welcome

Johns Hopkins Children’s Center
patient and family handbook
Hi there! Welcome to Johns Hopkins Children’s Center.

My name is Finn. Throughout this patient and family handbook, I will share useful tips to help make your stay with us as comfortable, convenient and safe as possible.
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Welcome to Johns Hopkins Children’s Center.

Thank you for trusting us with your child’s care. Rest assured: You are in good hands. Since our doors opened more than 105 years ago, we’ve continued to build on our reputation as one of the world’s leading academic medical centers in the diagnosis and treatment of disease.

Yet we recognize that most people don’t look forward to staying in a hospital. Please know that your child’s health and well-being are our top priorities. We want your experience to be as safe, comfortable and positive as possible. You are an important part of your child’s health care team. We urge you and your family to take an active role in your child’s care to ensure that we are sensitive to your specific needs.

This patient and family handbook was created by The Johns Hopkins Hospital staff members—with valuable input from patients and family members—to anticipate your concerns. Use it to help guide you through your hospital stay. If you have any questions about our services, policies or other information in this guide, please don’t hesitate to ask one of your caregivers.

Thank you again for choosing Johns Hopkins Children’s Center for your child’s medical needs.

Sincerely,

Tina Cheng, M.D., M.P.H.
Co-director
Johns Hopkins Children’s Center

David Hackam, M.D., Ph.D.
Co-director
Johns Hopkins Children’s Center
Amenities

Restaurants and Eateries
The hospital campus offers a variety of dining options. The Cobblestone Café is located off the Garden Corridor, between the Nelson/Harvey and Billings buildings. Retail eateries and coffee bars can also be found in the Weinberg Building and Sheikh Zayed Tower. Learn more: hopkinsmedicine.org/patient-handbook/dining

Discount Parking Coupons
Discount parking coupons may be purchased at the Cashier's Office. Learn more about parking on p. 9.

Gift Shops
Nelson/Harvey Building, hospital’s main level, Monday–Friday, 8:30 a.m.–4:30 p.m.; Saturday and Sunday, 10:30 a.m.–3 p.m.
The Arcade corridor, Sheikh Zayed Tower, main level, Monday–Friday, 8:30 a.m.–4:30 p.m. Limited floral selections available at this location. (Operated by The Johns Hopkins Hospital Women’s Board.)
Outpatient Center, level 1, Monday–Friday, 7 a.m.–3 p.m.

Optical Shop
Next to the Wilmer Eye Institute, Monday–Friday, 8:30 a.m.–5 p.m.
Wilmer Vision Center, Outpatient Center, level 1, Monday–Friday, 8:30 a.m.–5 p.m., on-site optometrist and lab.
Learn more: hopkinsmedicine.org/patient-handbook/optical

Pharmacy
The Arcade Pharmacy, Sheikh Zayed Tower, main level, room M2125, Monday–Friday, 8 a.m.–10 p.m.; Saturday and Sunday, 8 a.m.–6 p.m.
Weinberg Pharmacy, Johns Hopkins Kimmel Cancer Center, Monday–Friday, 9 a.m.–7 p.m.; Saturday and Sunday, 10 a.m.–6 p.m.
Outpatient Center Pharmacy, main level, Monday–Friday, 8 a.m.–6:30 p.m.
Learn more: hopkinsmedicine.org/patient-care/outpatient_pharmacy/locations

ATM
Bank machines are available on the hospital main level of the Sheikh Zayed Tower and in the Nelson/Harvey Building lobby and the main lobby of the Outpatient Center and the Weinberg Building.

Postal Services
Drop off your mail, purchase stamps and weigh your packages at the postal service center on the main level of the Nelson/Harvey Building next to the main cafeteria. Hours are 8 a.m.–2:30 p.m. Cash only.
To receive mail or packages while admitted to the hospital, use the following address:
Patient’s Name
The Johns Hopkins Hospital
1800 Orleans St.
Baltimore, MD 21287
Six Things You Need to Know About Your Child’s Stay.

1. **YOUR ROOM:** Each room has a nurse call button on a remote that you can use to call your nurse and control your TV and room light. Families and health care staff members can adjust your child’s bed position by using the controls on the outside of the bed rail. If you’d like the room temperature adjusted, ask any member of your health care team. We urge you to leave valuables and credit cards at home. Most rooms have a safe, should you wish to protect any valuable belongings. LEARN MORE: P. 10.

2. **IMMEDIATE ATTENTION:** You may notice a change in your child’s condition that our staff members might not see and that requires immediate attention. Please talk to the nurse right away. You can also call 5-4444 on your hospital phone to contact the Pediatric Rapid Response Team, or press the call button so the nursing staff members can respond quickly. LEARN MORE: P. 8.

3. **PATIENT MEALS:** Meals may be ordered between 7 a.m. and 6:30 p.m. Use the menu in your room to order. Guest meals are available for an additional fee and are charged to your hospital bill. LEARN MORE: P. 6.

4. **FAMILY PRESENCE:** Two parents or guardians are welcome at the bedside 24 hours a day. Others are welcome from 9 a.m. to 9 p.m., as long as they don’t have a cough, fever or sore throat. Please ask your nurse for more information. LEARN MORE: P. 6.

5. **ID:** We require photo identification for guests 16 years and older to obtain a parent or visitor badge. You will need a badge to go beyond the main level of The Charlotte R. Bloomberg Children’s Center building. LEARN MORE: P. 10.

