](http://ismp.org/newsletters/consumer/default.asp)

[bemedwise.org](http://bemedwise.org)

## SAFETY IN AND AROUND THE CAR

Protecting your child in a motor vehicle crash starts with keeping your child restrained in a “safe” car seat or a booster seat until they are tall enough so that the lap shoulder seat belt “fits.” Most crashes occur to the front of the vehicle ... make sure that your child is behind the driver!



A safe car seat is one that has not been in a crash, is less than six years old, and has not been recalled by the manufacturer and “fits” your child – the child’s weight and height are within the manufacturer’s recommendations (check the label for sizing information and date of manufacture).

- Children less than 2 years old are best protected in a car seat that “fits” – the harness is positioned at or below the shoulders and is installed in the car using either the seat belt or the lower anchors in a rear facing direction. The harness should be “snug.” You should not be able to “pinch” the webbing once you have tightened down the harness. The chest retainer clip should be positioned at the arm pit level. Children are best protected when they are riding rear facing.
- Children should remain in a car seat with a harness until they have outgrown the sizing recommendations (check the label). The car seat should be installed behind the driver using either the lap shoulder seat belt or the lower anchors and top tether (LATCH). Check the car seat and vehicle owner’s manual for installation information.

- Children should be restrained using a belt positioning booster (BPB) once they are too big for the car seat with a harness. They should use the BPB until they “fit” the adult lap/shoulder seat belt – about 57 inches tall.
- To protect your child from accidentally being run over, make sure that you always lock the car doors when exiting the car ... and walk around the car to make sure that no one is behind or in front of the car.

Every year, children die in hot cars. When you are busy and distracted, you might forget that your child is still inside. Always check the back seat before locking your car doors. Put your cell phone and/or your purse or wallet in the back seat, to remind you. Ask your child care provider to call you if your child does not arrive as expected, or set your watch or schedule to remind you to check on your child at day care. You can also buy alarm pads for the car seat that will alert you if your child is sitting in a hot car.

Turn off or silence your cell phone while you are driving so that you won't be tempted to answer it or become distracted if it rings. Calls can wait ... life doesn't.

If you would like to have your child's car seat checked, please call our office for an appointment: (816) 234-1607 or locate the nearest certified child passenger safety technician at [safercar.gov/cpsApp/cps/index.htm](http://safercar.gov/cpsApp/cps/index.htm). For more information, please visit the National Highway Traffic Safety Administration webpage: [safercar.gov/parents/home.htm](http://safercar.gov/parents/home.htm).

Thanks and buckle up each and every ride!



**TIP FOR PARENTS:** If your child is dependent on technology (uses a ventilator, home dialysis, etc.) or is unable to move around easily and has grown too big for you to easily lift, be sure to register your home with your local utility companies and fire department. If there is a power failure, a fire or other rescue, they will know that your home needs special service.



# FAMILIES COPING WITH ILLNESS

## THE PATIENT

Maintain age-appropriate expectations. After a day or two of letting your children get away with things, they lose their feeling of safety. All consistency and rules are gone and this makes them feel insecure. It also sends a message that things are so bad and that parents are so worried they think the child might die. Changing all the rules makes them feel less secure.

If you don't expect good behavior from your child, you might cure or manage the disease, but your child will have behavior problems. Stick to family rules about how to behave. Maintain your own standards as well. When you get up in the morning, at home or in the hospital, get dressed, wash your face, brush your teeth and comb your hair. It is important to your children to see that even when your child is ill, you are still living your life and trying to have a normal day. If you give up on your normal routine and personal grooming, this may frighten your children.



### TIPS FROM PARENTS:

"Parents have to set rules—don't excuse them because they are ill. The kid may need some time away from the parent. He may need to develop some independence."

"Try to establish a routine at the hospital (granted it will be different from home, but make this your home away from home). Get out of the room as much as possible. Walk and see other people. Engage in conversations about non-medical issues, even with strangers if the opportunity presents itself. Go outside!!! Take advantage of the support and programs the hospital offers."

## SIBLINGS

Try to keep the patient's brothers and sisters (siblings) in a fairly normal routine. Do include them as much as their ages allow. Ask the 5- or 6-year-olds (and older) if they want to visit the hospital. If you shield them too much and don't answer questions, they will imagine the worst.

## FAMILY STORIES

"Very soon after my daughter's premature (C-Section) delivery, I was advised to be very careful in requesting help from her brothers, then ages 2 and 5. The thought was that, if they were to see me struggle to care for her, they would offer to help on their own. Amazingly, they did! In this way, they have never resented their sister, and they take joy and pride in being allowed to help."

"Let siblings know what is going on, so they don't feel left out. Give them attention, too. Let them know they are loved. This can be hard to do when so much time and attention is needed by the ill child."

"When both kids have cystic fibrosis, it is important to explain to the non-hospitalized child what is happening. Don't keep them in the dark. Ask if the sibling can visit the hospitalized child."

## **WHAT TO SAY TO THE CHILDREN**

If they are ready to ask questions, they are ready to get answers. If your children signal that they don't want to know, respect that. Let the child guide you.

For both the patient and siblings, give the children plenty of chances to ask questions but don't probe and push.

## **MARRIAGE**

Communication is the key. This is one of the hardest things a marriage will have to endure. Parents may cope in different ways; one may cope by talking, expressing emotions, etc., while the other may try to distract himself or herself by mowing the lawn. Respect each other's differences and talk to each other. This isn't the time to change your partner's coping style. Support each other.



### **TIPS FROM PARENTS:**

"Take time out for you and your spouse. Help each other."

"Lean on each other. Be supportive, but don't forget to take a break and do some leaning, too. Know that what is happening now isn't forever – and there will come a time that you can focus on each other and make up for lost time."

## **RELATIVES AND FRIENDS**

They can be a great support, or they can complicate an already difficult situation. It is up to you to decide what to tell them and when. Blended families and divided custody can complicate the situation further. Try to keep the best interests of your child in mind.



### **TIPS FROM PARENTS:**

"Don't hesitate to ask for help, and don't hesitate to inform others of overstepping boundaries. Sometimes assigning tasks for certain individuals can take pressure off you, and really give others a sense of participating and helping when they feel out-of-the-loop and helpless."

"Get all the information you can before you talk to others, then think about how you can explain it. You can't worry about those who don't understand; you have enough to deal with."

"Say yes when people offer to help!"

## **WORK LIFE**

Parenting a chronically ill child can be a full-time job all by itself. You will be challenged to manage a paying job and family responsibilities, but some people are lucky enough to get both emotional and financial support from their employers and co-workers.



### **TIPS FROM PARENTS:**

"I don't work at this time. When I worked and went to school, it was important to talk to teachers and to my boss about my situation. The kids come first."

## CAREGIVING

It will be a challenge to care for your child in and out of the hospital, especially while you try to care for the rest of your family, your job, your home, etc. Don't forget to take care of yourself! For additional information about caregivers, see:

**Medlineplus on Caregivers:** [medlineplus.gov/caregivers.html](https://medlineplus.gov/caregivers.html)

**Family Caregiver Alliance:** (English, Spanish, Chinese)

[caregiver.org/programs-and-services-overview](https://caregiver.org/programs-and-services-overview)

**Caregiver Action Network:** [caregiveraction.org/](https://caregiveraction.org/)

**National Alliance for Caregiving:** [caregiving.org](https://caregiving.org)



### TIPS FROM PARENTS:

"Take care of yourself too. If you don't take care of yourself you can't take care of them."

"Care giving is not easy—it is stressful. The doctors and nurses here are really good. They helped me through the process [of providing medical care in the home]."

"Ask tough questions—and prepare yourself for the answers. Be patient—but not too much."

"Be active! You are your child's parent, but also his/her advocate, voice, support. Never give up."

### WHEN YOUR CHILD WAS FIRST DIAGNOSED, WHAT DID YOU LEARN THAT HELPED YOU THE MOST?

"I didn't learn a lot at once. I have learned things gradually about IEPs, doctors, etc., but it takes time to process it all."

"Develop a relationship with the main caretakers of your child. You will rely on these people for a lot of needs and having a working relationship is key."

"You have to educate yourself. Be active and seek advice, help and use any resource available (over time, pace yourself and focus on one piece of the puzzle at a time)."

### NOW THAT YOU HAVE BEEN CARING FOR A CHRONICALLY ILL CHILD FOR A WHILE, WHAT HAS THIS EXPERIENCE TAUGHT YOU ABOUT MEDICAL CARE?

"You have to be on top of it, or you end up in the hospital."

"If you live a long ways away, know your route—you will be driving it often—avoid construction."

"Don't be afraid to ask questions and to write everything down."

“It is truly a practice, and through trial and error we all learn. Experience, knowledge and compassion are equally important. Nurses, doctors, staff, etc., are humans, capable of mistakes, but they are usually dedicated and trying to do their best. Learn to forgive.”

### **TIPS FROM PARENTS:**

“If you’re in the hospital for a couple of weeks, make sure you get out (of the room, of the hospital) when you can.”

“For clinic visits, the doctor might be running late so be prepared, bring stuff to do.”

“In the hospital, remember that nurses have other patients and cannot always be there in an instant.”

“Check that the meds are right! Stay on top of this to prevent errors.”

### **TRAVELING WITH A CHRONICALLY ILL CHILD**

PREPARE ! PREPARE! PREPARE!

### **SHORT MEDICAL RECORD**

Have a brief record of your child’s medical condition, including diagnosis, list of medications with doses and schedule, contact information (names and phone numbers) for your child’s doctors, health insurance card, and any other critical information you might need to share with ER staff members or a doctor. You may need to carry a copy of prescriptions or a doctor’s letter for medical equipment as well.

### **EQUIPMENT AND SUPPLIES**

Before the trip, have medical equipment serviced to be sure it is working correctly. You may want to carry extra batteries, tubing, syringes, filters, spare parts, a screwdriver or other supplies depending on your needs.

### **DISCUSS WITH YOUR DOCTOR**

Before traveling abroad, camping outdoors or taking a fragile child on a challenging trip, discuss preparations with your doctor.

### **PLAN FOR EMERGENCY CARE**

Before a long road trip, you may want to make a list of hospitals and their phone numbers along your route, especially those that have emergency rooms or that specialize in children. Before traveling outside the country, you may want to have emergency phone numbers for English-speaking doctors.

