The Family Advisory Council at the Johns Hopkins Children’s Center promotes a culture of patient- and family-centered care. The Council is a group of patients’ families and hospital staff that supports collaboration, communication, and dignity and respect between the healthcare team and families to achieve the best possible outcomes. We meet monthly to give input about what it is like to be the family member of a sick child. Our families’ voices are being heard and their input is making a difference in our patients and families’ hospital experiences.
"I wish you knew..."

how confusing and difficult it is to be a parent of a seriously ill child. During the course of my child’s life, we experienced all the various units that an infant could visit and had consultations from almost all the services. I felt like I was Alice in Wonderland. I had stepped through “The Looking Glass” and was now on the other side, the patient side. The world looked very different.

No longer was I a competent, productive, intelligent member of society. I was “the mom” by the bedside. I was the anxious, exhausted, stressed parent of a sick infant. I had never felt so powerless, vulnerable, and scared in my whole life.

Hopkins Children’s Parent
Your Child’s Care Team

Because you know your child best, we encourage you to participate as much as possible in his or her care. You can help our staff by sharing information, and always feel free to ask questions. Doctors usually make rounds early in the morning, which is a good time to ask questions. Because Johns Hopkins Children’s Center is a teaching hospital, your child will be cared for by a team of pediatric healthcare professionals, including:

Attending Physicians
Each child has an attending physician who is a pediatrician or pediatric surgeon. Attendings (as they are called) are responsible for your child’s care. They can teach and supervise other residents and fellows (doctors in training). Your child’s attending physician may change during his or her time in the hospital.

Fellows
Fellows are doctors who have completed 3 years of residency in pediatrics and are now training to become pediatric specialists like pulmonologists, oncologists, or neurologists. Most fellowships last at least 3 years.

Senior Residents
After medical school, pediatric residents undergo a 3-year general pediatrics training program. Senior residents are doctors in their second and third year of this training. They supervise interns but are still in training. Senior residents are responsible for all aspects of your child’s care while in the hospital. You will have daily interactions with them.

Interns
Interns are doctors who are first-year residents in training. They are the doctors you may have the most contact with.

Hospitalists
Hospitalists are a group of board-certified pediatricians who consult and coordinate with surgical services within the Children’s Center.

Physician Assistants (PAs)
Physician assistants have specialized training and can help manage your child’s care along with the team. PA’s can also write orders for tests and medications.

Medical Students
Medical students are closely supervised by residents, fellows, and attendings. They are in the process of completing a 4-year program.

Nursing Students
Nursing students are closely supervised by a nursing instructor and/or a floor nurse. They are typically completing pediatric clinical time for a 4-year degree.

Nurse Practitioners
Nurse practitioners have completed advanced education and can assist the doctor in managing your child’s care. They can also write orders for tests and medications for your child.

Nurse Managers
Nurse managers are responsible for operations and administrative functions on the unit or floor to assure quality care for all patients. They must have a Masters or Doctorate in Nursing.

Case Manager/Discharge Coordinator
A case manager/discharge coordinator is a nurse who is automatically assigned to every patient and can help you and your child prepare to go home. The process begins with admission even though you may be here in the hospital for a long time. They can help with education, equipment, home services and many other things needed.

Nurses
Registered pediatric nurses give your child both physical and emotional care. They also help the family meet their needs. A bedside nurse is the nurse you will have the most contact with. If you have concerns about your child you should talk to your bedside nurse first. If you still have concerns that aren’t being addressed, you can ask to speak to the charge nurse. Your child will go through 2-3 shifts of nurses in one day.

Child Life Specialists
Child life specialists address the developmental and emotional needs of children and families. They help children adjust to being in the hospital by: providing therapeutic play to promote emotional expression and reduce stress, preparing children for medical procedures, and providing opportunities for developmentally supportive play, holiday celebrations and the support to keep up with schoolwork. Call 410-955-6276.

Social Workers
Social workers are trained to help parents and families cope with illness and the changes that occur when a child is in the hospital. They can provide emotional support and make sure that your voice is heard among all members of the healthcare team. They can help you find specific community resources such as counseling, special education, and agencies that provide public aid and insurance. Call 410-955-6518.

