A Guide to Inpatient Care for Cystic Fibrosis Families

A collaboration of
The Johns Hopkins Cystic Fibrosis Center and the Cystic Fibrosis Family Advisory Board
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A Message from the CF Care Team

A hospital stay is a very stressful time for children with cystic fibrosis (CF) and their families. The purpose of this guide is to provide you with a resource before and during your child’s stay that will help you understand how your child’s inpatient care is coordinated by many different members of the care team including: physicians, nurses, respiratory therapists, physical therapists, social workers, dietitians, and pharmacists. We all work together with the primary goal of improving your child’s health.

Many aspects of being in the hospital will seem unfamiliar, frightening, and even bothersome or frustrating at times. Why are there so many people involved in my child’s care? Why must people wear gowns and gloves when they walk into our room? Why do tests and procedures sometimes take so long to be scheduled and performed? Why can’t my child and I sometimes get enough rest? How will my child and I be able to do these types of treatments and medications at home? Does being in the hospital mean that my child’s condition is getting worse? What if my child’s condition does not improve after a long course of treatment? These are all perfectly natural and reasonable questions. This guide will help you understand who provides care for your child, what we do and how we do it, and most importantly, why.

We encourage you to read through this guide and ask questions if there is something that you do not understand or would like us to change about your child’s treatment. We also welcome your suggestions to help us improve the inpatient experience for others in the future. Good communication is the key to a successful inpatient stay, not only to make your child’s hospitalization comfortable, but also to help make the therapies as effective as possible so that we can meet our treatment goals for your child!

A Message from the Family Advisory Board (FAB)

Your child is being admitted to the hospital. This is one of the toughest parts about living with CF. We know this since we are also parents and caregivers to children with CF. Both family members and medical professionals created this guide to help alleviate your anxieties about a hospital stay by providing you information about what to expect when your child is admitted to the hospital. It describes resources available for children with CF and their families, provides information about the services offered at the hospital, and offers practical tips for packing.

Information in this guide generally applies to most hospitals, but you will also find specific guidance and tips for a hospitalization in the Johns Hopkins Children’s Center. Should you have questions pertaining to specific services not covered in this guide, start by asking a member of the CF clinic, a staff member on your floor, or by visiting the Children’s Center website: www.hopkinschildrens.org. Parent support and guidance can be an invaluable coping tool during an inpatient stay; we encour-
age you to participate in the Johns Hopkins CF Center’s parent listserv. Ask a member of your child’s CF team how to join the listserv or send an email to hopkinscf@jhmi.edu.

Your healthcare team is dedicated to providing the best possible care and the best outcome for your child. They are also your best source of medical information. Please consult a medical professional before making any changes to your child’s treatment. We suggest you visit the Johns Hopkins Cystic Fibrosis Center website to learn more about CF (www.hopkinscf.org). If you learn tips during your stay that you believe will be valuable to other parents, please send them in an email to hopkinscf@jhmi.edu for inclusion in updates to this guide.

With our best wishes to you and your family,
The Johns Hopkins CF Family Advisory Board

Preparing Yourself and Your Child for Hospitalization

Being hospitalized at any age is frustrating, overwhelming, and scary. Understanding why and having a great support network makes a big difference. Sometimes children with CF show no signs of infection, which can make it hard to understand why hospitalization is needed. There can be a build-up of mucus or a lingering symptoms that just won’t go away. Think of hospitalization as an assistant for your child’s immune system.

Ask questions to make sure you understand the treatment plan and encourage your child to ask questions as well. Explain to your child, in terms they can understand, what will be happening and why procedures need to occur. It is best to be honest and use positive words with your child.

Coping during a hospital stay is challenging for parents as well as the child. Stressful parental issues should ideally be handled away from your child. Children have greater difficulty coping when they see their parents unable to manage a situation. Distractions and special one-on-one time can help ease hospitalization stress. The child life staff has great tools that can help ease stress and promote understanding. Visit our website, www.hopkinscf.org, to help your child prepare for a hospital admission, or even before a clinic appointment.

Support is available from this guide, the hospital staff, other CF families, and from the CF Family Advisory Board. If you have any questions, please contact the Family Advisory Board at hopkinscf@jhmi.edu.