6. **COMMUNICATION:** A room phone with instructions is on the table near your child’s bed. To reach the nurses’ station and for the names of the people on your child’s care team, check your whiteboard. LEARN MORE: P. 10.
Quick Guide to Your Visit

IMPORTANT PHONE NUMBERS

Main Hospital Number ................................. 410-955-5000
Billing Coordinator ..................................... 410-955-8288
Billing Customer Service ............................... 855-662-3017
Child Life Services .................................... 410-955-6276
Children’s & Family Resource Library ............ 410-955-6442
Interpreter Services ................................. 410-614-INTL (4685)
Meal Service, using in-room phone .................. 410-502-FOOD (3663)
Parking and Transportation .......................... 410-955-5333
Patient and Guest Services ......................... 410-614-5100
Patient Relations ...................................... 410-955-2273
Pharmacy ............................................... 410-288-6100
Security/Walking Escorts on Campus .............. 410-955-5585
Spiritual Care and Chaplaincy ...................... 410-434-0909 (pager)
Social Work ........................................... 410-955-6518

Note: When calling any of these numbers (except Pharmacy, and Spiritual Care and Chaplaincy) from your room phone or from another Johns Hopkins phone, dial only the last five digits. For outside local calls, dial 1, then the area code and the complete phone number.

Long-Distance Phone Calls: For credit card, operator-assisted, third-party bill or collect, dial 9, 0, #, wait for the tone, then dial # again and wait for instructions.

Patient Meals: You may order your child’s meal between 7 a.m. and 6:30 p.m. from the menu in your room. Because we specially prepare many meals, it could take up to 75 minutes for delivery. Some items may not be available, based on your doctor’s instructions. Guest meals are available for an additional fee and charged to your hospital bill.

If a meal is missed because of tests or treatment, your child’s nurse can arrange for it to be delivered on your child’s return.

Certified kosher meals are available. The kosher hospitality suite is in Blalock 175. Please see your nurse for more information.

Family Presence: Two parents or guardians are welcome at the bedside 24 hours a day. We ask that other family members and friends visit between 9 a.m. and 9 p.m. Please talk to your child’s nurse to learn more.

Guests must not be ill with colds, flu or other contagious conditions, and must respect infection control policies.

Guest Guidelines: We appreciate the important role your family and loved ones play in your child’s care and the healing process. Still, for the comfort of other patients, we ask that you limit the number of visitors.
**Family and Guest Expectations:** We know that you are concerned about your child’s health and safety during your stay. We are too. Please know we have a policy that any person who takes part in inappropriate or illegal behavior will be asked to leave the hospital and may not be able to return. This behavior includes but is not limited to verbal or physical fighting; threats of harm, pressure, bullying or violent behavior; rude, disrespectful or abusive comments; possession of weapons of any kind, alcohol or illegal drugs; theft, including of medicines; or damaging Johns Hopkins Hospital property. Learn more about visiting guidelines at hopkinsmedicine.org/patient-handbook/visiting-hours.

**Patient and Guest Services**

**Language Interpretation and Services for Those with Vision or Hearing Impairments**

We want to make sure that the exchange of information between your family and your child’s health care team is as clear as possible. That’s why we offer our patients language or sign language interpreters. We have staff members who are fluent in many languages, including sign language. Staff members are available 24/7 at 410-614-4685 to assist patients or family members who have limited English proficiency or who are deaf or hard of hearing.

To learn more about language interpretation services, please call 410-614-IN TL (4685) or visit: hopkinsmedicine.org/the_johns_hopkins_hospital/services_amenities/services/interpreter_services.html.

If your vision is impaired, our staff members can help with reading documents and offer additional resources.

**Mobile Device Charging Kiosks**

Complimentary mobile charging kiosks are available for hospital guests and visitors on every unit as well as the lobbies of the Nelson/Harvey and Weinberg buildings and the Sheikh Zayed Tower.

**Spiritual Care and Chaplaincy Services**

Chaplaincy services are available to all patients and their families for emotional and spiritual support, with 24/7 emergency coverage, regardless of your religion. The Bunting Interfaith Chapel is in the arcade on the main level and is open 24/7. Meditation rooms—also open 24/7—are in the Johns Hopkins Kimmel Cancer Center lobby, in the arcade on the main level (2150B) and on the third floor of The Charlotte R. Bloomberg Children’s Center building (3351).

To arrange a pastoral visit, ask your nurse or contact the Spiritual Care and Chaplaincy Office in Halsted 144. It is open Monday through Friday from 8 a.m. to 5 p.m. The phone number is 410-955-5842.
**Wireless Internet Access**

Free wireless internet service is available throughout the hospital and in all patient rooms. The JHGuestnet wireless network is for hospital guests and visitors. For details about internet access, visit hopkinsmedicine.org/patient-handbook/wifi.

**Accommodations:** If you need short-term housing or hotel accommodations, please contact our Guest Services concierge at 410-614-5100 or visit hopkinsmedicine.org/patient-handbook/hotels-housing for a list of options. Please check with your social worker regarding the availability of the Ronald McDonald House and other housing.

**Your Room:** Your child’s room is well-equipped for your care and comfort. Please see the illustrated guide on page 11.

**When You Need Immediate Attention:** We recognize that you may notice changes in your child’s condition that may not be obvious to staff members. Talk to the nurse right away if you have concerns. If you can’t reach the nurse, contact the charge nurse manager on the floor.

If you notice a sudden change that requires immediate attention, call 410-955-4444 to contact the Pediatric Rapid Response Team. Also push the call button to alert the nursing staff members.

**Patient/Family Concerns:** At any time, should you or your family have any concerns or problems, please feel free to reach out to our family advocates: the clinical customer service coordinator (CCSC) on each unit or our patient and family centered care coordinator. If your concerns are still unresolved, please contact Patient Relations at 410-955-2273 and ask to speak to one of our Patient Relations representatives, or email them at PatientRelations@jhmi.edu. For more information regarding Patient Relations, visit hopkinsmedicine.org/patient-handbook/patient-relations.

**Smoke-Free Campus:** The Johns Hopkins Hospital is a smoke-free campus. Smoking is not allowed on Johns Hopkins Hospital property.

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**Our Privacy Practices**

We are committed to protecting your child’s health information. Our privacy practices are described in the *Johns Hopkins Notice of Privacy Practices*, a booklet that explains how this obligation will be followed by all health care professionals, trainees, students, staff members, volunteers and business associates of Johns Hopkins organizations. To obtain a copy of the booklet, call the Main Admitting Office at 410-955-5600. To see this booklet online, visit hopkinsmedicine.org/hipaa.