Chaplain
Chaplains are available to all people regardless of their faith background. When faced with illness and hospitalization, many of us struggle with questions of meaning, hope, faith, and doubt. Chaplains are available 24/7 to serve patients and their families. If you would like to speak with a Chaplain, please ask your nurse, or text a message to 410-434-0909. Please include your contact information.

Physical, Occupational, Speech and Respiratory Therapists
Therapists provide specialized care as needed and are consulted by your healthcare team.

Bereavement Support
Bereavement support offers grief and bereavement support to families facing serious losses. Provides printed resources, phone support, individual and group support to those who anticipate or have suffered significant loss.

Pharmacists
They review and provide the medicine your child is given in the hospital to assure safety.

Dieticians
A nutritionist, or Registered Dietitian, checks the nutritional status of patients and makes sure they receive the appropriate food, formula, or supplements in order to heal and grow while in the hospital.

Clinical Customer Service Coordinators (CCSC)
CCSCs serve as the initial point of contact for patients’ and families’ concerns. The CCSC’s main goal is to help create and maintain a 5-star customer experience for our patients and families. They round daily on patients and families to make sure the unit is meeting their needs as well as team up with other members of our healthcare team to help address and provide solutions to their issues and concerns.
Medical Terminology 101

COMMONLY USED ABBREVIATIONS

**NPO** = nothing by mouth

**NG** = naso-gastric, commonly a NG tube is placed for feeding, going into the nose and to the stomach.

**LP** = lumbar puncture. A test of the spinal fluid for infection.

**ICP** = intracranial pressure. The amount of pressure on the brain that is often caused by extra fluid or blood in the skull.

**ETT** = endo-tracheal tube. A tube that can help your child breathe.

**VENT** = machine to help your child breathe.

**O₂** = oxygen

**BP** = blood pressure

**IV** = a tube placed in a vein to give fluid or medicine

**KG** = kilogram. Children are weighed in kilograms, medicine is based in kilograms. The conversion is 1 KG = 2.2 pounds

**EKG or ECG** = electrocardiogram. A test that measures the heart rhythm and rate

**EEG** = electroencephalogram. A test that measures brain activity with the intent to look to see if there is a seizure or epilepsy focus.

**MRI** = Magnetic Resonant Imaging. A specialized kind of test that examines a part of the body, like the brain, heart, abdomen, chest or extremities, to give very detailed pictures to look for specific kinds of diseases.

**CT** = computerized tomography. A specialized kind of test that also examines a part of the body. Usually can be done more quickly, but the MRI gives more details.

**PCA** = patient controlled analgesia. Pain medication is administered through this device.

OTHER ABBREVIATIONS WHICH RELATE TO YOUR CHILD

**Ortho** – relates to bones

**Neuro** – relates to the head/spine/nervous system

**Pulmonary** – relates to the lungs

**Hepatic** – relates to the liver

**Renal** – relates to the kidneys

**Sats** – measured in percentages (%) by the light laser (pulse ox machine) attached to your child's finger or toe. This tells the amount of oxygen in your child's blood. Ask the nurse to show you where this number is located on the monitor. Observe what is normal for your child and remember sats may fluctuate while your child sleeps.

**Heart rate** – The number of heart beats in a minute. Ask your nurse where this number is on the monitor and what is the normal range for your child. Your child's heart rate may fluctuate while your child sleeps.

**Rounds** – Rounds refer to a daily meeting that your child's healthcare team has about your child's condition. It is often at the bedside and may include a variety of team members (attendings, residents, medical students, nursing, social work, etc.)

*Ask to be included as you are an important part of the healthcare team. Remember you are the expert on your child.*

**Anesthesia** – a way to either provide pain relief or to make the child sleep in order to do a necessary procedure.

OTHER MEDICAL TERMS WHICH RELATE TO YOUR CHILD

4 Patient – and Family – Centered Care

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**parent tip**

Avoid using words that may have a frightening or confusing double meanings for your child. For example, instead of being “put to sleep” it would be more reassuring to hear you say “there is some medicine that will help you sleep.” Instead of “dressing” use “bandage.” Instead of “gas” use “anesthesia or sleepy medicine.” Think about the hospital experience through your child’s eyes and you will come up with many more words with double meanings.
My Surroundings

What are the visitor guidelines for my child’s floor?

______________________________________________________________

Can I spend the night with my child?