### **SEEKING HEALTH CARE ABROAD**

#### **CDC**

Find more travelers’ health information, especially for traveling outside the country, at [wwwnc.cdc.gov/travel](http://wwwnc.cdc.gov/travel).

## **AIRLINE SEATS**

Ask for bulkhead seating to have more space to maneuver a disabled child. These seats face a blank wall rather than another row of seats. If bulkhead seating is not available, an aisle seat as close to the front of the plane as possible (not on an emergency exit row) is best. Forearm or collapsible crutches can fit under a seat or in overhead storage. Longer crutches will be stored by the crew.

Dry cell batteries are best for air travel, as wet cell batteries will have to be disconnected and stored separately. If you must transport any kind of large medical equipment, such as a power scooter, be sure to attach a copy of assembly instructions and keep a copy with you. The baggage handlers may take it apart to stow it in the hold of the plane.

Don't check your medicines with your other luggage!

## **ACCOMMODATIONS**

Be sure to mention any special needs when reserving tickets, hotels, meals, etc. Ask for what you need. Can the airport-to-hotel shuttle carry people in wheelchairs? Is there a shower seat in the bathroom? Can the restaurant provide food on your child's diet? If staying with relatives or friends be specific about what you will need. They may not realize what it takes to care for your child and to provide a safe visit for your family.

Travel advice for people with medical conditions going through Transportation Security Administration screening [tsa.gov/traveler-information/](http://tsa.gov/traveler-information/)

General travel health information [medlineplus.gov/travelershealth.html](http://medlineplus.gov/travelershealth.html)

AAA and many other travel agencies list accommodations for special needs travelers, and there are some travel agencies that specialize in planning trips for people with disabilities or health restrictions. Some popular vacation destinations, such as Disney World, offer special accommodations for visitors with special needs. Ask for what you need!

## **SUPPORT**

### **KEEPING IN TOUCH – Cards for Patients**

When your child is in the hospital, family and friends can create and send a personalized card to them through the Children's Mercy website. The card that is created will be printed and hand delivered to their room by one of our hospital volunteers. To make a card, go to [childrensmercy.org/patientcards](http://childrensmercy.org/patientcards).

There are free websites to help family and friends share encouragement, compassion and love. Here are a couple of sites:

Caring Bridge [caringbridge.org](http://caringbridge.org).

Lotsa Helping Hands [lotsahelpinghands.com](http://lotsahelpinghands.com).



**TIP FOR PARENTS:** For added security, when creating any web page, do not title it with your child's full name. Instead, call it something like "John's Journey."

## **CREATING A JOURNAL OR A DIARY**

Many studies show that writing about what happens to you and how you feel about those events helps you feel better. As a parent of a chronically ill child, it may help you to keep a journal or diary. An ill child or a sibling of that child may want to keep a journal also. Scrapbooks can mix journal writing with pictures. Younger children may prefer scrapbooks.

Writing can be therapy if you write about distressing events, such as the day you were told of a diagnosis, or the time you had to rush to the Emergency Room. For best results, write for at least 20 minutes a day for four days in a row. Don't worry about spelling or grammar; just get your story out.

Focus on what bothers you most. Your journal is private, so feel free to express your deepest thoughts and feelings. Write about the same event several times. Each time you put the event and your feelings about it into words, you will understand it better and feel more in control. When you finish writing each day, read over what you have written.

To learn more about the therapeutic effects of journaling or "expressive writing," read:

**Writing to Heal** by James W. Pennebaker, PhD

**The Writing Cure** by Joshua M. Smyth, PhD

**Journal Writing:** A Short Course at [journaltherapy.com/journaltherapy/journal-cafe-3/journal-course](http://journaltherapy.com/journaltherapy/journal-cafe-3/journal-course)

## **WHERE TO FIND SUPPORT**

You might want to meet other families who have ill children. You can share emotional support. You can get practical advice and information (such as, where can I find a babysitter who can reliably follow my child's diet and medication plan?). Some health professionals in Children's Mercy participate in a support group, or in summer camps for chronically ill children (for example, Camp Diastole for children with congenital heart defects). Ask your health care team if they have such a group. The librarian at the Kreamer Resource Center for Families can help you locate organizations worldwide, or local chapters of national organizations for children with your child's diagnosis.

Children's Mercy has parents on staff who are Family Centered Care Coordinators. They make up the Family Centered Care Team and are available Monday through Friday. Family Time is a program led by Family Centered Care Coordinators on inpatient units. This program gives parents a chance to take a break, grab a quick snack and connect with other parents.

Parents Offering Parent Support (POPS) is a parent peer mentoring program. Families can request a trained parent mentor who has been through similar experiences. Call (816) 983-6957 for more information.

The Hematology/Oncology Department offers a Parent-to-Parent program which includes on-site activities as well as support via phone or email. For information, contact the Parent-to-Parent Coordinator at (816) 234-3254.

## **WHERE TO GET INFORMATION**

The first place to get information about your child's specific condition is from your doctors. Ask questions! Write down what is said, and what you want to ask. If you don't know how to spell a diagnosis, medication or procedure, ask the doctor or nurse to write it down.

The librarian in the Kreamer Resource Center for Families will help you get books, articles, videos and pictures about an illness, medicine or procedure. You can get information about your child's illness to share with your family, your child's teachers and other people.

If you cannot come to the Kreamer Resource Center for Families, the librarian will mail, email or fax information. Call (816) 234-3900 or go to [childrensmercy.org/AskALibrarian](http://childrensmercy.org/AskALibrarian). Books and videos (VHS or DVD) can also be borrowed from your local public library.

Some books to consider:

### **Your Child in the Hospital: A Practical Guide for Parents**

by Nancy Keene and Rachel Prentice

### **Coping with Your Child's Chronic Illness**

by Alesia T. Barrett Singer

### **Chronically Happy: Joyful Living in Spite of Chronic Illness**

by Lori Hartwell

### **Shelter from the Storm: Caring for a Child with a Life-threatening Condition**

by Joanne Hilden, Daniel R. Tobin, and Karen Lindsey.

### **Making Informed Medical Decisions**

by Nancy Oster, Lucy Thomas and Darol Joseff

### **Navigating the Health Care Maze, 2009**

by Jeff Knott

### **100 Questions & Answers about Communicating with Your Health Care Provider, 2009**

by John A. King and Cynthia R. King

### **A Guide to Getting the Best Health Care for Your Child**

by Roy Benaroch

## **The Take-charge Patient: How You Can Get the Best Medical Care**

by Martine Ehrenclou

## **Doctor, Your Patient Will See You Now**

by Steven Kussin

# **COMMUNITY RESOURCES**

## **ACCESSIBLE ARTS**

Art programs for children with disabilities.

Call (913) 281-1133

[accessiblearts.org/](http://accessiblearts.org/)

## **CHILDREN'S THERAPEUTIC LEARNING CENTER**

3101 Main Street, Kansas City, MO 64111

Call (816) 756-0780

[childrenstlc.org](http://childrenstlc.org)

## **TURNING POINT**

Age appropriate art, music and play activities for children and siblings with illness in the family.

Call (913) 574-0900

[turningpointkc.org](http://turningpointkc.org)

## **UNITED WAY DIRECTORY OF SERVICES**

[kcunitedway.org](http://kcunitedway.org)

or dial 211

## **WISH-GRANTING for children with life-threatening conditions**

### **DREAM FACTORY OF GREATER KANSAS CITY**

Call (913) 905-2900

[kcdream.org](http://kcdream.org)

## **MAKE A WISH FOUNDATION OF KANSAS**

[kansas.wish.org](http://kansas.wish.org)

## **MAKE A WISH FOUNDATION OF MISSOURI**

[missouri.wish.org](http://missouri.wish.org)

## **MORE LOCAL RESOURCES**

There are local chapters of organizations for cancers, brain injuries, Down syndrome, diabetes, arthritis, cerebral palsy, epilepsy and many more disorders or conditions as well.

## **MISSOURI RESOURCE DIRECTORY:**

This online book lists many organizations and agencies that can help, listed by organization name, city or service.

[disability.mo.gov](http://disability.mo.gov)

**MISSOURI FAMILY TO FAMILY**

[moddrc.org](http://moddrc.org)

**KANSAS DEPT FOR AGING AND DISABILITY SERVICES**

(for all ages) [www.ksadrc.org](http://www.ksadrc.org)

**CONNECTED KANSAS KIDS**

For school-age kids with chronic illness

[connectedkansaskids.com](http://connectedkansaskids.com)

**FEDERAL GOVERNMENT RESOURCES**

[disability.gov](http://disability.gov)

**GENERAL RESOURCES****MEDLINEPLUS**

Medical encyclopedia, drug books, health topics, interactive tutorials, etc.

[medlineplus.gov](http://medlineplus.gov)

**KIDSHEALTH**

[kidshealth.org](http://kidshealth.org)

**BANDAIDES & BLACKBOARDS**

Chronic illness in school-age children

[www.lehman.cuny.edu/faculty/jfleitas/bandaides/](http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/)

**GENETIC ALLIANCE DIRECTORY**

[geneticalliance.org](http://geneticalliance.org)

**NORD**

Rare disorders; the Kreamer Resource Center for Families librarian can provide the full reports free

[rarediseases.org](http://rarediseases.org)

**FAMILY VOICES**

National network of families of children with special health care needs

Call toll free 1 (888) 835-5669

[familyvoices.org](http://familyvoices.org)

**OUR KIDS**

Raising special kids with special needs

[www.our-kids.org](http://www.our-kids.org)

**DR. MAC'S AMAZING BEHAVIOR MANAGEMENT ADVICE SITE**

[behavioradvisor.com](http://behavioradvisor.com) - Some free content

## **EDUCATION**

School is a very important part of a child's life in order to understand the wider world, as preparation for the future, and as a social network. You may want to visit the classroom to introduce the class to your child and his or her special needs. The Kreamer Resource Center for Families has many teaching materials for children to introduce them to various disorders. You will want to tell the school nurse and the teacher about your child's condition. Your child may need an Individualized Education Program (IEP).

Children's Mercy has certified teachers to work with your child while admitted to the hospital. You can bring your child's books and schoolwork, and your child's school can fax assignments to the teachers at (816) 983-6520.

The Hospital-Based School Teacher program can send records of attendance and progress to your child's school if asked. Call (816) 234-3390 to talk to a teacher and arrange for this service.