If you have a patient privacy concern, please call the Johns Hopkins Privacy Office at 410-735-6509 Monday through Friday between 8:30 a.m. and 5 p.m. If you have more questions about patient confidentiality and privacy, please visit hopkinsmedicine.org/hipaa.
Because social networks on the internet have created an endless and instant exchange of information, opinions and images, we ask everyone to respect your family’s privacy, and we ask you to respect the privacy of other patients and families. While it is OK to take and post a photo or video of your own child, please do not take or post photos or videos of any other patients or of areas where other patients are seen.

Preparing for Your Child’s Stay

Stay Informed

We invite you and your child to join us as active members of the care team. Learn about the tests and treatments planned for your child. Be sure to get answers to your questions that make sense to you. Remember that no question is unimportant. Identify a support network and talk with friends and family who can help with things that will be hard for you to do while you are in the hospital (meals, transportation, sibling care).

Family and Visitor Parking

Wherever you’re headed on campus, there’s a garage conveniently located near your destination. Discount parking coupons are available for purchase at the Cashier’s Office, Weinberg Building, McEderry Garage Office, and Orleans Garage Office. For families with extended stays, there are opportunities to obtain further reduced parking coupons. Please see your social worker for more information.

Valet parking is available at the hospital’s main entrance on Orleans Street, the Outpatient Center circle and the Weinberg Building on Jefferson Street.

Courtesy shuttle service and walking security escorts (24/7) are also available. For more information on shuttle hours or parking options, visit hopkinsmedicine.org/patient-handbook/parking.

Service Animals

Johns Hopkins welcomes your service animal during your inpatient or outpatient visit to any of our facilities. However, if the service animal poses a health risk, is not housebroken or is out of control, we may ask you to make other arrangements. For more detailed information, call Patient and Guest Services at 410-614-5100 or visit hopkinsmedicine.org/patient-handbook/service-animal.

If you need parking for an extended period of time, you may purchase discount coupons at the Cashier’s Office.
Your Child’s Room

Hand-Held Call Bell/Remote

Each room is equipped with a remote that works the TV and the call bell. Each room also has an Xbox that can play DVDs and games. Ask your child life specialist or CCSC for more information.

Your Bed

We have several types of beds for our patients based on their age and special needs. For all beds, we ask you to ensure that bedrails are kept raised for our younger patients. For older patients, seek guidance from your nurse regarding bedrail position.

Room Temperature

If you’d like the room temperature adjusted, ask any member of your health care team.

Communication Board (Whiteboard)

Your child’s room has a white communication board. On it, your child’s nurse writes the names of staff members who will be working with your child. The nurse will also list your goals and activities for each day. Please review the whiteboard with your child’s nurse. Please feel free to write any questions you may have on it.

Alarms

Each patient room has alarms for your child’s care and safety. Examples of alarms include heart monitors, bed alarms or medicine pumps.

• If no one answers an alarm after a short period of time, please tell a nurse. Push the patient call button to request assistance from a member of the clinical team.
• Nurses also get alarm messages on their phones or pagers to help them respond quickly.
• For your child’s safety, be careful not to touch other equipment.

Room Cleaning

Environmental care associates (EVCs) will routinely disinfect your child’s room and bathroom. They follow procedures designed to keep the room clean. As part of the standard procedures, our associates will clean the surfaces in your child’s room, including the bed rails and overbed table. Environmental care services are available 24/7. If you find the room in need of cleaning, please notify the nurse or press the nurse call button.

You need to understand your child’s care plan. Don’t hesitate to ask questions as often as you need to.
Illustrated Guide to Your Room

A-G. Inpatient Room
A. Overbed table  
B. Medication pump  
C. Oxygen flowmeter  
D. Patient room number  
E. Hand-held call bell  
F. Blood pressure machine  
G. Staff computer

H-N. Hand-Held Call Bell/Remote
H. Keyboard connection  
I. Access to the interactive main screen to view the patient’s care team, unit and hospital description  
J. Call button to request assistance from a member of the clinical team  
K. Headphone connection  
L. Arrow buttons to navigate the interactive screen  
M. Comprehensive list of channels  
N. Keypad to manually change television channels
If you have concerns about the temperature of your room, ask any member of our team to adjust the thermostat.

Personal Items and Valuables

Ask your nurse for assistance with toiletries or your child’s personal grooming needs. We provide soap, towels, sheets, hospital gowns and nonslip socks.

We urge you to leave valuables and credit cards at home. There is a safe in most rooms should you wish to protect any belongings of value, but large sums of money, keys, jewelry, personal papers and other valuables should be sent home. Laptop computers, tablets, cellphones, and DVD and MP3 players with headphones are allowed. Please try to keep track of your child’s comfort items from home (blankets, stuffed friends, etc.) as these special items can easily get lost when a bed is changed. The hospital is not responsible for lost or stolen items.

TV Services

If you have questions related to TV services, call 410-614-7721.

Learn more about your room at hopkinsmedicine.org/patient-handbook/room.

Comfort Services

There are family kitchens on each unit. Please feel free to label and store food in the refrigerator, use the microwave oven and access water and coffee.

In-Room Sleeping/Showers. We provide sleep surfaces for one parent to stay overnight with a child. Your nurse will provide pillows and linens. Several family showers are available in the pediatric and neonatal intensive care units. All other units have in-room showers that parents may use.

Children’s and Family Resource Library. The library on Bloomberg 3 provides a business center for families as well as a collection of books for kids of all ages as well as print resources for their parents. The librarian brings a book cart to every unit weekly and welcomes visitors to the library from 9 a.m.–4 p.m. Monday through Friday. Call 410-955-6442 for more information.

Cooley Fitness Center. There is an on-site gym for family use for $5/day. For more information, please contact your social worker.

Playrooms. Playrooms are available on each unit, and there is a Teen Room on 10N. These spaces are considered “safe.” No invasive procedures or confidential conversations should take place in these areas.