______________________________________________________________

What are the cafeteria hours?

______________________________________________________________

Are there shower facilities available for parents?

______________________________________________________________

Where is the closest ATM?

______________________________________________________________

Can I use my cell phone or laptop?

______________________________________________________________

Where is the closest parking garage and where do they sell parking coupons?

______________________________________________________________

Are lactation rooms available?

______________________________________________________________

Where are the closest restaurants?

______________________________________________________________

Are there laundry facilities?

______________________________________________________________

Where is the chapel or another quiet place?

______________________________________________________________

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Important Numbers

**Pediatric Admitting:** 410-955-8756  
**Patient Information:** 410-502-4000  
**Parking:** 410-955-5333  
**Chaplain:** 410-434-0909 (pager)  
**Patient Relations:** 410-955-2273  
**Billing:** 443-997-0100  
**Guest Services:** 410-614-5100, Monday through Friday, 8 a.m. to 4:30 p.m. Helps with the special needs of international patients and families.  
**Interpreter Services:** 410-614-4685, Johns Hopkins has a team of professional interpreters who speak more than 30 languages.  
**Children’s and Family Resource Library:** 410-955-6442, open Monday through Friday, 9 a.m. to 5 p.m. A collection of books for children of all ages and print resources for parents. A librarian is available full-time to do searches for parents on specific medical subjects. Other services include a book-cart which visits pediatric units, and morning coffee.  

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**GUESTNET: PATIENT AND FAMILY WIRELESS INTERNET ACCESS**

**Basic Equipment**  
A laptop running Windows or Macintosh operating system with wireless capabilities is required to access JHGuestnet. Your computer should be running a commercial anti-virus product to assist with improving the protection of computers on the infrastructure.

**Connecting**  
Open your wireless network configuration page and select JHGuestnet. Although you may be able to see other networks, you may not be able to access them. You may receive notification that information sent over the network is not encrypted. You will need to select "Connect Anyway" in order to proceed. Open the browser.

When complete scroll to the bottom to accept the terms and conditions. NOTE: JHGuestnet can be accessed from various locations in the hospital. It is not available in all hospital locations. Some websites may be blocked. If you need help, call 410-955-HELP. Access to corporate and personal e-mail should function normally.
Managing Pain

Children in the hospital may experience pain from surgery, certain procedures or illnesses, and both families and patients may have concerns about how this pain will be treated. Our goal is to prevent or minimize pain as much as possible. We believe that pain is very individual — pain is whatever the person experiencing it says it is — so we trust your child is in pain when he or she says so.

YOU SHOULD KNOW THAT:

• Fussiness, restlessness, poor feeding, poor sleep and decreased play may be signs that your child is in pain.

• Unrelieved pain can be harmful, and result in a longer hospital stay. Nurses will ask your child to rate his or her pain on a 0 to 10 scale, with 0 meaning no pain and 10 the worst pain imaginable. Nurses may use a pain-rating scale called FACES, and ask your child to point to the drawing of a face that best shows his or her pain. There are other pain scales as well.

• Medicines to treat your child’s pain may be given through an intravenous catheter, or orally as a tablet or liquid. You can help reduce pain by holding or rocking your child, distracting him with a favorite activity such as coloring, playing music or games, or by providing a comfort item from home.

• The Pediatric Pain Service at Hopkins Children’s is available for complex cases, and is staffed by pediatric nurse practitioners and pediatric anesthesiologists. Our physicians are trained to manage pain safely in children.

As parents, you know your child better than those of us who work in the hospital.

To help us care for your child:

• Tell us if you think your child is hurting/in pain.

• Tell us if your child has a special name for pain, such as “owie.”

• Tell us what works best to comfort your child.

• Let us know if you think your child’s pain is not being controlled.

“"My son never cried even as an 8-month old with a liver transplant, he was always a happy little guy. He amazed us. But one night he cried for three straight hours. I knew something was wrong — this was not how my son usually acted. I went to my doctor who told me he was fine, but I knew he wasn’t. I finally told my nurse who called the Pain Management team. They came, assessed him and gave him the medicine he needed to ease his pain. An hour later I had my happy little boy back. I am so thankful they listened.”