What to Expect at the Hospital

Children with CF who have significant respiratory or abdominal problems or require intravenous antibiotics may be admitted to the Bloomberg Children’s Center. The Children’s Center is a specialized part of the hospital that cares for children and young adults up to 21 years of age. Room assignment is generally based on the age of the child; however, due to infection control concerns, it is possible that a patient will be assigned to another floor. All rooms are private in the Bloomberg Children’s Center

- 9 South – Infants and Toddler Care (children 5 and younger)
- 9 North – Research/ Pediatric Medical –Surgical
- 10 South – School Aged Care (children 6-12)
- 10 North – Adolescent/Teen Care
Your child’s room - a temporary “home away from home” - typically includes:

- A bed (or crib) for your child, pillow, sheets, and a blanket
- A sleep sofa for one adult, pillow, sheets, and a blanket
- A bathroom
- Closet/storage space for personal belongings
- A rolling table
- Cable television, DVD player, and X-Box
- Climate control
- Phone (at additional cost)
- Wireless Internet connection

Please note: The Vest® or inCourage™ system is NOT provided by the hospital (due to infection control concerns), nor are electronic nebulizer devices such as the Trio™ or Altera™

Your child’s daily health and meal needs will be provided by the hospital as follows:

- All hospital (formulary) approved prescription and over-the-counter medications and medical equipment, such as nebulizers
- Meals, drinks, snacks, and nutritional supplements
- Hospital gowns
- Masks
- Hand sanitizer
- Tissues
- Disinfecting wipes
- High chair

Resources for parents within the hospital include:

- Community kitchens with a coffee for purchase, microwave, sink, and refrigerator. Feel free to use the refrigerator to keep your own food and drinks; be sure to label them with your name, room number and the date. Please note: once food has entered your child’s room, it cannot be put in the community refrigerator (due to infection control concerns).
- A cafeteria and food court to purchase meals
- Vending machines and coffee to purchase
- A gym on the hospital campus (check with the social worker or family care coordinator for access; there is a fee associated with use)
- The Grace Rea Garrett Children’s Library (for children’s recreational reading) and Mr. and Mrs. G. Lloyd Bunting Sr. Family Resource Library (for families to learn more about disease/illness) located on the 3rd floor.
- Chapel and Mediation Space
- Laundry facilities

What to Pack for Your Child’s Stay

We recommend that you bring personal items from home to help make you and your child more
comfortable. For packing suggestions, please refer to the “Packing Checklist” at the end of this guide.

Visiting Hours/Guidelines

- Parents/guardians may visit 24 hours a day. A parent or guardian may stay in the patient’s room overnight.
- All visitors must obtain a visitor’s pass from the security desk at various points of entry.
- Any age sibling may visit, but an adult must accompany siblings under the age of 12.
- Too many visitors at one time can be overwhelming to a child, so no more than four visitors, including parents and guardians, can visit at one time.
- Family members or friends experiencing diarrhea, cold or flu symptoms, or who have been exposed to chickenpox within the past two weeks, should not visit.
- During RSV and influenza seasons, visitors under the age of 16 are not allowed to visit in the Children’s Center.
- Beds and cribs are for patient use only. Side-rails or crib rails should be up when an adult is not at your child’s bedside.

Day One

Parking

The preferred parking garage is the Orleans Garage, adjacent to the Bloomberg Children’s Center, which is open 24 hours a day, seven days a week. Be sure to carry your parking ticket with you; you will need to pay for parking before returning to your car and exiting the garage. You can purchase a coupon book for discounted parking tickets at the following locations:

- Cashier’s Office, Nelson 161, Monday through Friday, 7:30 a.m. to 5 p.m.
- Satellite Cashier’s Office, Zayed Lobby Monday through Friday, 5:30 a.m. to 1:30 p.m.
- Weinberg Admitting Office, Monday through Friday, 7:30 a.m. to 5 p.m.
- Orleans Parking Garage Manager’s Office, Monday through Friday, 4 p.m. to 8 a.m., weekends and holidays, 8 a.m. to 9 p.m.

There is also valet parking available at both the main entrance to the hospital and at the entrance to the Outpatient Center.

For more information about parking, rates, and coupons, contact the parking office at 410-955-5333 or visit [www.hopkinsmedicine.org/security_parking_transportation](http://www.hopkinsmedicine.org/security_parking_transportation).

Admission Planning

Planning for your child’s admission often begins in CF clinic where the care team will answer questions you may have about the process, and discuss your child’s individualized care plan. This care plan has been designed by CF staff and parents to give an overview of the medical aspects of your child’s stay, as well as how the team plans to achieve discharge goals.