## **THE LAW AND YOUR CHILD'S EDUCATION**

Disability laws are civil rights laws. Their purpose is to help people with disabilities participate in society. From birth to age 21, these laws help people with disabilities get the education and tools they need to take part in society. There are federal laws that can help your child get services, including an education.

### **Rehabilitation Act of 1993**

Sections 504 and 508

### **ADA**

Americans with Disabilities Act

### **Telecommunications Act of 1996**

The state government and your local school district must decide how to put these laws into practice. They will not always agree with each other or with you about how to do this. Use the resources listed below (MPACT, Families Together) to find out how to get school services for your child.

### **IDEA**

#### **Individuals with Disabilities Education Act of 1990**

(PL 101-476), and amendments. This law says that disabled and chronically ill children are entitled to a "free and appropriate public education" and related services from ages 3 to 21, and early intervention services for infants through age 2.

### **IEP**

**Individualized Education Program.** This is a written plan outlining the special education and other services to be provided for a child with disabilities, or to conditions that might hinder learning. Even if a child does not qualify for services under an IEP, special assistance may be available under a 504 Accommodation Plan. By the time the child is 16, the IEP must include a plan for transition to employment or secondary education.

To learn about the definitions for different tests (assessments, inventories, scales, etc.), laws and educational terms, see the Dictionary of Developmental Disabilities Terminology available in the Kreamer Resource Center for Families or see [www.ddrcco.com/resources-and-training/glossary-of-developmental-disability-terms.php](http://www.ddrcco.com/resources-and-training/glossary-of-developmental-disability-terms.php).

## **KANSAS**

**Kansas Infant-Toddler Services:** [ksits.org](http://ksits.org)

### **Families Together, Inc.:**

Parent Training and Information for Kansas parents

Call 1 (877) 499-5369 or 1 (888) 815-6364 | [familiesitogetherinc.org](http://familiesitogetherinc.org)

## **MISSOURI**

### **First Steps:**

Early education for special needs toddlers and preschoolers

[dese.mo.gov/special-education/first-steps](http://dese.mo.gov/special-education/first-steps)

### **MPACT:**

Parent Training and Education for Missouri parents of special needs children

Call 1 (800) 743-7634 | [ptimpact.org](http://ptimpact.org)

### **SCHOOL TIP:**

Try to schedule doctor and dentist appointments outside of school hours or during school breaks. If the person who schedules appointments will not work with you, talk to the doctor or dentist directly. Keep medical equipment in good condition to avoid missing school due to equipment failures.





## **TRANSITION**

- When chronically ill children grow up to be adults, they will need health care. They may also need or want to go to college and find a job. They may want a home and family of their own. As with all children, preparing them for adult life is a long process. As teenagers, they must learn to understand their condition and treatment, so as young adults they will be able to manage their health care. When your child turns 14, begin to help him or her take part in health decisions, learn about medications, speak up about needs, and keep track of scheduled appointments.
- For more information on transition, go to [childrensmercy.org/transition/](http://childrensmercy.org/transition/).

## **PROJECT RISE**

- Project RISE (Reaching for Independent Successful Employment) creates employment opportunities for individuals with disabilities at Children's Mercy. We have identified paid jobs and volunteer opportunities within the hospital to help individuals acquire hands-on work experience.
- Young adults with disabilities are employed throughout the hospital in a variety of roles. We focus on tasks that may be learned through on-the-job training as opposed to formal education.

## **TRANSITION FROM SCHOOL TO WORK**

Children's Mercy partners with local school districts to mentor student volunteers from special education programs throughout the school year. Students spend their school day immersed in the hospital work environment. School district and partner agency staff accompany the students to help hospital departments with training and support. The Project RISE Program Manager is also available to assist current patients transitioning to adulthood with employment-related services such as career exploration, resume development and interview preparation. Please contact the Project RISE office at (816) 983-6994.

# MEDICAL

## MEDICAL TERMINOLOGY

Medical terms are usually based on Greek or Latin roots, and can be translated from right to left.

Common word endings can be looked up in a medical dictionary:

—itis (inflammation of)

—emia (condition of the blood)

—ology (study of)

—al (pertaining to)

Word roots can be strung together with the connecting “o” syllable.

Hepatosplenomegaly = hepat (liver) -o- splen (spleen) -o- mega (enlarged) -ly (pertaining to)

Reading right to left, hepatosplenomegaly means to have an enlarged spleen and liver.

Do not be afraid of medical terminology, but look it up rather than think you know what is meant. Some words look and sound similar, but have very different meanings. Many drugs also have names that sound or look alike, but are very different. Always double check to be sure!

Ask your nurse or doctor to write down words you want to look up.

There are many medical dictionaries in the Kreamer Resource Center for Families. A good dictionary such as Mosby’s Medical, Nursing and Allied Health Dictionary contains medical words, pictures, diagrams, conversion charts, acronyms and more.

## MEDICAL TERMINOLOGY

There is an online medical dictionary and medical encyclopedia with pictures at <http://medlineplus.gov/>.

## MEDICAL WORDS: A

### ABG-ARTERIAL BLOOD GAS

This is a lab test on blood drawn from an artery to find the levels of oxygen, carbon dioxide, and acid. It tells the doctor how well the air the patient breathes is getting into and out of the body.

### ABDOMEN

“Belly” or “tummy.” Contains the stomach, intestines, kidneys, liver, pancreas, gallbladder and other structures.

**ACUTE**

Severe illness or symptom that begins suddenly and lasts a short time (hours or days rather than weeks or months or years).

**AIRWAY**

Breathing passages in the body that bring air from the nose or mouth to the lungs. Also used for tubes to bring air into the lungs.

**ALBUMIN**

The protein part of the blood serum important for maintaining blood volume.

**ALVEOLI**

Tiny air sacs in the lungs.

**AMINO ACID**

Protein component needed by body cells.

**ANALGESIA**

Pain medication.

**ANAPHYLAXIS, or ANAPHYLACTIC SHOCK**

Sudden and severe allergic reaction, sometimes fatal (causing death). Can be caused by a medication, specific food, chemical, insect venom (bee sting), etc. Symptoms may include intense anxiety, weakness, sweating, shortness of breath, itchy rash, drop in blood pressure, shock, irregular heartbeat and airways swelling shut.

**ANEMIA**

Lower than normal hemoglobin and hematocrit levels in the blood.

**ANESTHESIA**

Medication that reduces the sensation of pain, or makes the patient unconscious and unable to feel pain.

**ANOMALY**

Congenital birth defect. Some part of the baby is not normal at birth. May be mild or severe.

**ANOXIA**

No oxygen reaching the body cells. Hypoxia is not enough oxygen reaching the body cells.

**ANTIBIOTIC**

A drug that kills bacteria or reduces their growth. Used to fight infection.

**ANTIBODY**

A disease-fighting substance in the blood. Antibodies attack foreign substances, like germs, in the body.

**ANTICONVULSANT**

Medication that stops or reduces seizures.

**APNEA**

Pauses in breathing of 20 seconds or longer, or any pauses with cyanosis (blue-tinged skin) and bradycardia (slow heart beat).

**ARRHYTHMIA**

Irregular heart beat.

**ARTERIAL LINE**

Tube inserted into a major artery, used to give fluids or medications, or to monitor blood pressure. Can sometimes be used to draw blood.

**ARTERIOLES**

Small branches of an artery, leading into many small blood vessels.

**ASPHYXIA**

Result of not enough oxygen reaching the body cells; can lead to permanent brain or organ damage, or death.

**ASPIRATE**

Breathing something other than air into the trachea (windpipe) or lungs. For example, if the child vomits, then breathes some of the vomit into the lungs. Aspirate can also mean removing fluids from the body by suctioning.

**ASSESSMENT**

Checking the patient's condition. The doctors and nurses assess the patient's condition often, and note any changes.

**ATELECTASIS**

Collapse of groups of alveoli (air sacs) in the lungs.

**ATRESIA**

A birth defect in which a passage (such as a valve, a vein, an artery or the esophagus) is completely blocked or is absent.

**AUDIOLOGY**

Specialty concerning hearing problems.

**MEDICAL WORDS: B****BACTERIA**

Germ or single-cell microorganisms. Some cause infections, and some help or protect the body. Different drugs treat different bacterial infections.

**BILIRUBIN**

Sometimes called “bili.” This substance is released when the body breaks down red blood cells, which is converted by the liver and excreted in the stool. Buildup of bilirubin in the blood may cause jaundice (yellowish skin and eyes). Newborn infants and children with liver disorders may have this.

**BLOOD CULTURE**

A lab test in which blood is collected in sterile bottles, then put on a special dish to see what microorganisms (germs) grow. It may take several days to get results from this test.

**BLOOD GLUCOSE LEVEL**

The amount of glucose (sugar) in the blood.

**BOARD CERTIFIED**

A doctor is “board certified” if he or she has passed an exam in a medical specialty, usually after several years of study beyond the medical degree.

**BOLUS**

A volume of fluid given all at once, instead of over a long period of time.

**BRACHYCARDIA or BRADYCARDIA**

Slow heart rate.

**BRAIN STEM**

The stalk of the brain, which connects the spinal cord to the higher brain centers (cerebrum and cerebellum).

**BRONCHIOLES**

Small airways in the lungs; branches off the bronchial “tree.” Inflammation of the bronchi is called bronchiolitis. Pronounced bronk-ee-oles and bronk-ee-o-lie-tis.

**BRONCHI**

The larger airways that branch off to each lung from the trachea (windpipe). Inflammation of the bronchitis. Pronounced bronk-I and bronk-I-tis.

**BRONCHOPULMONARY DYSPLASIA (BPD)**

Chronic lung disease most often seen in premature infants.

**BRONCHOSPASM**

Contraction of the smooth muscle in the bronchi causing narrowing of the air passages leading to the lungs. Seen in asthma and bronchopulmonary dysplasia.

**BULB SYRINGE**

Tool used to suction secretions (goo) from the nose and mouth by hand.

**BUN**

A lab test for blood urea nitrogen. Urea nitrogen is usually excreted (cleared from the body) by the kidneys. BUN is normally measured along with creatinine to see how well the kidneys are working.

**BUTTON GASTROSTOMY**

A gastrostomy (feeding tube from outside the tummy directly into the stomach) with a valve (button) on the skin. This allows the tube to be removed and the hole closed between feedings.

**MEDICAL WORDS: C****CALORIE**

A measure of the energy value of food.