Hopkins Children’s Parent
Being In the Hospital

GATHER YOURSELF FIRST

• Gather information before speaking with your child
• Talk with your child’s doctor about the plan for treatment
• Learn about the tests and treatments planned for your child
• Be sure to get answers to your questions that make sense to you
• Recognize your own feelings and perceptions about your child’s hospitalization
• Identify a support network
• Talk with friends and family to help with things that will be hard for you to do while you are in the hospital (for example: meals, transportation, sibling care, and daily errands)
• Make arrangements for child care for your other children

HOW TO TALK TO YOUR CHILD

You know your child best of all. Use that knowledge, along with the information you have gathered, to talk openly and honestly with your child. Find what questions he/she has and what he/she may be wondering about being in the hospital. How much to tell your child will depend on:

• Age and developmental stage
• Personality
• Past healthcare experiences
• Understanding of the illness

INFANTS/ TODDLERS/ PRESCHOOLERS

What You May Want to Prepare For:

• Change in routine
  - Diet restrictions
  - Changes in sleep patterns
  - Mobility restrictions
• Separation from caregivers
• Unfamiliar environment and people
• Possible interruption of typical development
  - Learning to sit up, crawl, and stand for infants; toilet-training for toddlers and talking about and sharing wants and needs with preschoolers.

How to Help Your Infant:

• Bring familiar comfort items from home
  - Blankets, stuffed animals, pacifiers, soothing music, as well as any items you think may be helpful
• Create a plan for consistent caregivers (make a schedule of who can be at the hospital at different periods of time)

How to Help Your Toddler/Preschool Child:

• Ask your child to help choose familiar comfort items from home
• Select a favorite blanket or pillow, stuffed animal, soothing music, play activities (toys, books, arts and crafts), as well as any items you think may be helpful
• Create a plan for consistent caregivers (make a schedule of who can be at the hospital at different periods of time)
• Provide your child an opportunity to participate in healthcare play
• Purchase a play “doctor’s kit”

parent tip

Common Questions You Should Ask

• How long will the procedure/surgery take?
• What kind of equipment will be used and what will it sound/look like?
• What kind of preparation does my child need to have before the procedure/surgery?
• What, if anything, is expected of my child?
• Can I stay with my child for the procedure?
• Can I be there when my child wakes up?
• How will my child’s pain be managed?
• How long will my child be in the hospital?
• What medications will my child be taking and what are the side effects?
• Will my child have any dietary/activity restrictions?

• When talking about the hospital, describe what your child may hear, see, and smell.
• Remind your child that family and friends will be able to come visit them.
• Let your child know its okay to have feelings about the hospitalization, listen to their feelings and help your child talk about them.
• Read books about being in the hospital.
• Play with a doctor kit, letting your child be the doctor and a doll or teddy bear be the patient.
• Young children will often let you know their true feelings by expressing them through play.
• Label your child’s belongings with their initials.
**SCHOOL AGE**

**What You May Want to Prepare For:**
- Change in routine
  - Diet restrictions
  - Changes in sleep patterns
  - Mobility restrictions
  - Time away from school
  - Time away from sports and activities
- Separation from peers and caregivers
- Unfamiliar environment and people
- Feeling homesick
- Loss of independence

**How to Help Your School-Age Child:**
- Bring familiar items from home
  - Favorite blanket, pillow, slippers, activities (toys, books, music, arts and crafts, games, laptop) as well as any items you think may be helpful
  - Encourage your child to help with the packing to be sure your child’s favorite items are included
- Create a plan for consistent caregivers (make a schedule of who can be at the hospital at different periods of time)
- Communicate with your child’s teachers about ways to keep up with school work
- Provide your child an opportunity to participate in health care - through asking questions and being included in basic discussions

**ADOLESCENTS**

**What You May Want to Prepare For:**
- Change in routine
  - Diet restrictions
  - Changes in sleep patterns
  - Mobility restrictions
  - Time away from school
  - Time away from sports and activities
- Separation from peers and caregivers
- Unfamiliar environment and people
- Feeling homesick
- Loss of independence
- Concerns about changes in physical appearance