Outside Spaces. Sara's Garden and the Meditation Garden are found in the outdoor courtyard. They are accessible through the food court area off the arcade/main level of the Zayed Tower.
Your Child’s Health and Safety

Our health care partnership begins with our commitment to your child’s safety. Patients and families who are involved with their hospital care heal better. By working together with your health care team, you can lower your risk of harm and make your child’s stay safer.

**Family and Guest Expectations:** We know you are concerned about your health and safety. Johns Hopkins Children's Center wants to keep you and your family safe and healthy during your stay. We do this by following safety rules, including a policy about inappropriate and illegal behavior. Any person who takes part in such behavior will be asked to leave the hospital and may not be allowed to return. This behavior includes but is not limited to:

- verbal or physical fighting
- threats of physical harm, pressure, bullying or violent behavior
- rude, disrespectful or abusive comments
- possession of weapons of any kind, alcohol or illegal drugs
- theft, including medicines, or damaging Johns Hopkins Hospital property

**Patient ID for Procedures and Medications**

Every child who is admitted is provided a safety band that includes name, date of birth and a medical record number. This safety band must be worn at all times during your child's hospitalization. Staff members will always check the safety band before giving your child any medicine or performing any test or procedure. We use bar code technology to help make sure medicine is matched to the patient. In some cases, they may ask your child for his/her name and date of birth. Please be patient—this is for your child’s safety.

For surgical procedures, the parent or guardian should always confirm what procedure the child will undergo and where on the body it will take place. The area of the procedure should always be marked prior to surgery, when possible. Our team will also call “timeouts” to ensure your child’s safety.

For questions related to patient safety, visit hopkinsmedicine.org/patient_safety.

**Preventing Infections**

*Clean your hands and remind others to clean theirs, too.* Use hand sanitizer gel or wash your hands with soap and water after using the bathroom, before eating and after touching anything that might be soiled. If your hands are visibly dirty, wash them well with soap and water for 15 seconds.

Health care providers are required to wash or sanitize their hands before and after seeing a patient. They should wear gloves when they perform tasks such as drawing blood, touching wounds or handling body fluids. Don’t hesitate to remind your care team members to clean their hands or to wear gloves.

Make sure your family, visitors and companions wash or sanitize their hands before and after seeing your child. If they are sick, please ask them to stay home or to leave.
**Preventing the spread of respiratory infections:** Cover your mouth and nose when sneezing or coughing by using tissues or the bend of the elbow. Tissues and masks are available upon request. We urge you to use them if you have a runny nose or cough, or if you are sneezing.

**Patients on precautions/isolation:** Your child may have a condition that requires precautions/isolation. A sign will be posted on your child’s room door. Staff members and visitors will be required to wear a protective gown and gloves, and in some cases, a mask. If your child is in isolation, unfortunately your child, family and other visitors cannot use the playroom. Please speak to your nurse about handwashing before leaving your room.

**Vaccinations:** When your child is admitted to the hospital, you may be asked about your child receiving a flu shot. This is very effective at reducing the spread of disease.

If you have questions related to preventing infection, visit hopkinsmedicine.org/patient-handbook/infection-prevention.

**Risky behaviors screening:** When your child is admitted, nurses will ask your child some basic questions regarding risky behaviors such as suicide, drug and alcohol use or sexual activity. We ask all our patients of a certain age these questions as another way to ensure their safety.

**Preventing Injuries from Falls**

While in the hospital, your child may be at a higher risk of falling. We will ask you about your child’s history of falls and may assess his/her risk using the Humpty Dumpty Falls Risk Assessment Tool.

To improve your child’s safety, follow these guidelines:

- Make sure you and your child are oriented to your room.
- Use nonskid footwear and appropriate-size clothing to help prevent accidental falls.
- Make sure the bed is in the lowest position, the brakes are on and rails are up at all times for preschool-age children, and as indicated for older children based on developmental age or condition.
- Crib rails should be kept in the raised position unless direct care is being provided.
- Help your child to and from the bathroom if appropriate.
- Please do not let your child climb or play on the windowsill.

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Prevent falls by always keeping the crib rails and bedrails up for young children.
Your Child’s Care and Treatment

Surgery and Procedures

Being an active and informed member of your child’s health care team will make your child’s care safer. You will always be asked to sign an informed consent form before any surgery or procedure. Read it carefully. Make sure it has your child’s correct identification information as well as the kind of surgery/procedure.

Pain Management

Children in the hospital may experience pain from surgery, certain procedures or illnesses. 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 and trust your child is in pain when he or she says so. Your child’s nurse may use the pediatric pain scale called FACES to ask your child to point to a drawing of a face that best shows his or her pain. In infants, fussiness, restlessness, poor feeding or sleeping, and decreased play may be signs your baby is in pain. The Pediatric Pain Service is available for complex cases. It is staffed by physicians who are specially trained to safely manage pain in children. As parents, you know your child best, so please tell us if you think your child’s pain is not being controlled.

<table>
<thead>
<tr>
<th>MILD (Green)</th>
<th>MODERATE (Yellow)</th>
<th>SEVERE (Red)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>Notice pain, does not interfere with activities</td>
</tr>
<tr>
<td>2</td>
<td>3</td>
<td>Sometimes distracts me</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>Distracts me, can do usual activities</td>
</tr>
<tr>
<td>6</td>
<td>7</td>
<td>Interrupts some activities</td>
</tr>
<tr>
<td>8</td>
<td>9</td>
<td>Hard to ignore, avoids usual activities</td>
</tr>
<tr>
<td>10</td>
<td></td>
<td>Focus of attention, prevents doing daily activities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Awful, hard to do anything</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Can’t bear the pain, unable to do anything</td>
</tr>
<tr>
<td></td>
<td></td>
<td>As bad as it could be, nothing else matters</td>
</tr>
</tbody>
</table>
Family-Centered Rounds

Rounds refers to a daily meeting held by your child’s health care team about your child’s condition. It is often at the bedside and may include a large number of team members (residents, interns, medical students, nurses, social workers, etc.). Ask to be included, as you are an important part of the health care team. Remember: You are the expert on your child.