Admission/Patient Registration

Sometimes your child will be admitted directly to the Bloomberg Children’s Center from CF clinic. In this case, you will be able to go to the floor where
your child is being admitted, and nursing staff will direct you to your child’s room. If your child needs to be admitted to the Children’s Center from clinic, but a bed is not yet available, or your child is very sick, you will be instructed to go the Emergency Department where care can be started until a bed becomes available. Other times when admission is planned ahead, you will proceed to the Bloomberg Children’s Center Admitting Office, located on the first floor, in the Emergency Department.

When your child is admitted to the hospital, the hospital’s Admitting Office takes care of the details related to such issues as insurance company notifications and claims. Please be sure to bring your insurance card to the hospital and provide the patient registrar with accurate, up-to-date demographic information to avoid delays in processing your child’s claim.

Key Players

Attending Physician

The attending physician is a pediatric pulmonologist who is a faculty member of the Johns Hopkins School of Medicine. An attending physician will supervise the care of your child throughout his or her stay.

Pediatric Pulmonary Fellow

The fellow is a physician who has completed a residency in pediatrics and is training to become a pediatric pulmonologist. He or she will manage the day-to-day care of your child in conjunction with the attending physician.

Senior Resident

The senior resident is in his or her third year of pediatric training. There is one resident assigned to the pediatric pulmonary team. The senior resident supervises the intern on the team.

Intern

The intern has completed medical school and is in his or her first year of pediatric residency. The intern is the physician you will likely see the most. He or she is responsible for writing orders for any medication or tests that are required.

Nurses

Nurses, sometimes assisted by techs, will provide care to your child around the clock during your child’s stay. From the time you and your child come to the room, the nurse assigned to your child will begin helping your child settle in and will:

- make sure your child receives an ID band, plus any allergy bands (if applicable);
- check your child’s vitals, height, and weight;
- collect information about your child’s medical history, including current medications and doses; and
- administer medication and treatments that have been ordered.

Be aware that nurses often care for several other patients at a time. Rest assured they do their best to respond to your call as soon as possible.

Specialized nurses, such as PICC nurses, may see your child for certain procedures.

Respiratory Therapists

Respiratory therapists (RTs) will visit your child regularly to give breathing treatments or other types of respiratory therapy. Therapists generally stay in the room during each treatment session.
Your child’s respiratory therapists will typically use treatments and equipment that you are already familiar with, although your child might receive therapy more frequently while in the hospital.

**Physical Therapists**

Physical therapists (PTs) will visit your child two to three times a day for airway clearance treatments and exercise. They will review your home routine and provide suggestions to change and improve as necessary.

**Social Workers**

The social worker can assist with specific problems related to your child’s illness and hospitalization. The social worker will help you communicate with other members of the care team and may arrange family meetings to ensure the needs of your child and family are being met. The social worker can help you locate community resources such as counseling and financial assistance.

**Discharge Coordinator**

The discharge coordinator is responsible for coordinating your child’s transition from hospital to home, or to Mt. Washington Pediatric Hospital for continued care, if appropriate. The discharge coordinator facilitates nursing services, home antibiotics, durable medical equipment, and other supplies required after discharge, as well as follow-up care at CF clinic for your child. If your child will continue IV antibiotic therapy at Mt. Washington, the discharge coordinator will facilitate arrangements for transfer to that facility.

**Child Life Specialist**

The child life specialist helps your child adjust to being hospitalized. The child life specialist can provide therapeutic play to help development, reduce stress, and prepare children for medical procedures. The child life specialist also provides opportunities to celebrate holidays, allow children to play, and keep up with necessary schoolwork.

**Dietitians**

Registered dietitians (RDs) work closely with physicians and nurses to ensure that patients receive proper nutrition during their stay. The RD is available to answer questions or concerns related to the nutritional health of your child. They can also help accommodate patients’ special needs or requests, such as ordering high calorie, kosher, and vegetarian meals.

**Pharmacists**

Pharmacists review and dispense all of the medications your child receives while in the hospital. They assure that your child’s drug regimen is dosed appropriately and screen for unwanted drug interactions. The pharmacist can help answer any specific drug information questions you may have.
Hospital Routine

Morning Rounds

The medical team will come to your child’s room between 8-10am to “round.” The events that occurred during the previous day will be discussed and plans for the day will be made. You are encouraged to participate in rounds to give your opinion and ask questions.