**How to Help Your Teen:**
- Bring familiar items from home
  - Favorite blanket, pillow, slippers, activities (books, music, arts and crafts, games, laptop) as well as any items you think may be helpful
  - Ask your teen to make a list of things that they want from home
- Create a plan for consistent caregivers (make a schedule of who can be at the hospital at different periods of time)
- Communicate with your teen’s teachers about ways to keep up with school work
- Provide your teen an opportunity to participate in health care – encourage her to ask questions and take part in decision making
- Plan ways for your teen to keep in touch with peers

Talk to your child about being in the hospital and the reason for admission openly and honestly. Children are more likely to maintain a trusting relationship if they feel included in the experience and older children like being a part of the decision making process. Give your child a chance to talk about what questions he/she may have as well as what he/she may be thinking about. Clarify any misconceptions that may arise in your conversation. Talk with your older child about ways to share his/her upcoming hospital stay with peers.

**Tutoring in the hospital:**
For children who will miss more than two weeks of school, the Child Life Department can help arrange Home and Hospital School Services.

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**Books about being in the hospital**
- **Toddlers**
  - *Miffy in the Hospital* - Dick Bruna
  - *A Visit to the Sesame Street Hospital* - Debbie Hautzig
- **Preschoolers**
  - *Curious George goes to the Hospital* - Margaret and H.A. Rey
  - *Frankie and Fuzzy* - Susan Murray
- **School-Aged Children**
  - *When Molly was in the Hospital: A Book for Hospitalized Children* - Debbie Duncan
  - *This is a Hospital not a Zoo* - Roberta Karim
- **Teens**
  - *Plastic Eggs or Something? Cracking Hospital Life* - a video
  - *What am I, Chopped Liver?* - a video
Child Life... Who We Are
Play, Prepare, Support

Child Life Specialists know how hard it can be when a child is sick and in the hospital. The Child Life Department works with the healthcare team to teach kids and families skills they can use before, during, and after their time in the hospital.

HOW WE HELP

• Use developmentally appropriate language and tools to help your child understand her illness
• Prepare your child for upcoming procedures
• Encourage your child’s use of effective coping skills during procedures
• Support your child during procedures using play and distraction techniques
• Provide your child with opportunities to express his feelings related to healthcare experiences
• Support your child’s growth and development while in the hospital
• Help your child feel connected to school and peers
• Provide opportunities for your child to play
• Coordinate special events and activities
• Support siblings by helping them understand their sibling’s illness and treatment
• Provide support during grief and bereavement
• Provide parents and caregivers the opportunity to express their feelings related to the healthcare experience
• Act as an advocate for you and your family

PLAY

Play is an essential, natural part of childhood, important in its own right. Play facilitates coping, mastery, self-expression, creativity, achievement and learning, and it is vital to a child’s optimal growth and development. The hospital maintains a variety of playrooms and spaces staffed by Child Life Specialists. Hospitalized children benefit from daily opportunities to play, whether it is in the playroom or at the bedside.

COPING WITH HEALTHCARE EXPERIENCES

Effective coping allows children to gain a sense of control over hospital experiences. Everyone copes in different ways. Child Life Specialists help to identify the parts of hospitalization that might be most difficult. They work with you and your child to create and practice a plan to cope with these experiences. The following list provides examples of coping techniques that have proven to be successful.

Coping Methods

• Blowing bubbles
• Breathing deeply
• Reading picture books; look and find books
• Listening to music
• Singing
• Massaging your child’s hand, foot, or forehead
• Holding a soft comfort item
• Praying
• Reading sacred texts
• Helping your child think of a favorite thing, event, memory

Notes
SIBLING SUPPORT

We recognize that siblings can often be affected by their brother or sister’s healthcare experiences. Child Life Specialists can serve as a resource for helping caregivers understand and support their children at home.

**Difficulties for Siblings:**
- Separation from caregivers and sibling
- Change in familiar routines
- Feelings of guilt related to thoughts about their ill sibling
- Fears or misconceptions regarding hospitalization
- Decrease in attention from caregivers

**Behaviors to Expect from Siblings:**
- Eat or talk less
- Show withdrawn behavior
- Act out in a way to get more attention
- Outbursts of stored up feelings
- Return to behaviors of an earlier age

**Child Life Specialists Can Help Your Child:**
- Prepare for a visit to the hospital
- Stay connected with hospitalized sibling
- Cope with feelings
- Process events

**How You Can Help**
- Maintain connections between siblings (via e-mail, text messaging, photos, Skype, phone)
- Bring siblings to the hospital; if visits are not possible, have them stay in touch by telephone.
- Send home pictures, art work and audio/video dvd’s.
- Prepare the sibling for changes in the ill child’s appearance.
- Prepare the sibling for any medical equipment that may be needed in the home

“**So many of us have sat where you sit now,** at the bedside of your sick child, anxious, tired, and in disbelief that your child is here. Know that you are not alone. Know that it will get better. Know that there is hope.”