Child Life Specialists

Child life specialists build relationships with children, teens and families by providing them opportunities for play and self-expression during health care encounters. Play is an essential, natural part of childhood. It promotes effective coping when children are in distress due to new or potentially frightening health care experiences. To contact Child Life Services, call 410-955-6276.

How they help:

- Use developmentally appropriate language and resources to help your child understand his/her illness.
- Prepare your child for upcoming health care experiences.
- Encourage your child’s use of effective coping skills.
- Support your child during procedures using play and distraction techniques.
- Provide your family with opportunities to express feelings related to your health care experiences.
- Encourage your child’s engagement in developmentally supportive play and activities.
- Help your child feel connected to school and peers through our librarian/home health and hospital liaison.
- Support siblings by helping them understand their brother or sister’s illness and treatment.
- Provide support during grief and bereavement.
- Act as an advocate for you and your family.

Social Work

Social workers are specially trained to build relationships between your family and community resources that support access to and use of health care. Your unit has an assigned social worker Monday–Friday during the day. Call 410-955-6518.

Services may include:

- helping you gain a better understanding of what to expect with illness and treatment
- supporting your balance between home and hospital obligations
- sharing your family values and strengths with the medical team
- providing supportive counseling and referrals for mental health services
• sharing information on how to apply for health insurance
• giving information about transportation and resources
• performing family safety assessments and clarifying who can make medical decisions
• offering grief and bereavement support

Pediatric Palliative Care Team

The Pediatric Palliative Care Team provides extra support, alongside primary medical teams, for patients with a serious or life-threatening illness. The care can begin at any stage of life or in any stage of illness. Team goals are to relieve pain, symptoms and suffering, and to provide the best quality of life for your child and family. This multidisciplinary team can be reached at hlccsupport@jhmi.edu or by discussing this with your primary medical team.

Understanding Your Child’s Medications

While in the hospital, your child’s medicines might change. Learning about new medications the doctor has prescribed for your child is very important during recovery.

During the first day in the hospital, we ask you what medicines your child takes at home. Make sure you tell us about all prescriptions, over-the-counter drugs, vitamins and herbal supplements your child is taking. Also, we need to know about any allergies or bad reactions your child may have to medicines, foods or supplements.

Ask your health care team the following questions:

• What is the name of the medicine and why is my child taking it?
• When and how does my child take it and for how long?
• Are there foods, drinks and activities my child should avoid while taking this medicine?
• Are there side effects? What should I do if my child experiences them?
• Will this new medicine work safely with the other medicines my child already takes?

Always ask about any new medications given to your child and what side effects they may have.
Important Information About Antibiotics

Antibiotics are medicines that treat or prevent infections caused by bacteria and some other germs. Your health care team may start your child on antibiotics if it thinks your child might have an infection caused by bacteria. Your child may also need an antibiotic to prevent an infection after surgery or if the immune system doesn’t work well.

Some things your health care team thinks about before prescribing an antibiotic include:

- the kind of infection
- the kind of bacteria
- how well your child’s liver and kidneys work
- other medications your child may be taking
- any antibiotic allergies your child may have
- potential side effects

Talk with your health care team to find out why your child is receiving antibiotics and how to best take them.

Staying Active

Being an active child makes the transition to home easier after discharge. Children need to stay active to support their developing minds and bodies. Activity in the hospital will also help prevent the negative effects of bed rest and immobility. There are many activities to help your child stay active in the hospital. Some examples include:

- Spend time out of bed or sit in a chair for meals.
- Have your child walk to the bathroom with assistance.
- Encourage walks in the hallways. Visit the playrooms, with supervision and/or equipment as needed.
- Units have access to ride-on cars for younger children. Wagons and wheelchairs can assist children who are unable to walk.
- There are fun places to explore that can help motivate your child to get up and move. Each patient unit has a playroom or activity rooms where children can play or borrow toys. The Great Room on the 11th floor has a schedule of activities. The planetarium on the ground level has an interactive giant screen on which children create music and designs through their body movements. The Children's and Family Resource Library on the third floor is a quiet space to borrow a book and grab a cup of afternoon coffee.

Prevent infection by washing your hands or using hand sanitizer often. And don’t hesitate to remind your care team members to do the same.
Caregiver Identifier

At Johns Hopkins Children’s Center, we have a highly trained staff of health care professionals working together to provide you with quality care. Below is a guide to help you clearly identify staff members you may see throughout your child’s stay.

### CLINICAL STAFF

<table>
<thead>
<tr>
<th>Role</th>
<th>Color</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registered Nurse</td>
<td>NAVY</td>
</tr>
<tr>
<td>Clinical Support</td>
<td>OLIVE</td>
</tr>
<tr>
<td>Lab Personnel</td>
<td>PURPLE</td>
</tr>
<tr>
<td>Respiratory Therapy and Technical Staff</td>
<td>CARIBBEAN BLUE</td>
</tr>
<tr>
<td>Physical Therapy, Occupational Therapy,</td>
<td>BURGUNDY</td>
</tr>
<tr>
<td>Speech Therapy</td>
<td></td>
</tr>
<tr>
<td>Pharmacist</td>
<td>DARK GREEN</td>
</tr>
<tr>
<td>Pharmacy Technician</td>
<td>BLACK</td>
</tr>
<tr>
<td>Radiology Imaging Technologist, Cardiology</td>
<td>GRAY / BLACK</td>
</tr>
<tr>
<td>Testing, Vascular Surgery Testing, Neurology</td>
<td></td>
</tr>
<tr>
<td>Testing, Radiation Therapy</td>
<td></td>
</tr>
</tbody>
</table>

### SUPPORT STAFF

<table>
<thead>
<tr>
<th>Role</th>
<th>Color</th>
</tr>
</thead>
<tbody>
<tr>
<td>Environmental Care Associate</td>
<td>ROYAL BLUE / NAVY</td>
</tr>
<tr>
<td>Sitter</td>
<td>RED / BLACK</td>
</tr>
</tbody>
</table>
Your Child’s Care Team

Because Johns Hopkins is a teaching hospital, you will be cared for by a team of providers including your doctor, other specialists, nurses, medical students and residents, and physician assistants. Every day, your attending physician will direct that team and will remain closely involved in your child’s care.