Contact with CF Clinic

One thing that may feel different about being admitted to the hospital is feeling disconnected from your regular care providers in the CF clinic. The inpatient pulmonary care team may include physicians that you do not already know. Staff from the CF clinic keep in regular contact with the inpatient team and will stay informed about your child’s progress.

Nutrition

When admitted to the hospital, children with CF are typically placed on a high calorie, high fat diet, including meals and snacks three times a day. Patients may be prescribed another type of diet depending on food allergies or other medical conditions (e.g., pancreatitis, intestinal blockage/DIOS).

Patients will order their food through At Your Request room service. They will receive a menu in their room, and the patient or a family member can call to place an order. Orders can be placed between the hours of 7:00 a.m. and 6:30 p.m. and the meals are served to the patient within an hour of ordering. Meals can be ordered up to four times daily. Patients are encouraged to choose multiple items on the menus to meet nutrition goals in the hospital of weight gain or prevention of weight loss. Home tube feeding regimens and medication dosing will commonly continue in the hospital unless the medical team recommends a change.

The registered dietitian (RD) will visit you and your child to learn about your child’s diet and meal patterns along with enzyme and vitamin dosing, stool pattern, weight history, tube feeding regimen, and oral supplements. The RD will discuss options for oral and enteral supplementation. The hospital offers an opportunity to try out supplements for use later at home or at times when your child’s appetite is poor. The RD will also evaluate the need for nutrition education, which may include high calorie, high fat diets, tube feeding, Cystic Fibrosis-Related Diabetes (CFRD,) and other possible CF-related nutrition issues.

For parents who are staying with their child, there is a guest tray purchase option. The cost of the guest tray will be added to your child’s hospital bill and is not covered by insurance. If you would like to have a guest tray, please let your child’s nurse know at admission.

Sleep

It is important that you and your child find and keep a sleep routine that works while in the hospital. You should strive to establish a normal bedtime and discuss options with your physicians and nurses for minimizing overnight vitals and breathing treatments, maximizing sleep, and maintaining a quiet environment. Be flexible and expect occasional sleep interruptions. Working with the inpatient staff, you and your child should be able to find a happy medium that allows for much needed, healing rest.

Inpatient Pulmonary Function Testing (PFT)

Patients old enough to perform PFTs in the CF clinic will also perform PFTs before discharge. One of the respiratory therapists or PFT techs from CF
clinic test your child in the PFT lab located within the Bloomberg Children’s Center. The results will be given to both the inpatient team and the CF clinic team.

**Respiratory Therapy**

For parents who usually administer their child’s inhaled medications on a daily basis, handing that duty over to a respiratory therapist (RT) can be either a welcome break or an anxiety-inducing event. Respiratory therapists (RTs) want you and your child to feel confident in their hands and to work closely with them to ensure your child is getting the best possible treatment.

Respiratory therapists may have different styles of practice but should always follow the same basic principles. At Johns Hopkins, RTs dispose of nebulizer equipment after every use. When your child is given inhaled medications, they should always be in proper order; however, the timing may vary from your child’s schedule at home. Some medications may be given more frequently, and some (such as albuterol) may be given via a metered dose inhaler instead of a nebulizer. All treatments are given without compromising your child’s care. Inpatient stays provide excellent opportunities for parents and patients to learn new respiratory tips and techniques.

**Physical Therapy**

Physical therapists (PTs) will see your child two to three times a day to provide airway clearance and exercise. The PT will tell you or post a therapy treatment schedule when they see your child for
their morning treatment. Knowing the day’s therapy schedule will allow you and your child to plan for the day. Meals can be ordered around treatment times, and your child will know when they are free to participate in other hospital activities.

Your child’s hospital stay is the perfect time to review his or her home airway clearance routine. Physical therapists may suggest modifications to improve it. Please bring your Vest® or InCourage™ system to the hospital. Physical therapists will optimize settings and check jacket size. You may also learn about alternative airway clearance techniques to determine the best strategy for your child.

At least one of your child’s daily PT sessions will focus on exercise. Please bring exercise clothes and shoes to the hospital. Exercise improves your child’s endurance, posture, strength and flexibility. It may also help with airway clearance. Improved lung health and general well being are potential benefits of using exercise and airway clearance together. A goal of a hospital exercise program is to set your child on the right path for exercising at home.