Hopkins Children’s Parent
Social Workers... Who We Are

Social Workers are trained to be experts on families and related community systems. We help build relationships between the family and community resources.

How Social Workers Can Help

• Learn about your family’s strengths and needs in relation to your child’s illness or injury
• Provide support and counseling for your family related to coping with illness, hospitalization, and ongoing treatment
• Help you gain a better understanding of the illness and learn what to expect while receiving treatment
• Provide education about the healthcare system, including insurance and transportation needs
• Help you talk with your child or other children about the hospital stay
• Support your family’s experience with grief and bereavement
• Promote a safe family environment with family violence assessment and safety planning
• Support your family as members of the healthcare team
• Link your family to community resources

Social Work Services include:

• Advocacy
• Counseling
• Assessment of psychosocial needs
• Education
• Assess and provide ways to deal with difficult behaviors
• Crisis intervention
• Link you to community resources

Receiving Information

THOUGHTS FROM AN INTENSIVE CARE NURSE®

Everyone processes information differently. Think about how you process information and ask yourself these questions:

• Do you need to know small bits at a time or the whole picture?
• Do you want the overview or every small detail?
• Are you able to really hear what the doctors and nurses are saying?
• Are you remembering what is being said to you enough to repeat this information to your spouse, close friends and family?
• Would you like to have explanations of what is happening to your child drawn out? Use the space below or the note section at the end of this journal to have members of your healthcare team explain visually what is going on.

TIPS FROM AN INTENSIVE CARE NURSE®

• Have explanations repeated until you understand.
• Ask another family member or friend to be with you so they can also help absorb information.
• Write things down—it will be easier to handle all the information.

Know how you process information and decide what’s best for you. It’s okay for you to write down your questions and ask them later. Or for you to ask the doctor or nurse to give you some time to digest what was just told to you.

It’s difficult to gauge your state of mind right now, but as a parent you want to remember all the details. These questions will help you focus on some of your needs. Use this space to make notes about what help you need in order to hear what’s being said to you.


parent tip

• Flu/RSV season can last from September through May. Parents, guardians or a designated adult (18 years of age or older) are welcome any time of day. Other family members, friends, or siblings (16 years of age or older) are welcome to visit any time between Noon–8 pm.
• If your child is on isolation procedures this means your child has a potentially contagious illness. This prevents spread to others and usually includes instructions that visitors must wear a gown, gloves and possibly a mask, and that your child cannot leave his/her room.
My Feelings

Writing down your feelings can be a positive step in coping with your child’s hospitalization. All feelings are valid.

**Why My Child?**

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

_________________________

I’m Overwhelmed! Write down your swirling thoughts, fears, or to-do lists.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

How is my spouse or other family members coping with this hospital stay? Everyone copes differently, write down what you observe, and what would help you cope better.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

I’m frustrated! For every step forward sometimes you take two steps back. Write down what’s happening.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

How do you feel about the care your child is receiving? What if anything would you change if you could?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

How can I share my family’s race, spiritual, ethnic and cultural needs with our healthcare team?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
### Medication Log

<table>
<thead>
<tr>
<th>Name of Medicine</th>
<th>Dosage</th>
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<tbody>
<tr>
<td>Date Started</td>
<td>Date Stopped</td>
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<tr>
<td>Prescribing Physician</td>
<td>Contact Info</td>
</tr>
<tr>
<td>Purpose</td>
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<tr>
<th>Side Effects</th>
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<tr>
<td>Questions</td>
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</table>

Name of Medicine __________________________ Dosage ____________
Date Started __________________________ Date Stopped ____________
Prescribing Physician _________________ Contact Info ________________
Purpose ___________________________________________________________________

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Purpose ___________________________________________________________________