Members of your child’s care team wear different-color uniforms. To help you understand who’s who, refer to the color-coded illustrations and descriptions on the previous page and below. If you have any questions about your care team, please talk to your nurse or doctor.

<table>
<thead>
<tr>
<th>Health Care Team</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>You and Your Family</td>
<td>You, the patient and your immediate family are the center of your health care team.</td>
</tr>
<tr>
<td>Physicians (white coats)</td>
<td>The attending physician or physician of record is the doctor who supervises treatment. He or she may be assisted by other doctors, interns, residents, fellows and medical students.</td>
</tr>
<tr>
<td>Hospitalists</td>
<td>These board-certified physicians manage your child’s care if you do not have a primary care provider or if your provider prefers that a hospitalist handle your child's inpatient care.</td>
</tr>
<tr>
<td>Intensivists</td>
<td>These physicians, who are board certified in critical care medicine, manage your child’s care while in our intensive care units. They coordinate patient care and work together with specialists, surgeons and your primary physicians.</td>
</tr>
<tr>
<td>Nurse Practitioners/Physician Assistants (white coats)</td>
<td>These licensed professionals work closely with your attending physician to provide care 24/7.</td>
</tr>
<tr>
<td>Registered Nurses (navy uniforms)</td>
<td>These licensed professionals have primary responsibility for your child's care and direct the care provided by other members of the nursing team. They may be assisted by nursing students.</td>
</tr>
<tr>
<td>Clinical Technicians (olive uniforms)</td>
<td>These assistants support the nurse in taking care of your child.</td>
</tr>
<tr>
<td>Case Manager/Discharge Coordinator</td>
<td>A case manager or discharge coordinator is a nurse who is automatically assigned to every patient. They can help you and your child prepare to go home. They can also help with education, equipment, home services and many other needs.</td>
</tr>
<tr>
<td>Health Care Team</td>
<td>Description</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Child Life Specialists</strong></td>
<td>Child life specialists are trained to help children and teens understand their fears related to diagnosis, hospitalization and treatment. They help facilitate effective coping by providing opportunities for play, preparation and self-expression activities. Child life specialists also provide emotional support to the entire family, including addressing the specific needs of siblings.</td>
</tr>
<tr>
<td><strong>Social Workers</strong></td>
<td>Social workers are trained to help parents and families cope with illness and the demands on the family when a child is in the hospital. They can provide emotional support, help you find community resources and make sure your voice is heard within the health care team.</td>
</tr>
<tr>
<td><strong>Clinical Customer Service Coordinators (CCSCs)</strong></td>
<td>CCSCs welcome and orient families to the unit, create and maintain a positive patient stay, and are points of contact for patient and family concerns. They round daily with patients and families to make sure the unit is meeting their needs.</td>
</tr>
<tr>
<td><strong>EVC Associates (royal blue top and navy pants)</strong></td>
<td>These team members clean and disinfect your child’s room.</td>
</tr>
<tr>
<td><strong>Imaging Technologists (gray uniforms)</strong></td>
<td>These professionals perform diagnostic imaging examinations. Imaging technicians include radiologic technologists, sonographers, MRI technologists and nuclear medicine technologists.</td>
</tr>
<tr>
<td><strong>Phlebotomists (purple uniforms)</strong></td>
<td>Lab Personnel are authorized to draw blood for various laboratory tests.</td>
</tr>
</tbody>
</table>

Don’t hesitate to ask staff members to identify themselves and what they do.
Preparing to Leave the Hospital

Understand Your Child’s Discharge Information

We want to make your child’s transition from hospital to home as smooth as possible. This 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.

As you prepare to leave the hospital, your child’s nurse will give you a discharge summary. It will list all medicines and will provide the after-hospital plan of care. This will include when you should schedule a follow-up outpatient appointment with your child’s doctors. Please discuss any questions you or your family may have with the nurse during this review. Make sure you have a phone number to call if you have questions after you leave the hospital.

If you need a visiting nurse, home health care or special equipment to help in recovery, your case manager/discharge coordinator can help you.

Remember, at discharge you will need:

• clothes and shoes for your child
• an infant or child car seat
• transportation arrangements
• any special equipment your child may need for home

Understand Your Medications

The more you know and understand about each medicine your child takes, the easier it will be to give them correctly. This will set your child on the path to recovery. If your child needs medication at home, you may have the prescriptions filled at your local pharmacy or the hospital pharmacy. It is important to find out and write down exactly when to give your child medicine for the first time at home once you’re discharged. Also, make sure your child’s pediatrician is informed of any changes or new medications.

Follow-Up Care After Leaving the Hospital

To schedule an appointment for outpatient services with Johns Hopkins, please call 443-997-5437 (KIDS) weekdays, from 8 a.m.—6 p.m.:

If you’re not sure about when to give your child medicines at home, ask the nurse to review them with you again. Be sure to write down the information.
Feedback on Our Services

We welcome your feedback!

You may receive a survey via email. We would appreciate it if you would take a few minutes to complete the survey. It will help us ensure that we’re delivering the best possible patient- and family-centered care. We also like to recognize our staff members for their outstanding work and learn of areas where we can improve. So, if a nurse, medical associate or any other member of your health care team deserves praise, please include his or her name on the survey.

Patient Choice Statement

Your doctor may prescribe facility or home care services. Equipment may also be prescribed to assist you in the transition from hospital to home. Should your physician order such services or equipment, we will arrange all referrals to meet your facility or home care needs, according to your choices. By federal law, you have the right to select your post-hospital care providers.