**PICU Transfer**

Try not to be alarmed if your child is transferred to the Pediatric Intensive Care Unit (PICU) on the 4th floor of the Bloomberg Children’s Center. The PICU specializes in caring for acutely ill patients,
but your child may be transferred there to start a new drug, a new therapy (such as BiPAP), or for closer monitoring. The PICU has open visiting hours for parents and grandparents, but may restrict visiting hours for others. Your child’s nurse will explain the PICU policies to you should a transfer to become necessary. Child life and social work support will also be available to help you cope with the move.

**Procedures**

The physician may discuss the possibility of your child having certain kinds of procedures during a hospital stay. Common procedures include intravenous (IV) line placement or bronchoscopy, sometimes called a “bronch.” These procedures help your child’s physicians to treat lung infection.

**Intravenous (IV) Lines**

Intravenous (IV) lines are used to give your child the antibiotics needed to treat lung infection. There are different types of IV lines that may be used or discussed with you:

- a peripheral line
- a peripherally inserted central catheter (PICC)
- a surgically placed central line (MediPort or just Port)

Nurses, residents, or a designated IV team insert peripheral IV lines. These IV lines are short (about 1 inch long) and can be used for IV antibiotics, fluids, and other medications. The main advantage of the peripheral line is that it can be inserted reasonably quickly by trained staff into veins just beneath the skin (usually on the back of the hand or forearm). A disadvantage of peripheral lines is that they do not last very long (1-4 days at the most). They sometimes have to be replaced frequently if medications irritate or inflame the vein. A major disadvantage of peripheral IV lines is that they cannot be used for home IV therapy. The child generally uses peripheral IV lines at the beginning of the hospitalization until a longer lasting line, usually a PICC, can be placed.

The **PICC** is a longer IV line that is inserted by a specialized team of surgical nurses. A PICC is inserted in the forearm or upper arm. It runs from the insertion point at the skin to the large vein in the chest that leads directly into the heart (superior vena cava). PICC placement usually requires that your child be sedated. It is a sterile procedure, which means that the area where the line will be placed must first be carefully cleaned and draped with special sterile covers to prevent infection. PICCs can be placed by the PICC team at the bedside or scheduled as a procedure in the operating room. When PICCs are placed in the operating room, an anesthesiologist administers sedation.

The major advantage of the PICC is that it can be used for the entire time that your child will be on IV antibiotics, allowing your child to finish the course of IV antibiotics at home. Disadvantages of the PICC are that it requires sedation to be placed and that placement has to be scheduled with the PICC team. The team will discuss the procedure with you and obtain your written permission (consent) to perform it. PICCs are not placed on weekends. Your child will receive IV antibiotics
through a peripheral line until the PICC can be scheduled and placed.

Sometimes the PICC team has difficulty placing a PICC, mainly if the areas where they try to place the line are scarred from previously IV placement. The PICC team may make this discovery at the time when they do the procedure. If this is the case for your child, the PICC team will discuss options with you and the attending pulmonologist. The team will determine safe and reasonable alternatives for giving antibiotics to effectively treat your child’s lung infection. They may suggest placement of a **surgically placed central line**, known as a MediPort or Port-a-cath, if your child needs frequent courses of IV antibiotics. Medi-Ports are only placed under anesthesia by general surgeons. This procedure requires separate consultation and scheduling with the operating room.

**Bronchoscopy**

Bronchoscopy and **bronchoalveolar lavage** is a procedure known as a “bronch and BAL”. Bronch and BAL help pediatric pulmonologists directly examine the airways and mucus secretions. Sometimes the procedure is necessary to suction mucus from the airways. The mucus can then be examined for different types of bacterial infections that are found in children with CF, especially if they typically do not or cannot cough out any mucus. Sometimes bronchoscopy is needed to look at the airways when there is a new or abnormal finding seen on an x-ray or CT scan. Bronchoscopy may also be needed in the middle of a course of IV antibiotics to assess for different types of infections if the patient is not getting better fast enough on IV antibiotics.

If bronchoscopy is needed for your child, your child’s CF physician or the inpatient attending pulmonologist or fellow will discuss all the details with you and obtain your written permission (consent) to perform the procedure. Bronchoscopy is performed in the operating room under anesthesia. It is sometimes scheduled in conjunction with the PICC team so that both procedures can be performed safely and efficiently using one administration of anesthesia.

**About Infection Control**

Similar to when staff come in contact with your child in CF clinic, inpatient staff will be wearing
gowns and gloves in the hospital. This is done for your child’s protection. Some staff may be caring for more than one patient with CF and take these precautions to avoid spreading germs between children with CF.