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<th>Side Effects</th>
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<tbody>
<tr>
<td>Questions</td>
</tr>
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</table>
Tests & Procedures

Test Name: ___________________________ Date: ________________

Location (Dept.): ____________________________________________

Time Scheduled: ____________________ Time Started: __________

Physician Name and Contact: ___________________________________

Purpose: _____________________________________________________

______________________________________________________________

Side Effects: __________________________________________________

______________________________________________________________

Who gives results and when: ___________________________________

______________________________________________________________

Test Name: ___________________________ Date: ________________

Location (Dept.): ____________________________________________

Time Scheduled: ____________________ Time Started: __________

Physician Name and Contact: ___________________________________

Purpose: _____________________________________________________

______________________________________________________________

Side Effects: __________________________________________________

______________________________________________________________

Who gives results and when: ___________________________________

______________________________________________________________

Test Name: ___________________________ Date: ________________

Location (Dept.): ____________________________________________

Time Scheduled: ____________________ Time Started: __________

Physician Name and Contact: ___________________________________

Purpose: _____________________________________________________

______________________________________________________________

Side Effects: __________________________________________________

______________________________________________________________

Who gives results and when: ___________________________________

______________________________________________________________
Daily Care

Date __________ Room Number/Phone ______________________

Where did I park today? ______________________________

Your Health Care Team today is:

Day RN ______________________ Night RN ______________________

Other ______________________

Dietary Restrictions ______________________________

Physician Visits:

Physician Name _____________________________ Specialty ______________________

Contact ________________________________

Comments ________________________________

What went well today? ________________________________

What could have been better? ________________________________

What is one goal for tomorrow? ________________________________

Questions ________________________________

__________
Daily Care

Date __________ Room Number/Phone __________________________

Where did I park today? _________________________________________

Your Health Care Team today is:

Day RN __________________________ Night RN ________________________

Other __________________________________________________________

Dietary Restrictions _____________________________________________

Physician Visits:

Physician Name __________________________ Specialty __________________

Contact _______________________________________________________

Comments ______________________________________________________

_________________________________________________________________

What went well today? ___________________________________________

_________________________________________________________________

What could have been better? _____________________________________

_________________________________________________________________

What is one goal for tomorrow? __________________________________

_________________________________________________________________

Questions ______________________________________________________

_________________________________________________________________

Daily Care

Date __________ Room Number/Phone __________________________

Where did I park today? _________________________________________

Your Health Care Team today is:

Day RN __________________________ Night RN ________________________

Other __________________________________________________________

Dietary Restrictions _____________________________________________

Physician Visits:

Physician Name __________________________ Specialty __________________

Contact _______________________________________________________

Comments ______________________________________________________

_________________________________________________________________

What went well today? ___________________________________________

_________________________________________________________________

What could have been better? _____________________________________

_________________________________________________________________

What is one goal for tomorrow? __________________________________

_________________________________________________________________

Questions ______________________________________________________

_________________________________________________________________
Discharge/What To Expect At Home

We want to make your child’s transition from hospital to home as smooth as possible, which is why we begin planning your child’s discharge the day of admission. You will participate in discharge planning and learn about any continuing care your child may need at home.

DISCHARGE PLANNING

Whether your child’s hospital stay is short and uncomplicated, or longer and more complex, discharge planning is a process that begins within 24 hours of your stay. Your healthcare team will plan with you when your child will go home and what you will need. A Nurse Case Manager or Nurse Discharge Coordinator will meet with you and your child to discuss how we can help you be prepared to take your child home.

If your child will need special equipment or visits by a home-care nurse, we will provide a list of home-care companies approved by your insurance company. We will work with you and the company to make sure you have the equipment, supplies, medications and support you need. If you have any questions about going home, please write them down as you think of them and ask your care team. If your child needs medications at home, you may have prescriptions filled at your local pharmacy or at one of the pharmacies in the hospital.

At discharge you will need:

- Clothes and shoes for your child
- An infant/child car seat
- Any special equipment your child may need
- Transportation arrangements

What to expect at home:

Your child may experience behavior changes, which are normal and temporary responses to hospitalization.