**CANNULA**

Tubing or catheter. A nasal cannula is soft plastic tubing that wraps around the child's face with openings under the nose to give the child oxygen.

**CAPILLARIES**

Very tiny blood vessels that form networks in our tissues (skin, fat, muscles) to supply cells with oxygen and nutrients, and to carry away wastes.

**CARBON DIOXIDE (CO<sub>2</sub>)**

A waste product of the body that is removed from the blood as it passes through the lungs and is exhaled (breathed out). CO<sub>2</sub> should not be too high.

**CARDIAC OUTPUT**

The amount of blood the heart pumps out in a given period of time.

**CARDIOPULMONARY RESUSCITATION (CPR)**

Artificial respirations (breathing for the patient) and cardiac compressions (pumping the heart) to revive someone who has stopped breathing and whose heart has stopped beating.

**CARDIORESPIRATORY MONITOR**

An electronic device that monitors (watches) the heart rate and breathing rate (how fast or slow the heart beats and the child breathes), usually used in the ICU. It sounds an alarm when the breathing and heart rate gets too fast or too slow.

**CARDIORESPIRATORY SYSTEM**

Heart, lungs and blood vessels in the body.

**CARDIOVASCULAR**

Involving the heart and blood vessels.

**CAROTID ARTERIES**

Large arteries in the neck that carry oxygenated blood from the heart to the brain. You can feel them throb, or pulse, with each beat of your heart.

**CASE MANAGER**

Person who coordinates health services. This may be a nurse or social worker in the hospital. Insurance companies may have a case manager who oversees financial aspects of hospital or home care.

**CATASTROPHIC ILLNESS**

A major illness usually involving a long hospital stay and large medical bills. An insurance carrier who offers catastrophic coverage pays for most or all of these bills.

**CATHETER**

A thin, flexible tube to deliver fluids into the body (for example, intravenous line or feeding tube) or out of the body (urinary catheter).

**CATHETERIZATION**

Inserting a thin, flexible tube into the body.

**CBC (COMPLETE BLOOD COUNT)**

A lab test that measures red blood cells (RBCs), white blood cells (WBCs) and platelets in the blood. Red blood cells carry oxygen; white blood cells fight infection; platelets help the blood to clot.

**CEREBELLUM**

The rounded portion of the hindbrain. It coordinates movement, posture and balance.

**CEREBRAL CORTEX**

Outer layer of the brain.

**CP—CEREBRAL PALSY**

A condition in which posture or movement is not normal because the brain did not form properly or because the brain was damaged around the time of birth. The cause is often not known.

**CEREBRUM**

The largest and uppermost part of the brain, divided into two halves, or hemispheres, connected by the corpus callosum. This part of the brain does our thinking, sensing and feeling.

**CHROMOSOME**

One of 46 threadlike structures (23 coming from the mother and 23 coming from the father) that make up the center of each cell in the human body. Chromosomes carry genes.

**CHROMOSOME DEFECTS**

When extra copies of chromosomes or parts of chromosomes appear in the cells of the body, or when parts of chromosomes are missing, or genes are out of order in the chromosomes. A chromosome defect may be mild or severe.

**CHRONIC**

Lasting a long period of time.

**CIRCULATORY SYSTEM**

Vessels through which blood moves (circulates)—heart, arteries, veins, capillaries.

**CNS—CENTRAL NERVOUS SYSTEM**

Made up of the brain and the spinal cord. The nerves that branch off the spinal cord to the rest of the body make up the peripheral nervous system, but nobody calls it the PNS.

**CONGENITAL**

Existing at birth.

**CONGENITAL HEART DEFECT**

The heart or blood vessels near the heart did not form correctly. The defect may be mild or life-threatening.

**CONSENT**

Permission for a medical procedure, often a surgery (operation). Informed consent means that you understand what you are giving permission for and all your questions have been answered.

**CONSTRICIT**

To narrow or compress.

**CONTRACTURE**

Tightness or stiffness of a muscle or joint (unable to stretch easily).

**CONTRAINDICATION**

A reason a patient may not receive a medicine or treatment.

**CONTRAST**

A dye or other material injected into the body to make certain body structures show up more clearly on an X-ray or CT scan.

**COPING**

Dealing with a situation, such as your child's illness.

**CPAP—CONTINUOUS POSITIVE AIRWAY PRESSURE**

Air or an air oxygen mixture pushed by a machine into the child's lungs through tubes in the nose or down the throat, so the patient has less work to breathe.

**CREATININE**

A waste product excreted (cleared from the body) by the kidneys. Normally used along with BUN to see how well the kidneys are working.

**CSF—CEREBROSPINAL FLUID**

The fluid that surrounds the spinal cord and the brain, and fills the ventricles of the brain. It acts as a cushion, or shock absorber. A spinal tap is a test in which a small amount of this fluid is drawn up with a needle into a syringe and tested in the lab for glucose, blood cells, bacteria, etc.

**CT SCAN**

Computed tomography scan, also called a CAT scan or computer-assisted tomography. An imaging technique like an X-ray, which shows pictures of the inside of the body in "slices."

**CULTURE**

Lab test in which a body fluid (blood, sputum, etc.) is put on a special dish and watched to see which microorganisms (germs) grow. This test looks for infection, and results may take days.

**CYANOSIS**

When skin and mucous membranes (such as the lips) look blue, caused by lack of oxygen in the body.

**CYST**

A membrane-covered sac, often filled with liquid or semi-solid material, that develops in the body.

**MEDICAL WORDS: D****DECANNULATION**

Removal of a tube or catheter.

**DEDUCTIBLE**

The amount you must pay before your health insurance company begins to cover your bills.

**DEHYDRATE**

To lose body fluids or water.

**DESATURATION, OXYGEN**

Too little oxygen in the bloodstream.

**DEVELOPMENTAL DELAY**

Slowness in developing motor skills (such as lifting the head, rolling over, sitting, walking), behavioral skills (such as calming down), and living skills (feeding and dressing oneself, doing schoolwork), etc.

**DEVELOPMENTAL MILESTONE**

Each important skill a child learns by a specific age, such as sitting with support by 6 months of age.

**DIAGNOSIS**

The name of a child's disease or condition.

**DIAGNOSTIC IMAGING**

Taking pictures of the insides of the body without performing surgery, such as CT scans, ultrasound, MRI and X-ray.

**DIAPHRAGM**

Dome-shaped muscle below the lungs and above the stomach, which separates the chest cavity from the abdominal cavity. Important for breathing.

**DIARRHEA**

Frequent watery or liquid stools (feces), often smells bad.

**DIGITAL READOUT**

Shows results in numbers, like a microwave oven or a digital thermometer.

**DILATE**

To enlarge, stretch or widen.

**DISABILITY**

A physical or mental abnormality or limitation.

**DISCHARGE PLANNING**

When hospital staff make sure that all needed medical care, tests, and parent or patient teaching is complete before going home from the hospital, and that follow-up home care, prescriptions or clinic visits have been arranged.

**DISTENTION**

Enlargement or swelling, usually caused by pressure from inside the body.

**DIURETIC**

Medicine that removes excess fluid from the body by increasing urine production (medicine that makes the patient pee a lot).

**DNR OR DNAR**

Do not resuscitate or do not attempt resuscitation. A medical order written when a dying patient is to be allowed to die peacefully, without futile (pointless) attempts to keep the patient alive longer.

**DOPPLER ULTRASOUND**

Test to detect blood flow disturbances. Used for an echocardiogram (echo).

**DTaP— DIPHTHERIA-TETANUS-PERTUSSIS VACCINE**

Injection (shot) protects against these three diseases.

**DURABLE MEDICAL EQUIPMENT COMPANY**

A company that provides medical equipment (wheelchairs, nebulizers, etc.) prescribed by a physician for home use, trains the patient family in its use, and deals with equipment problems.

**MEDICAL WORDS: E****EARLY INTERVENTION PROGRAM**

Public program designed to prevent developmental delays in children at risk, and to help children already showing delays.

**ECG OR EKG—ELECTROCARDIOGRAM**

This test records the electrical activity of the heart.

**ECHOCARDIOGRAM**

Ultrasound test of the heart.

**ECMO—EXTRACORPOREAL MEMBRANE OXYGENATION**

A type of heart-lung bypass machine used for babies with lung failure.

**EDEMA**

Excess fluid in the body tissues, usually causes swelling.

**EEG—ELECTROENCEPHALOGRAM**

A test that records the electrical impulses of the brain.

**ELECTRODES**

Also called leads. Patches stuck to the head, chest or abdomen that connect to a heart monitor or other medical device.

**ELECTROLYTES**

Also called “lytes,” these are basic body chemicals in the blood needed for proper cell function. They include sodium (Na), potassium (K), chloride (Cl), calcium (Ca) and magnesium (Mg).

**EMBOLUS**

Object that blocks blood flow through a blood vessel. It may be a bubble of air (air embolus) or a blood clot. Emboli means more than one embolus.

**ET TUBE—ENDOTRACHEAL TUBE**

A tube placed in the trachea (windpipe) through the nose or mouth to help breathing. The ET tube is often attached to a ventilator or a CPAP machine. Intubation means putting in a tube, extubation means taking out a tube.

**ENZYME**

A complex protein produced by body cells to help chemical reactions happen in the body. There are many different enzymes in the body.

**ER—EMERGENCY ROOM**

Also called ED, or Emergency Department. Open 24 hours a day, every day, for emergencies. If your child can barely breathe, is bleeding a lot, has been hit by a car or otherwise severely injured, is having a severe allergic reaction, has a very sudden high fever, or is at risk of death or severe disability for any other reason, call an ambulance (dial 911) or go to the ER immediately.

**ERCP—ENDOSCOPIC RETROGRADE CHOLANGIOPANCREATOGRAPHY**

A test to look at the pancreas, gallbladder and bile ducts.

**ERYTHROPOIETIN**

A hormone that controls red blood cell production.

**ESOPHAGUS**

The tube or “pipe” that connects the mouth to the stomach, also called the food pipe.

**ESRD—END-STAGE RENAL DISEASE**

Also called kidney failure. Dialysis is a treatment, but a kidney transplant is needed to replace the failed kidneys.

**EXOGENOUS**

Not produced by the body.

**EXPIRATION**

Breathing out. Inspiration is breathing in.

**MEDICAL WORDS: F****FAILURE TO THRIVE**

When a baby or young child does not grow and develop normally, for no clear reason.