While playrooms are found on every patient floor, they are not always a good idea for CF patients. Playrooms and other shared spaces may be off-limits to patients with CF; however, toys and games can always be brought into your child’s room by staff, including child life specialists. Check with the nursing staff or the child life specialist on your floor about the rules regarding shared spaces such as playrooms, the play deck, and the basketball court. Child life specialists will be happy to assist your child in finding ways to make their hospital visit as fun and entertaining as possible.

Discharge Day

Discharge day has finally come! Your child’s hospital treatment plan is complete and the attending physician has decided it is time to go home. You and your child will be anxious to head out, but be patient. Hospital discharge can sometimes be a long process.

Discharge planning actually began back at admission. The inpatient team will provide you with detailed discharge instructions before you leave the hospital. These instructions will be similar to the care plan you received when your child was admitted. Be sure you understand the instructions and that you will feel comfortable following them. Do not hesitate to ask questions before you leave the hospital. You should call the CF clinic if a question comes up once you get home.
Before your child leaves:

- Check for all personal belongings. Remember to check in cabinets and drawers and take items like cell phone chargers.
- Be sure to schedule a follow up appointment at CF clinic.
- Be sure any necessary home health arrangements are made.
- Be sure authorization for any new medications is obtained from the healthcare team and prescriptions have been filled at your local pharmacy prior to discharge, if possible.

The Transition Piece
Sometimes individuals with CF are not hospitalized until they are adolescents or teenagers. Being admitted at this age takes on a whole new aspect of anxiety for both the patient and parent. However, it is a good opportunity to begin the educational road to transition.

Transition is a process that doesn’t happen overnight; it is a path to developing a sense of self-responsibility and self-advocacy. By the time your child is an adolescent, he or she should have an idea of what CF is, be able to name their medications, remember to take enzymes with meals and snacks, and do airway clearance with minimal assistance. High school-aged patients should be able to list the dosages of their medications and the times when taken, answer questions independently, recognize changes in symptoms, and do airway clearance without help. Older teens and emerging adults should be able to discuss their health status with any medical professional. It is a good idea to encourage your older child to maintain an electronic record, preferably on a thumb drive, of their ongoing medications and airway clearance techniques. Your child can bring printed copies to review with their care team at clinic and at admission.

Being in the hospital affords parents the opportunity to teach transition skills to their children without interference from school, sports, social events, and peers. Bring a small notebook so your child can write down questions to ask at rounds and encourage them to ask for an explanation of anything they don’t understand. Many parents serve as a role model for these tasks, and then turn it over to the older child after a couple of days in the hospital. Teaching your child to ask questions in a positive, mature way is a lifelong skill that will serve them well in the future and pave the way to a successful transition.

Packing Checklist
This checklist is compiled of recommendations from other CF parents at Johns Hopkins. It is not all-inclusive but is meant to help you think about what to bring for your child’s inpatient stay.
• Insurance cards, medication lists, important legal documents (e.g., custody, etc.)
• Comfy clothes for child and parents (sweats, zip up hoodies)
• Socks, slippers, slipper socks
• Pajamas/robe
• Exercise/gym clothes and shoes for physical therapy
• Toiletries
• Airway clearance devices (Acapella®, Vest®, inCourage™ system)
• Books, crosswords, puzzle books, etc.
• iPods, mp3 players, and chargers
• Cell phone and charger
• Laptop computer with Skype™ access, and charger
• Favorite pillow and blanket, pillow and blanket for parent(s)
• Arts and crafts supplies
• Favorite stuffed animal
• Card and board games
• School work
• DVDs
• Blackout material to darken room
• Earplugs and eye mask
• Empty suitcase/duffle bag
• Cooler that can be filled with ice for perishables (request ice from RN on floor)
• Extra snacks, microwave meals
• Handheld game systems

Resources

Web Links
Johns Hopkins CF Center website: www.hopkinscf.org

Johns Hopkins Children’s Center website
www.hopkinschildrens.org

Preparing for your child’s hospital visit:
www.hopkinschildrens.org/patients-and-families/your-visit.aspx

Hopkins Kids website
www.hopkinschildrens.org/kids/kidshome.aspx

Email
Hopkins CF Center Family Advisory Board:
CF.FABM@gmail.com

Hopkins CF Center:
hopkinscf@jhmi.edu

Phone Numbers
Children’s Center Admitting
410-955-6190

Child Life
410-955-6276

Family Care Coordinator
410-955-5503

Family Resource Library
410-955-6442

Pastoral Care
410-955-5842