Your child may:

- Act younger (bedwetting, thumb sucking and temper tantrums)
- Show changes in sleeping, eating or toileting
- Have new fears
- Be more dependent

Ways you can help:

- Ask your child to talk about the hospital
- Have your child draw pictures or write about the hospital
- Play hospital with your child
- Make a hospital scrapbook with your child
- Read books about hospitals and doctors with your child

Be patient, and stay with your child as much as possible for awhile. Children who feel that they have some control over their illness and hospitalization are more likely to feel confident and be cooperative.
One healthcare team has many patients. I only have one, my son. I can be a set of eyes and ears that notices something a busy team might miss. Use me, please!

Hopkins Children’s Parent
# Family Health History

*Please remember to share this information with your doctor.*

<table>
<thead>
<tr>
<th>Name</th>
<th>____________________________</th>
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<tbody>
<tr>
<td>Ethnicity</td>
<td>____________________________</td>
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| Date of Entries | ____________________________ |

<table>
<thead>
<tr>
<th>Child’s brothers and sisters (include half siblings)</th>
<th>Male/ Female</th>
<th>Birthdate</th>
<th>Deceased</th>
<th>Y/N</th>
<th>Age &amp; Cause of Death</th>
<th>Allergies</th>
<th>Arthritis</th>
<th>Asthma</th>
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<tbody>
<tr>
<td>Child’s Mother</td>
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<td>Child’s Grandmother</td>
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<tr>
<td>Child’s Grandfather</td>
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<tr>
<td>Child’s Aunts &amp; Uncles</td>
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<td>Child’s First Cousins</td>
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<tr>
<th>Birth defects (cleft lip, heart defects, etc.)</th>
<th>Cancer</th>
<th>Diabetes</th>
<th>Genetic conditions (Cystic fibrosis, sickle cell, etc.)</th>
<th>Hearing loss</th>
<th>Heart conditions</th>
<th>Intellectual disability, learning problems</th>
<th>Mental illness (depression, schizophrenia, etc.)</th>
<th>Obesity</th>
<th>Premature births</th>
<th>Senility</th>
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List any other conditions & give details for checked boxes.
• Please check the appropriate box(es) for each relative and list only those relatives related to you by blood.
• Please do not include adopted family members, foster children, or family friends.
• Half-siblings are brothers and sisters who have either the same mother or father as you.
• First cousins are the children of your aunts and uncles.

### Father’s Side

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<thead>
<tr>
<th>Child’s Father</th>
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<tbody>
<tr>
<td>Child’s Grandmother</td>
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<tr>
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<tr>
<td>Child’s First Cousins</td>
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### Father’s Side (Additional Conditions)

- Birth defects
- Cancer
- Diabetes
- Genetic conditions
- Hearing loss
- Heart conditions
- Intellectual disability
- Mental illness
- Obesity
- Premature births
- Seizures

Please remember to share this information with your doctor.
Consider setting up a blog or online journal on your child’s progress. One such free site is [www.caringbridge.org](http://www.caringbridge.org). This tool allows you to stay connected to family and friends during a medical crisis.

**TigrNet** is a bedside interactive system that turns the patient’s television and pillow speaker into a powerful education, entertainment and information center. Please ask your nurse for more details on how to use this system.
For more information on any of these topics please visit www.HopkinsChildrens.org

For more specific information on your child’s diagnosis, such as web resources, printed materials, or support groups, ask your Nurse, Social Worker, or Child Life Specialist.

We hope this journal has helped inform and support you during your child’s hospital stay and has let you see how important a voice you are in your child's healthcare team. We wish you a speedy recovery.

**Notes**

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**parent tip**

Please take a few minutes to complete the patient satisfaction survey you will receive after your child is back home. It is a great way for us to learn more about you and your child’s hospital experience. Your voice matters to us!

---

**parent tip**

What do I do if my voice is not being heard? What do I do if I have a serious concern about the care my child is receiving?

- Talk to a Clinical Customer Service Representative
- Talk to your bedside Nurse
- Talk to a Nurse Manager
- Talk to your Attending Doctor, Fellow, Resident
- Talk to your Social Worker, Child Life Specialist, Chaplain
- Contact a Family Relations Representative for help
- If after going through all of the above there are still concerns not being addressed, call a Family Care Conference

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Please take a few minutes to complete the patient satisfaction survey you will receive after your child is back home. It is a great way for us to learn more about you and your child’s hospital experience. Your voice matters to us!