**FEEDING TUBE**

A thin, flexible tube passed through the child’s nose (nasogastric) or mouth (orogastric) down to the stomach for liquid food. Also called a gavage tube. See also G-tube.

**FISTULA**

Abnormal passage or connection between two parts of the body. For example, a tracheoesophageal fistula is a connection between the trachea (windpipe) and the esophagus (food pipe) so that food can pass to the lungs and air can pass to the stomach.

**FONTANEL**

Soft spot on the top of a baby’s head. This is a normal opening to allow room for the baby’s brain to grow. The bones of the skull will grow together later.

**FUNDOPLICATION**

Operation for severe gastroesophageal reflux (GERD). Fundoplication prevents food and stomach acids from moving back up from the child’s stomach to the esophagus.

**FUNGUS**

A microorganism that can cause infection. There are many types of fungus; yeast (Candida) is one.

**FUO**

Fever of unknown origin (cause).

**MEDICAL WORDS: G****GAS EXCHANGE**

In the lungs, oxygen is added to the blood and carbon dioxide is removed. Oxygen and carbon dioxide are gases.

**GASTROENTERITIS**

Inflammation of the stomach and intestines (bowels), usually due to infection.

**GI TRACT OR GASTROINTESTINAL TRACT**

The stomach and intestines, also called the gut.

**G-TUBE OR GT— GASTROSTOMY TUBE**

A feeding tube inserted through an opening in the abdominal wall into the stomach. A tube may also be inserted into a portion of the intestines (jejunostomy tube) when the child is not able to eat by mouth for a long period of time.

**GENE**

Inherited from the parents, found in the chromosomes in each cell of the body, the genes tell the body how to develop and function.

**GENETIC DEFECTS**

May involve just one gene, or several genes that work together. Their effects may be mild or severe.

**GENERIC DRUGS**

A drug without a brand name controlled by a single drug company. For example, acetaminophen is a generic name, Tylenol is a brand name for an acetaminophen product.

**MEDICAL WORDS: H****HEMATOCRIT OR "CRIT"**

The percentage of red blood cells in the blood. Red blood cells carry oxygen.

**HGB—HEMOGLOBIN**

The substance in red blood cells that carries oxygen to body cells.

**HEMORRHAGE**

Heavy or uncontrollable bleeding.

**HEPARIN**

A substance that keeps the blood from clotting.

**HEROIC MEASURES**

Extraordinary medical treatments to keep a dying patient alive, these measures may be futile (useless) or may be a burden for the patient.

**HORMONE**

Substance produced by glands in one part of the body to work in other parts of the body. The adrenal glands produce adrenaline, the pancreas produces insulin, etc.

**HYDROCEPHALUS—"WATER ON THE BRAIN"**

Cerebrospinal fluid (CSF) backs up into the ventricles (chambers) of the brain, causing pressure, head **enlargement and possibly brain damage.**

**HYPERGLYCEMIA**

Higher than normal glucose (sugar) in the blood.

**HYPERTENSION**

High blood pressure.

**HYPERVENTILATION**

Faster than normal breathing while at rest.

**HYPOCALCEMIA**

Lower than normal calcium in the blood.

**HYPOTENSION**

Lower than normal blood pressure.

**HYPOTHERMIA**

Lower than normal body temperature.

**HYPOVOLEMIA**

Lower than normal blood volume (amount of blood circulating in the body).

**HYPOXIA**

Not enough oxygen in the body.

**MEDICAL WORDS: I****I & O—INTAKE AND OUTPUT**

Keeping track of how much your child eats or drinks, and how much comes out as urine (pee) or feces (poop).

**ICU—INTENSIVE CARE UNIT**

Where seriously ill or injured patients get specialized care. A pediatric intensive care unit (for children) may be called a PICU. A neonatal intensive care unit (for newborn babies) may be called a NICU or an ICN (intensive care nursery).

**IDEA—INDIVIDUALS WITH DISABILITIES EDUCATION ACT OF 1990**

(PL 101-476), see also Amendments of 1997 (PL 105-17). This law says that disabled and chronically ill children are entitled to a free public education and related services from ages 3 to 21, and early intervention services for infants through age 2.

**IDIOPATHIC**

The cause is not known.

**IEP—INDIVIDUALIZED EDUCATION PROGRAM**

This is a written plan outlining the special education and other services to be provided for a child with disabilities or a condition that might hinder learning. Even if a child does not qualify for services under an IEP, special assistance may be available under a 504 Accommodation Plan. By the time the child is 16, the IEP must include a plan for transition to employment or secondary education (college).

**IG—IMMUNOGLOBULIN**

Kinds of immunoglobulins (Igs) are IgA, IgD, IgE, IgG and IgM. Also called immune serum globulin, these antibodies are part of the immune system.

**IM—INTRAMUSCULAR OR INTO THE MUSCLE**

Injections (shots) may be intramuscular.

**IMMUNE SYSTEM**

Protects the body against infection, with antibodies, white blood cells, etc.

**INCISION**

The cut into the body made with a knife or a scalpel for a surgical procedure.

**INFECTION**

Invasion of the body by harmful microorganisms (bacteria, viruses, fungi or protozoa) that generally multiply once they get established. The body may react with fever, high white blood cell count or other symptoms and signs.

**INHALER**

A device that allows the child to inhale (breathe in) medicine, often called a “puffer.”

**INSULIN**

A hormone produced by the pancreas, which helps move glucose from the blood into the cells.

**INTRACRANIAL BLEEDING**

Bleeding in or around the brain. Also called a “brain bleed.”

**INTRATHECAL INJECTION**

Use of a needle to put medicine into the spinal fluid.

**INTUBATION**

Putting in an endotracheal (ET) tube.

**INVASIVE**

Describes a diagnostic or treatment procedure that involves cutting into the skin or inserting something (tube, pump, scope, other device or foreign substance) into the body.

**IV—INTRAVENOUS, OR INTO THE VEIN**

An IV line or catheter puts fluids or medicine directly into the vein. Also called a peripheral line. An infiltrated IV is an IV line that has moved out of position in the vein so that it leaks fluid into the surrounding tissue. An infusion IV may use a pump to put medicine into a vein slowly over time.

**MEDICAL WORDS: J****JAUNDICE**

Yellow skin and eye color caused by buildup of bilirubin in the body; usually a sign of poor liver function.

## **MEDICAL WORDS: K**

### **KANGAROO CARE**

Parent holding a newborn infant skin-to-skin (usually against your chest). Babies often get more stable vital signs, better feeding and weight gain, and more restful sleep from this. Parents get a sense of closeness with their new baby.

### **KIDNEY**

A bean-shaped organ in the body that filters waste from the blood to make urine (pee). Humans have two kidneys, one on each side of the spine.

## **MEDICAL WORDS: L**

### **LACTATION**

Milk production in the breasts of a woman for breastfeeding.

### **LASER THERAPY**

A treatment that uses a high-energy light beam to destroy problem tissue.

### **LEARNING DISABILITY**

A disorder that makes learning to read, write or use numbers difficult, even if the child has normal or above normal intelligence. It often comes with slow development of perceptual skills, such as how the brain understands what the eyes see.

### **LESION**

Any break in normal tissue or change in the structure of an organ because of disease or injury. May be a wound, rash, sore, boil, etc.

### **LETHARGY**

Lack of energy.

### **LUMBAR PUNCTURE—SPINAL TAP**

A needle is put into the lower back to draw up some spinal fluid (CSF) for testing.

### **LYMPHOCYTE**

A type of white blood cell that fights invading microorganisms. White blood cells are also called leukocytes.

## **MEDICAL WORDS: M**

### **MRI—MAGNETIC RESONANCE IMAGING**

A diagnostic imaging technique that takes pictures of the inside of the body using a magnetic field instead of radiation. The MRI machine makes a loud jackhammer noise.

### **MALFORMATION**

Some part of the body that did not form correctly.

### **MENINGITIS**

Inflammation of the membranes covering the brain and spinal cord, usually caused by a bacteria or a virus.

**METABOLISM**

Chemical reactions and processes in the cells of the body as energy is produced and used.

**MEDICAL WORDS: N****NARCOTIC**

A medication that dulls the senses (and so relieves pain). For example, morphine.

**NG TUBE— NASOGASTRIC TUBE**

Tube that goes through the nose, down the throat, into the stomach.

**NEBULIZER**

A machine that gives medicine in a fine spray to be breathed in, a type of inhaler or “puffer.”

**NEONATAL**

The first 28 days of a baby’s life, newborn.

**NERVE BLOCK**

A type of anesthesia that blocks the pain from a small (local) area of the body or a larger portion of the body (regional nerve block).

**NERVOUS SYSTEM**

Carries information to and from all parts of the body in the form of nerve impulse. Made up of the brain and spinal cord (central nervous system) and the nerves that reach through the rest of the body (peripheral nervous system).

**NEUROMUSCULAR**

Involving both the nerves and the muscles.

**NEURON**

A nerve cell.

**NPO—NOTHING BY MOUTH**

Do not give the child anything to eat or drink.

**NSAID—NONSTEROIDAL ANTI-INFLAMMATORY DRUG**

Any of a group of drugs that treats inflammation, pain and fever but are not steroids. Examples are aspirin, ibuprofen, ketoprofen and indomethacin.

**NUTRIENTS**

Proteins, carbohydrates, fats, vitamins and minerals that humans need for life.

**MEDICAL WORDS: O****OR**

Operating room.

**ORAL**

Having to do with the mouth.

## **ORAL-MOTOR DEVELOPMENT**

Learning to control the mouth, for sucking, swallowing and speaking.

## **ORGAN**

A body structure that has a specific function. For example, the heart, lungs, kidneys, brain, skin and liver are all organs.

## **OSTOMY**

A surgical opening into an organ or body part. For example, a colostomy is an opening through the belly wall into the colon, which is a part of the large intestine. A gastrostomy opens into the stomach. An ileostomy opens into the ileum, and a jejunostomy opens into the jejunum, which are parts of the small intestine. A tracheostomy is an opening into the trachea (windpipe). The opening that you see on the outside of the body is called a stoma.

## **OUTPATIENT CLINIC**

“Doctor’s office” where patients are seen without staying overnight. Also called ambulatory care clinic.

## **O<sub>2</sub>—OXYGEN**

Part of the air we breathe, absorbed into the blood from air breathed into the lungs.