• Your insurance company may have preferred providers with whom they have a contract. **If you choose another care provider, this may affect your insurance coverage.**

• We can make arrangements for you with the Johns Hopkins Home Care Group, a full-service provider of home health care services, infusion therapy, medical equipment and respiratory services, which is jointly owned by the Johns Hopkins Health System and The Johns Hopkins University, **OR**

• We can make home health care arrangements for you with Potomac Home Health, a full-service provider of home health care services, which is jointly owned by Sibley and Suburban hospitals with the Johns Hopkins Health System, **OR**

• We can make hospice arrangements through our affiliate, Gilchrist Hospice Care, **OR**

• You may be familiar with an area provider through previous experience.

We maintain a full list of area providers for your review. The hospital makes no representations as to licensure or quality of care, nor does it recommend or endorse any agency.

We want to provide you with a smooth and safe transition back to your home, and we want you to be secure in the knowledge and understanding of your follow-up care. If you have any questions, please contact your doctor, nurse, case manager or social worker.
Our Commitment to You

Nondiscrimination Promise
It is the policy of The Johns Hopkins Hospital to provide services to all people, regardless of age, race, color, ethnicity, national origin, religion, culture, language, physical or mental disability, socioeconomic status, sex, sexual orientation, gender identity or expression, or any other protected classifications identified under applicable federal, state and local laws, regulations or statutes. The Johns Hopkins Hospital does not discriminate against visitors based on age, gender, race, national origin, religion, sexual orientation, gender identity or disabilities.

Grievance Process
You and your family members have the right to express concerns with your doctor, nurse manager or department manager about the care your child is receiving. You may also contact Patient Relations at 410-955-2273 to speak to one of our Patient Relations Specialist. You are also welcome to place your concerns in writing and send them to Patient Relations, The Johns Hopkins Hospital, 1800 Orleans St., Baltimore, MD 21287, or email them to patientrelations@jhmi.edu.

Special Services

Injury Prevention Team/Rehabilitation Team
Members of the injury prevention team and the rehabilitation team (PT and OT) are available to assist with car seat safety fittings and other needs you may have.

Maryland Medical Orders for Life Sustaining Treatment
MOLST (Medical Orders for Life Sustaining Treatment) is a document recognized in the state of Maryland that is similar to an advanced directive and contains orders about cardiopulmonary resuscitation and other life-sustaining treatments. It helps increase the likelihood that a patient’s wishes to accept, limit or decline life-sustaining treatments are honored across the continuum of care. As it is most commonly used with adults, parents are not expected to be familiar with the MOLST document prior to admission. Transport teams are required to ask parents about current or active MOLST prior to transporting a child by helicopter or ambulance, and it is part of the hospital’s standard admission screening questions.
Your Medical Bill and Insurance Information

Even though your biggest concern is your child getting better, there are important things you can do now that relate to the costs of your child’s care.

Learn about your child’s insurance coverage by calling the benefits information phone number on your insurance card.

Expect to receive two bills: One bill, called the Statement of Account of Hospital Charges, is for the hospital and references the Patient Account Number. One bill, called the Statement of Physician Services, is for the doctors and references the Medical Record Number.

Medical costs are often unanticipated, and not all expenses are covered by insurance. Please know that we have payment plans, and financial assistance programs that in certain circumstances can make your payments more manageable.

Insurance

Our financial counselors are committed to help your insurance billing work smoothly. If you need assistance, please call one of the following numbers weekdays during business hours.

Inpatient/outpatient hospital bill: 443-997-0100 or 800-757-1700
Physician bill: 410-933-1200 or 800-657-0066

For more information on understanding your medical bills and for payment information, visit hopkinsmedicine.org/patient_care/pay_bill/.

Financial Assistance

If you are unable to pay for medical care, you may qualify for free or reduced-cost medically necessary care. You are eligible if you:

1. have no other insurance options.
2. meet specific financial criteria.

If you don’t qualify for Maryland Medical Assistance or financial assistance, you may be eligible for an extended payment plan for your medical bill.

If you do not have insurance, you can meet with on-site certified application counselors who can assist you and your family with applying for Maryland Medical Assistance and all Qualified Health Plan options available through the Maryland health insurance exchange. For more information, visit marylandhealthconnection.gov.

To reach the Hopkins financial assistance office, call 443-997-0159 or 443-997-3626.
We are here to help your child feel better, but you know your loved one best. Please let us know what we can do to make your child’s stay easier. Write down concerns as you think of them and ask questions as often as necessary.

Speak Up!

Speak Up is a collaborative effort between The Johns Hopkins Hospital and the Joint Commission, a nonprofit organization that accredits and certifies health care organizations. Speak up encourages you to help us prevent medical errors in the delivery of your child’s care.

Speak up if you have any questions. If you don’t understand, ask again.

Pay attention to the care being received. Always make sure your child is getting the right treatments and medicines. Don’t assume anything.

Educate yourself so you fully understand your child’s diagnosis and treatment.

Ask questions and advocate for your child.

Know what medicines your child takes and why. Medication errors are among the most common health care mistakes.

Use an accredited health care facility, such as The Johns Hopkins Hospital, which has completed a rigorous survey to ensure safety and quality.

Participate in all decisions about your child’s treatment plan. The patient and family are the center of the health care team.

For more information on this initiative, please visit jointcommission.org/speakup.aspx.
Medical Record: MyChart

This secure website provides medical information available to you about your child’s care here and at other Johns Hopkins hospitals and physician offices.

Using MyChart, you can:

• View portions of your child’s medical record, including many test results, diagnoses, medications and immunizations (this access may change when your child turns 13).
• View a schedule of your child’s upcoming appointments, or schedule an appointment.
• View a visit summary and post-appointment instructions.

Learn more about MyChart at mychart.hopkinsmedicine.org/MyChart/.

To receive a copy of your medical record:

Parents or legal guardians may request a copy of their child’s medical record. There is a fee for copying the medical record. Complete an Authorization for Release of Medical Information at bit.ly/jhhmedicalrecords and send it to the Medical Records Office at:

The Johns Hopkins Hospital
600 N. Wolfe St.
Health Information Management
Phipps Building, Room B150
Baltimore, MD 21287

If you have any questions, call 410-955-6044 Monday through Friday between 8 a.m. and 5 p.m.