## **OXYGENATION**

Level of oxygen in the blood. Also, supplying oxygen to the blood.

# **MEDICAL WORDS: P**

## **PALATE**

Roof of the mouth.

## **PALLIATIVE CARE**

Treatment that provides relief from a condition but does not cure it.

## **PEG—PERCUTANEOUS ENDOSCOPIC GASTROSTOMY TUBE**

A type of gastrostomy tube that connects to the stomach through skin of the abdomen (belly) rather than down the throat.

## **PERFORATE**

To tear or rupture.

## **PERFUSION**

Passage of fluid through body tissue, usually refers to blood passing through the lungs to pick up oxygen.

## **PERITONITIS**

Infection of the abdominal cavity.

## **PLATELET**

A component (part) of the blood involved in clotting. Also called a thrombocyte.

**PNEUMONIA**

Inflammation or infection of the lungs.

**POSTOPERATIVE**

Time period after surgery, after an operation.

**PREMATURE—PREMIE, PRETERM INFANT**

Baby born before the 38<sup>th</sup> week of gestation (mother's pregnancy).

**PROGNOSIS**

Outlook or forecast for the child's future condition.

**PRONE**

Lying on the stomach.

**PROPHYLACTIC TREATMENT / PROPHYLAXIS**

Treatment to prevent a disease or condition from happening.

**PROTOCOL**

A standard plan or standard instructions for a situation.

**PULMONARY**

Concerns the lungs.

**PULMONARY EDEMA**

Fluid has leaked into the lung tissues.

**PULSE**

A measurement of the rate the heart is beating; the heart rate. Each time the heart "beats" it pumps blood out through the arteries; you can easily feel the blood pulsing through the arteries at the wrist or neck and other places.

**PULSE OXIMETER**

A device that fits on the hand or foot of an infant, or the finger of an older child, and uses a light sensor to measure the amount of oxygen in the blood. Also called an oxygen saturation monitor.

**MEDICAL WORDS: R****RADIOLOGY**

Department that performs and reads imaging studies (X-rays, ultrasounds, CT scans, MRIs).

**RECTAL**

Involving the rectum, the last part of the intestine just inside the anus (opening in the bottom) where the feces (poop) comes out.

**RBC—RED BLOOD CELL**

RBCs contain hemoglobin, which carry oxygen to the cells of the body.

**REFERRAL**

Recommendation to a care provider (another doctor or therapist).

**REFLUX, GASTROESOPHAGEAL—ALSO CALLED GERD, FOR GASTRO-ESOPHAGEAL REFLUX DISEASE**

The backward flow of stomach contents (food, stomach acid) into the esophagus (food pipe). Causes a burning feeling in the chest (heartburn).

**REGRESSIVE BEHAVIOR**

A return to past ways of acting, often to younger behavior. Children under stress who are toilet-trained may start wetting themselves again, or a child who gave up the bottle may want to be bottle-fed again.

**RENAL**

Concerns the kidneys.

**RESPIRATIONS**

Breaths.

**RSV—RESPIRATORY SYNCYTIAL VIRUS**

A virus that often causes infections in the respiratory tract, especially bronchiolitis and pneumonia in young children.

**RESPIRE CARE**

An outside person or facility takes total care of a person who is ill or disabled for a short time (usually days or weeks, not months) so the family caregivers can have a break to rest and re-energize.

**RESUSCITATE**

Restore breathing and/or heart function and circulation.

**RETICULOCYTE COUNT—“RETIC”**

A lab test that shows how many red blood cells the body is producing. A reticulocyte is an immature red blood cell.

**RISK FACTOR**

Some reason that makes it more likely (increases the risk) that your child will have a problem. For example, if you smoke around your child, your child is more likely to get respiratory infections. Smoking is a risk factor.

**MEDICAL WORDS: S****SALINE, NORMAL**

A liquid solution of 0.9 percent sodium chloride used to dilute some drugs for injection, to flush IV lines, or to increase plasma volume and increase blood pressure.

**SATURATION, OXYGEN— “O2 SAT”**

The degree to which oxygen is bound to hemoglobin in the red blood cells. Expressed as a percentage. In children and adults, arterial oxygen saturation should be 95-98 percent, oxygen saturation from veins should be 60-80 percent. Newborn babies are different.

**SCREENING TEST**

A test to look for possible problems. For example, school children may get a screening eye test and a test for signs of scoliosis (curved spine).

**SECRETION**

A substance (such as mucus, saliva or tears) produced by a gland and released to an external (outside) or internal (inside) body surface.

**SEDATION**

Medication to calm a patient and make the patient sleepy.

**SEIZURE**

Abnormal brain electrical activity, often accompanied by muscle spasms (involuntary contractions and relaxations). An EEG is a test for seizure activity in the brain.

**SENSORY SYSTEM**

The body system made up of the organs used to see, hear, taste, touch and feel.

**SEPARATION ANXIETY**

If your child feels anxious or fearful about what will happen when leaving a familiar environment (such as home) or familiar people (such as parents) for an unknown situation (such as the hospital).

**SEPSIS**

The presence of harmful microorganisms in the blood and their effects on the body, serious infection throughout the body. Septicemia is infection in the blood.

**SEQUELA**

A consequence from a previous disease or treatment. For example, polio may cause paralysis, so paralysis is the sequela of polio.

**SHOCK**

An unstable condition marked by circulatory collapse: not enough blood flow, not enough oxygen to the brain and other tissues, not enough removal of waste products (such as CO<sub>2</sub>) from the body. This can happen because of sepsis, acute (sudden and severe) blood loss, heart problems or allergic reaction.

**SHORT BOWEL SYNDROME**

Having only a small length of healthy bowel (intestines, gut) to absorb nutrients and water from the stool. This can happen as a sequela to diseases such as NEC (necrotizing enterocolitis) or Crohn's disease.

**SHUNT**

A thin tube used to drain fluid from one area of the body to another. For example, a shunt is used to drain excess CSF (cerebrospinal fluid) from the ventricles of the brain in hydrocephalus. Also, an abnormal connection between two areas of the body. For example, a left-to-right shunt and a right-to-left shunt refers to abnormal patterns of circulation of blood through the heart or from the heart to the lungs, which can occur in certain congenital heart defects.

**SI—INTERNATIONAL SYSTEM (OF UNITS)**

A way to measure, as in lab results.

**SIBLING**

Brother or sister. Sometimes called “sib” for short.

**SIDE EFFECT**

An effect of a drug or medication, that is not the intended effect. A side effect may or may not be harmful.

**SPECIAL NEEDS CHILD**

A child who needs technological support (such as a ventilator) or medications to live, or who needs special education or therapy to develop and grow.

**SPINA BIFIDA OR SPINAL DYSRAPHISM**

A birth defect in which the spinal column (backbone) does not close completely and the covering of the spinal cord, or even part of the spinal cord itself, pushes out of the protective spinal column. One type of spina bifida is called “myelomeningocele.”

**STENOSIS**

A narrowed, or constricted, passage in the body. A baby may be born with stenosis in a blood vessel, valve or other passage, or it may develop later. For example, pyloric stenosis is a narrowing of the pyloric sphincter (the outlet of the stomach) causing an obstruction that blocks the flow of food from the stomach into the intestines. Subglottic stenosis is a narrowing of the trachea (windpipe) that can be caused by repeated intubations or use of mechanical ventilation.

**STEROID**

A large family of drugs. The human body produces steroids. Corticosteroids are used to fight swelling and inflammation, and can be used as pills, injections, inhalers or topical creams, to treat many diseases such as Crohn’s disease, asthma or poison ivy dermatitis. These are powerful drugs and higher doses used for longer periods of time have powerful side effects. Anabolic steroids are drugs sometimes used by athletes to build muscle, a dangerous and illegal practice.

**STIMULUS**

Something that excites or promotes activity. A loud noise, your touch, or the smell of cookies may stimulate a response in your child.

**STOMA**

The artificial opening of a hollow organ. For a tracheostomy, the stoma is on the neck. For a colostomy the opening is on the abdomen (belly).

**STOOL**

Feces, poop. The result of a bowel movement.

**STRESS**

The body's reactions to disturbances in the environment. This can be emotional stress (worry, fear, etc.), noise, light in the eyes, pain, infection in the body, too cold or too warm temperatures in the room, etc. The body may react with changes in heart rate, breathing, blood pressure and oxygen consumption.

**STRESSOR**

Something that causes stress.

**SUBARACHNOID**

Located beneath the innermost membrane covering the brain.

**SUBDURAL**

Located below the outermost membrane covering the brain.

**SUCTION**

Mechanical removal (drawing out) of air or fluid from the body.

**SUFFOCATION**

An inability to breathe, as in drowning or smothering. Can cause unconsciousness or death.

**SUPINE**

Lying on one's back.

**SUPPORT GROUP**

A group of people who share information, feelings and concerns about a particular topic.

**SUTURE**

The material or "thread" to sew up a surgical wound or incision (cut). It can also refer to the thin line of connective tissue between two bones, as in cranial suture.

**SYNDROME**

A pattern of signs and/or symptoms occurring together that form a specific disorder.

**SYRINGE**

A device for injecting fluids into or withdrawing fluids from the body. For example, a syringe may be used to inject medicine (give a "shot") or to draw blood for a lab test.

**SYSTEMIC**

Something affecting the whole body.

## **MEDICAL WORDS: T**

### **TACHYCARDIA**

Faster than normal heart rate. Pronounced tack-ee-CARD-ee-uh.

### **TACHYPNIA**

Faster than normal breathing. Pronounced tack-IP-nee-uh.

### **TEACHING HOSPITAL**

Hospital associated with a university and/or medical school. It may have student doctors, nurses and therapists assisting in your child's care.

### **TECHNOLOGY DEPENDENT**

Needs mechanical equipment to survive. For example, a ventilator.

### **TERATOGEN**

A drug, chemical, toxin or other environmental agent that can cause birth defects if the fetus is exposed to it, especially during the first three months. For example, alcohol is a teratogen which can cause the baby to have Fetal Alcohol Syndrome.

### **THORACIC**

Having to do with the chest.

### **THROMBOCYTOPENIA**

Low platelet count in the blood.

### **TIDAL VOLUME**

The amount of air breathed in (inhaled) and breathed out (exhaled) with one normal breath.

### **TITRATE**

To adjust the dose of a drug to use the smallest amount that will do the job.