For information on images and reports, visit http://www.hopkinsmedicine.org/radiology/patient-information/images-and-reports/.

Please take a few minutes to complete the patient experience survey. All surveys are reviewed, and with your feedback we can improve the health care experience. Your voice matters!
Patient Rights and Responsibilities

To promote patient safety, we encourage you to speak openly with your health care team, be well informed, and take part in care decisions and treatment choices. Join us as active members of your health care team by reviewing the rights and responsibilities listed below for patients and patient representatives.

You or your designee have the right to:

Respectful and Safe Care

1. Be given considerate, respectful and compassionate care.
2. Have a family member/friend and your doctor notified when you are admitted to the hospital.
3. Be given care in a safe environment, free from abuse and neglect (verbal, mental, physical or sexual).
4. Have a medical screening exam and be provided stabilizing treatment for emergency medical conditions and labor.
5. Be free from restraints and seclusion unless needed for safety.
6. Know the names and jobs of the people who care for you.
7. Know when students, residents or other trainees are involved in your care.
8. Have your culture and personal values, beliefs and wishes respected.
9. Have access to spiritual services.
10. Have conversations with the Ethics Service about issues related to your care.
11. Be treated without discrimination based on race, color, national origin, age, gender, sexual orientation, gender identity or expression, physical or mental disability, religion, ethnicity, language or ability to pay.
12. Be given a list of protective and advocacy services, when needed. These services help certain patients (e.g., children, elderly, disabled) exercise their rights and protect them from abuse and neglect.
13. Ask for an estimate of hospital charges before care is provided.

Effective Communication and Participation in Your Care

14. Get information in a way you can understand. This includes sign language and foreign language interpreters and vision, speech and hearing aids provided free of charge.
15. Get information from your doctor/provider about:
   • your diagnosis
   • your test results
   • outcomes of care
   • unanticipated outcomes of care
16. Be involved in your plan of care and discharge plan or request a discharge plan evaluation at any time.
17. Involve your family in decisions about care.
18. Ask questions and get a timely response to your questions or requests.
19. Have your pain managed.
20. Refuse care.
21. Have someone with you for emotional support, unless that person interferes with your or others’ rights, safety or health.
22. Ask for a chaperone to be with you during exams, tests or procedures.
23. Choose your support person and visitors and change your mind about who may visit.
24. Select someone to make health care decisions for you if at some point you are unable to make those decisions (and have all patient rights apply to that person).

End of Life Decisions

25. Create or change an advance directive (also known as a living will or durable power of attorney for health care).
26. Have your organ donation wishes known and honored, if possible.

Informed Consent

27. Give permission (informed consent) before any non-emergency care is provided, including:
• risks and benefits of your treatment
• alternatives to that treatment
• risks and benefits of those alternatives
28. Agree or refuse to be part of a research study without affecting your care.
29. Agree or refuse to allow pictures for purposes other than your care.

Privacy and Confidentiality

30. Have privacy and confidential treatment and communication about your care.
31. Be given a copy of the HIPAA Notice of Privacy Practices.
Complaints and Grievances

32. Complain and have your complaint reviewed without affecting your care. If you have a problem or complaint, you may talk to your doctor, nurse manager or a department manager.

33. You may also contact patient relations at 410-955-2273 or email PatientRelations@jhmi.edu.

34. If your issue is not resolved to your satisfaction, other external groups you may contact include:

- **Hospital's Quality Improvement Organization (QIO) for coverage decisions or to appeal a premature discharge:**
  KEPRO
  Organization for Beneficiary Family Centered Care (BFCC-QIO)
  5201 West Kennedy Blvd., Suite 900
  Tampa, FL 33069
  1-844-455-8708

- **State Agency:**
  Maryland Department of Health & Mental Hygiene
  Office of Health Care Quality, Hospital Complaint Unit
  Spring Grove Hospital Center, Bland Bryant Building
  55 Wade Avenue
  Catonsville, Maryland 21228
  Toll free: 1-877-402-8218

- **Accreditation Agency:**
  The Joint Commission Office of Quality and Patient Safety
  One Renaissance Blvd.
  Oakbrook Terrace, IL 60181
  1-800-994-6610
  patientsafetyreport@jointcommission.org

- **To address discrimination concerns, you may also file a civil rights complaint with the U.S. Department of Health and Human Services:**
  Office for Civil Rights
  200 Independence Ave., SW
  Room 509F, HHH Building
  Washington, DC 20201
  1-800-368-1019, 1-800-537-7697 (TDD)
  OCRMail@hhs.gov
  Complaint forms are available at: http://www.hhs.gov/ocr/office/file/index.html
You have the responsibility to:

1. Provide accurate and complete information about your health, address, telephone number, date of birth, insurance carrier and employer.
2. Call if you cannot keep your appointment.
3. Be respectful of your hospital team, from the doctors, nurses and technicians to the people who deliver your meals and the cleaning crews.
4. Be considerate in language and conduct of other people and property, including being mindful of noise levels, privacy and number of visitors.
5. Be in control of your behavior if feeling angry.
6. Give us a copy of your advance directive.
7. Ask questions if there is anything you do not understand.
10. Take responsibility for the consequences of refusing care or not following instructions.
11. Leave valuables at home.
12. Keep all information about hospital staff or other patients private.
13. Do not take pictures, videos or recordings without permission from hospital staff.
14. Pay your bills or work with us to find funding to meet your financial obligations.
Use this space to jot down any other important information you might need. We wish your child a speedy recovery.
Mission of Johns Hopkins Children’s Center

To deliver exceptional health care in partnership with patients, families and communities in a diverse and inclusive environment, to be a leader in innovative research that leads to prevention and effective treatment of childhood diseases, and to train and inspire future global leaders in pediatric medicine.