### **TOLERANCE**

Tolerance for a drug is the need, over time, to use higher and higher doses to have the same effect.

### **TOPICAL**

Applied to a limited area of skin.

### **TPN—TOTAL PARENTERAL NUTRITION**

Also called hyperalimentation. Nutrition (proteins, fats, sugar, vitamins and minerals) delivered through an IV line when a patient is not able to take in enough nutrition by mouth.

### **TEF—TRACHEOESOPHAGEAL FISTULA**

A birth defect in which there is an abnormal connection between the trachea (windpipe) and the esophagus (food pipe). Pronounced tray-kee-o-ess-off- uh-gee-ull fist-you-la.

## **TRACHEOMALACIA**

A condition in which the trachea (windpipe) is soft instead of rigid and collapses during breathing. Pronounced tray-key-o-mal-ay- shuh.

## **TRANSFUSION**

Giving fluid, such as blood, directly into the bloodstream through a catheter.

## **TUBE FEEDING**

See G-tube.

## **THERMOMETER**

Device that measures the temperature (degrees of heat or cold). Thermometers used in the body may be tympanic (used in the ear), oral (used in the mouth) or rectal (used in the rectum).

## **MEDICAL WORDS: U**

### **ULTRASONOGRAPHY**

A diagnostic imaging technique that uses sound waves instead of radiation to take pictures of the inside of the body. Ultrasound.

### **UTI—URINARY TRACT INFECTION**

Infection of the kidneys, ureters, bladder and/or urethra.

## **MEDICAL WORDS: V**

### **VACCINE**

A killed or weakened version of disease bacteria or virus given to stimulate the body to produce antibodies (blood proteins that attack foreign substances) so the body will have immunity (resistance to infection) from the disease.

### **VALIDATE**

To be sure that someone understands what has been said, perhaps by asking the person to repeat the information in his or her own words. For example, your doctor should validate your understanding of how to give your child's medicines.

### **VASOCONSTRICTION**

Narrowing or partial closure of blood vessels, reducing blood flow through them.

### **VASODILATE**

Widen or open blood vessels, allowing blood to move easily through them.

### **VENTILATOR**

A mechanical device that assists breathing and supplies an air/oxygen mixture to the lungs through a tube down the throat and through the windpipe (endotracheal), or directly into the windpipe through an opening in the neck (tracheostomy). Also called a respirator.

## **VIRUS**

An infectious microorganism that can live and multiply in the cells of the body; different from a bacterium.

## **VITAL SIGNS**

Body temperature, pulse (heart) rate and rate of respirations (breathing). Sometimes includes blood pressure.

## **V/Q RATIO—VENTILATION/ PERFUSION RATIO**

The ratio of pulmonary alveolar ventilation to pulmonary capillary perfusion. In other words, a way to measure how much air is getting from the alveoli (air sacs in the lungs) to the bloodstream.

## **MEDICAL WORDS: W**

### **WEAN**

To gradually stop one method of doing something while introducing another method. For example, a baby may be weaned from breast milk while learning to take in other food or drink. A patient may be weaned from a ventilator when strong enough to begin breathing on his or her own. A patient may also be weaned from medication.

### **WBC—WHITE BLOOD CELL**

Also called leukocyte. The part of the blood that helps to fight infection. There are different types of white blood cells: lymphocytes, monocytes, eutrophils, basophils and eosinophils. Leukopenia means not enough white blood cells in the body.

## **MEDICAL WORDS: X**

### **X-RAY**

A picture of the inside of the body using an electromagnetic wave (a form of radiation). Also, the wave itself.



# NOTES

## TEMPERATURE CHART

36.0 C = 96.8 F	38.0 C = 100.4 F	40.0 C = 104.0 F
36.5 C = 97.7 F	38.5 C = 101.3 F	40.5 C = 104.9 F
37.0 C = 98.6 F	39.0 C = 102.2 F	41.1 C = 105.8 F
37.5 C = 99.5 F	39.5 C = 103.1 F	42.0 C = 107.6 F

## WEIGHT CHART

3 pounds = 1361 grams	3 1/2 pounds = 1588 grams
4 pounds = 1814 grams	4 1/2 pounds = 2041 grams
5 pounds = 2268 grams	5 1/2 pounds = 2495 grams
6 pounds = 2722 grams	6 1/2 pounds = 2948 grams
7 pounds = 3175 grams	7 1/2 pounds = 3402 grams
8 pounds = 3629 grams	8 1/2 pounds = 3856 grams
9 pounds = 4082 grams	9 1/2 pounds = 4309 grams
10 pounds = 4536 grams	10 1/2 pounds = 4763 grams
12 pounds = 5443 grams	13 pounds = 5897 grams
14 pounds = 6350 grams	15 pounds = 6804 grams
16 pounds = 7257 grams	17 pounds = 7711 grams
18 pounds = 8165 grams	19 pounds = 8618 grams
20 pounds = 9072 grams	22 pounds = 9979 grams

## [KG = KILOGRAMS]

10 pounds = 4.53 kg	
15 pounds = 6.80 kg	20 pounds = 9.07 kg
25 pounds = 11.34 kg	30 pounds = 13.60 kg
35 pounds = 15.87 kg	40 pounds = 18.14 kg
45 pounds = 20.41 kg	50 pounds = 22.68 kg
55 pounds = 24.95 kg	60 pounds = 27.21 kg
65 pounds = 29.48 kg	70 pounds = 31.75 kg
75 pounds = 34.02 kg	80 pounds = 36.28 kg
90 pounds = 40.82 kg	100 pounds = 45.36 kg

The librarian can give you more detailed charts for weight, blood pressure, heart rate, etc.

## **CONVERSION FORMULAS**

### **CENTIGRADE OR CELSIUS TO FAHRENHEIT DEGREES**

Multiply the centigrade degrees by  $\frac{9}{5}$  and add 32 to the result.

### **FAHRENHEIT DEGREES TO CENTRIGRADE OR CELSUIS**

Subtract 32 from the Fahrenheit degrees, then multiply the result by  $\frac{5}{9}$ .

### **POUNDS TO KILOGRAMS**

Multiply by 0.45.

For example, if your child weighs 16 pounds, multiply  $16 \times 0.45$ .  
Your child weighs 7.2 kilograms.

### **KILOGRAMS TO POUNDS**

Multiply by 2.2.

### **CUBIC CENTIMETERS (CC) TO OUNCES**

Multiply by 0.34.

### **OUNCES TO CUBIC CENTIMETERS (CC)**

Multiply by 30.

### **TABLESPOONS TO CUBIC CENTIMETERS**

Multiply by 0.001.

### **TEASPOONS TO CUBIC CENTIMETERS**

Multiply by 5.

## SHORT MEDICAL RECORD

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**Name of Patient and Date of Birth**

---

**Medical Record Number**

---

**Name of Parent(s) or Guardian**

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**Street Address, City, State, Zip**

---

**Home phone/cell phone/email**

---

**Diagnoses (diseases or disorders of patient)**

---

**Name of primary doctor or nurse practitioner**

---

**Telephone number**

---

**Place**

# WEIGHT AND HEIGHT MEASUREMENTS

**Date**                      **Weight**                      **Height**


---

**Allergies**

---

**Prescription medications**

---

**Nonprescription medications**

---

**Food allergies/intolerance**

---

**Other allergies (latex, animal dander, mold, ragweed, tobacco smoke, etc.)**





## **MAJOR ILLNESSES AND INJURIES**

(Please indicate problems that required a visit to doctor or ER)

---

**Date**

---

**Symptoms**

---

**Diagnosis**

---

**Medications**

---

**For how long?**

---

**Other treatments**

---

**Reactions?**

---

**Complications?**

---

**Date**

---

**Symptoms**

---

**Diagnosis**

---

**Medications**

---

**For how long?**

---

**Other treatments**

---

**Reactions?**

---

**Complications?**











## **CLINIC/LAB PHONE NUMBERS**

**CHILDREN'S MERCY – 2401 Gillham Road | Kansas City, MO 64108**

**(816) 234-3000 | Toll free 1 (866) 512-2168**

Abdominal Pain Clinic	(816) 983-6975
Arrhythmia Clinic	(816) 234-3325
Autism Clinic	(816) 234-3674
Bedwetting (Enuresis) Clinic	(816) 234-3030
Bone and Mineral Disorders Clinic	(816) 234-3030
Burn Clinic	(816) 234-3199
Cardiology Clinic (Heart Center)	(816) 234-3880
Cardiovascular Surgery Clinic	(816) 234-3880
Cleft Palate/Craniofacial Clinic	(816) 234-3020
Cystic Fibrosis Clinic	(816) 983-6490
Dental Clinic	(816) 234-3257
Developmental/Behavioral Sciences	(816) 234-3674
Dialysis/Kidney Transplant Clinic	(816) 234-3030
Dialysis Unit	(816) 234-3100
Down Syndrome Clinic	(913) 960-2856
Ear, Nose and Throat Clinic (ENT)	(816) 234-3040
Enuresis (Bedwetting) Clinic	(816) 234-3030
Gastroenterology Clinic	(816) 234-3066
General Surgery Clinic	(816) 234-3199
Genetics Clinic	(816) 234-3771
Headache Clinic	(816) 234-3490
Hematology/Oncology Clinic	(816) 234-3460
Hypertension Clinic	(816) 234-3030
Inflammatory Bowel Disease Clinic	(816) 234-3066
Infectious Disease Clinic	(816) 983-6325
Integrative Pain Medicine Clinic	(816) 983-6750
Kidney Care Center	(816) 234-3030
Lab (Outpatient)	(816) 234-1530
Lactation (Breastfeeding) Clinic	(816) 346-1309
Laser Surgery Clinic	(816) 234-3020
Liver Care/Transplant Clinic	(816) 234-3066
Lupus Clinic (Rheumatology)	(816) 234-1666
Metabolic Genetics Clinic	(816) 234-3771
Neonatal Clinics (BPD, FUNN, ICND, LBW, etc.)	(816) 234-3791
Nephrology (Kidney, Renal) Clinic	(816) 234-3030
Neurology Clinic (Seizures, brain, nerves)	(816) 234-3490
Neurosurgery Clinic	(816) 234-3199

Nutrition Clinic	(816) 234-3468
Ophthalmology (Eyes/Vision) Clinic	(816) 960-8000
Orthopedic (Bones, Joints) Clinic	(816) 234-3075
Otorhinolaryngology (ENT)	(816) 234-3040
Outpatient Lab	(816) 234-1530
Pacemaker Clinics (Cardiology)	(816) 234-3325
Pain Management Clinic	(816) 983-6750
Plastic Surgery Clinic	(816) 234-3020
Prenatal Genetics Clinic	(816) 234-3771
Preventive Cardiology Clinic	(816) 234-3325
PT/OT (Physical/Occupational Therapy)	(816) 234-3380
Pulmonology (Lungs) Clinic	(816) 983-6490
Radiology	(816) 234-3270
Rehabilitation Clinic (Baclofen Pump, Botox, Muscle and Nerve, Brachial Plexus, Amputee/Prosthetic, Seating/Wheelchair, Spinal Defects, Tone Management, EMG)	(816) 234-3791
Rheumatology Clinic	(816) 234-1666
SCAN (Safety, Care and Nurturing)	(816) 234-3424
Sleep Clinic	(816) 983-6355
Special Care Clinics (Rehabilitation)	(816) 234-3791
Spine Clinic	(816) 234-3075
Urologic Surgery Clinic	(816) 234-3199
Urology Clinic	(816) 234-3199

### **CHILDREN'S MERCY BROADWAY – 3101 Broadway, Kansas City, Mo.**

Allergy/Asthma/Immunology Clinic	(816) 960-8900
Dermatology Clinic	(816) 960-4051
Diabetes Clinic	(816) 960-8802
Endocrine Clinic	(816) 960-8803
Growth Hormone Clinic	(816) 960-8801
Toll free	(888) 563-3070
Ophthalmology (Eyes/Vision) Clinic	(816) 960-8000
Pediatric Care Center (PCC)	
Yellow Clinic	(816) 960-3080
Purple Clinic	(816) 960-3090
Green Clinic	(816) 960-3060
Orange Clinic	(816) 960-3070
Speech/Language/Hearing Clinic	(816) 960-4001
Teen Clinic (Adolescent Medicine)	(816) 960-3050
Weight Management Clinic (PHIT)	(816) 960-2852

**CHILDREN'S MERCY COLLEGE BOULEVARD - 5520 College Blvd.,  
Overland Park, Kan.**

Developmental/Behavioral Sciences Clinic	(913) 696-8261
PT/OT (Physical/Occupational Therapy)	(913) 696-8800
Hearing and Speech	(913) 696-8844
Nutrition Clinic	(913) 696-5050
Pulmonology Clinic	(913) 696-5050

**CHILDREN'S MERCY HOSPITAL KANSAS - 5808 West 110th,  
Overland Park, Kan.**

**(913) 696-8000 | Toll free 1 (866) 572-0158**

Allergy/Asthma/Immunology Clinic	(913) 696-8220
Cardiology Clinic	(913) 696-8700
Cleft Palate/Craniofacial Clinic	(913) 696-8220
Dermatology Clinic	(913) 696-8220
Diabetes Clinic	(913) 696-8220
Ear, Nose and Throat Clinic	(913) 696-8620
Endocrine Clinic	(913) 696-8220
Fetal Health Center Clinic	(913) 696-5700
Gastroenterology Clinic	(913) 696-5819
General Surgery	(913) 491-0880
Genetics Clinic	(816) 234-3771
Kidney Clinic (Nephrology)	(913) 696-8220
Lab	(913) 696-8210
Nephrology (Kidney, Renal) Clinic	(913) 696-8220
Neurology Clinic	(913) 696-8220
Ophthalmology (Eyes, Vision)	(913) 696-8832
Orthopedic Surgery Clinic	(816) 234-3075
Otorhinolaryngology (ENT) Clinic	(913) 696-8620
Pharmacy	(913) 696-8200
Plastic Surgery Clinic	(913) 696-8220
Radiology	(913) 696-8181
Rehabilitation/Seating Clinic	(913) 696-5050
Rheumatology Clinic	(913) 696-5050
Sleep Disorders Clinic	(913) 696-5050
Hearing and Speech Clinic	(913) 696-5750
Urology Clinic	(913) 696-8570

**CHILDREN'S MERCY NORTHLAND - 501 NW Barry Road, Kansas City, Mo.**

**(816) 413-2500 | Toll free 1- (800) 918-6691**

Adolescent (Teen) Clinic	(816) 413-2500
Audiology (Hearing) Tests	(816) 413-2519

Cardiology Clinic	(816) 413-2500
Dermatology Clinic	(816) 413-2500
Down Syndrome Clinic	(816) 960-2856
Ear, Nose and Throat Clinic (ENT)	(816) 413-2500
Endocrinology/Diabetes Clinic	(816) 413-2500
ENT Clinic (DUPLICATE of above)	(816) 413-2500
Hearing and Speech	(816) 413-2500
Laboratory	(816) 413-2520
Neurology Clinic	(816) 413-2500
Nutrition Clinic	(816) 413-2500
Ophthalmology Clinic	(816) 413-2546
Orthopedic Clinic	(816) 413-2500
Radiology	(816) 413-2517
Urgent Care Center	(816) 413-2500
Urology Clinic	(816) 413-2500

**CHILDREN'S MERCY EAST - 20300 East Valley View Parkway, Independence, Mo.**

Urgent Care Center	(816) 478-5200
Cardiology Clinic	(816) 478-5200
Ear, Nose and Throat Clinic	(816) 478-5200
Endocrinology/Diabetes Clinic	(816) 478-5200
Gastroenterology Clinic	(816) 478-5200
Hearing and Speech Clinic	(816) 478-5200
Neurology Clinic	(816) 478-5200
Orthopedics Clinic	(816) 478-5200
Rehabilitation Medicine Clinic	(816) 478-5200
Sports Medicine Clinic	(816) 478-5200

**CHILDREN'S MERCY WEST/THE CORDELL MEEKS JR. CLINIC - 4313 State Ave., Kansas City, Kan.**

Pediatrics Clinic/Teen Clinic	(913) 233-4400
Pharmacy	(913) 233-4452

**OPERATION BREAKTHROUGH - 3039 Troost, Kansas City, Mo.**

Pediatrics Clinic	(816) 329-5202
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**CHILDREN'S MERCY BLUE VALLEY - 6750 West 135th Street, Overland Park, Kan.**

Sports Medicine Clinic	(913) 717-4750
Sports Therapy	(913) 717-4700
Urgent Care Clinic	(913) 717-4700

<b>NURSE ADVICE LINE</b>	(816) 234-3188
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**1 Children's Mercy  
Adele Hall Campus**  
2401 Gillham Road  
Kansas City, MO 64108  
(816) 234-3000

**2 Children's Mercy  
Hospital Kansas**  
5808 West 110th Street  
Overland Park, KS 66211  
(913) 696-8000

**3 Children's Mercy  
College Boulevard**  
5520 College Boulevard  
Overland Park, KS 66211  
(913) 696-8000

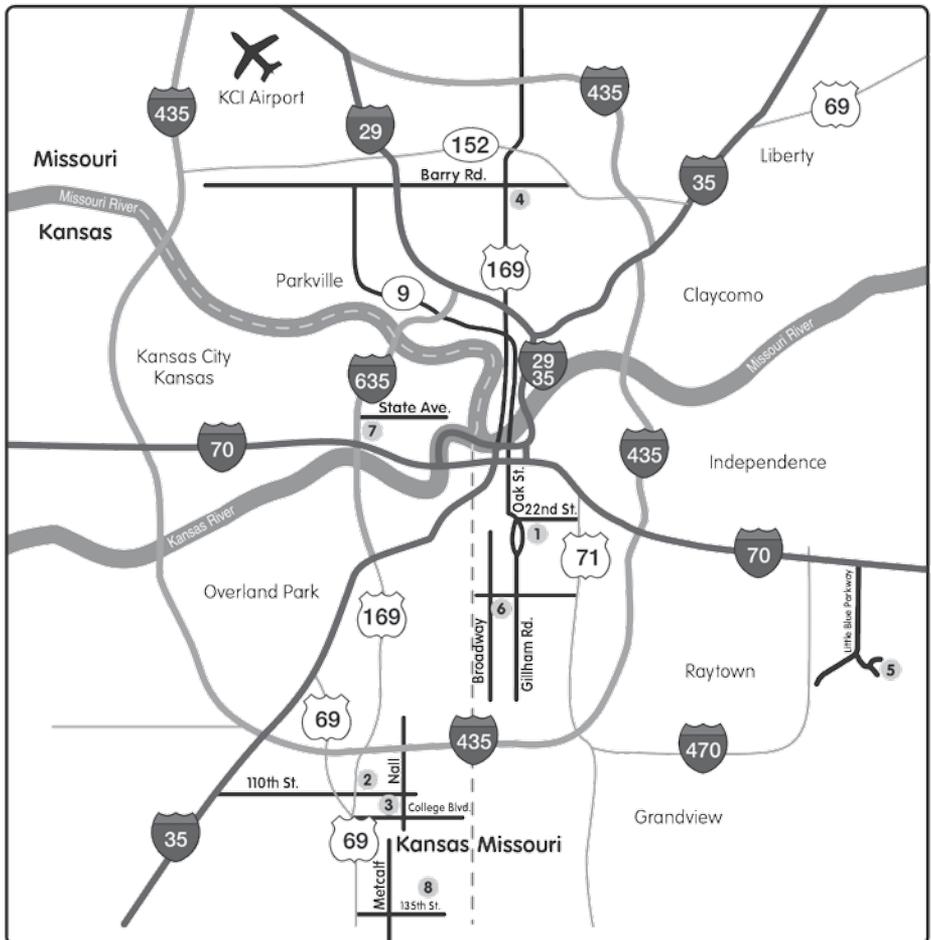
**4 Children's Mercy Northland**  
501 NW Barry Road  
Kansas City, MO 64155  
(816) 413-2500

**5 Children's Mercy East**  
20300 East Valley View Parkway  
Independence, MO 64057  
(816) 478-5200

**6 Children's Mercy Broadway**  
3101 Broadway  
Kansas City, MO 64111

**7 Children's Mercy West-  
The Cordell Meeks Jr. Clinic**  
4313 State Avenue  
Kansas City, KS 66102  
(913) 233-4400

**8 Children's Mercy Blue Valley**  
6750 West 135th Street  
Overland Park, KS 66223  
(913) 717-4700







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06/17