

CHILDREN'S HOSPITAL OF THE KING'S DAUGHTERS

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CYSTIC FIBROSIS CENTER

IN-PATIENT GUIDE

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THIS GUIDE WAS A COLLABORATION OF  
THE CHKD CYSTIC FIBROSIS TEAM AND  
CF ADVISORY BOARD PARENTS

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## LETTER TO PARENTS

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Hospitalization can be a stressful time for children with Cystic Fibrosis (CF) and their families. The purpose of this guide, written in conjunction with parents of children with CF is to provide you with a resource that will help you understand how your child's inpatient care is coordinated by the many different members of the hospital care team: physicians, nurses, respiratory therapists, physical therapists, social workers, dietitians, child life specialists, pharmacists and other hospital staff. We will all work together towards the goal of improving your child's health.

CHKD will provide you a Care Journal upon admission. This small booklet details useful information about the hospital. It can be used as a daily journal to record your child's progress and take notes about treatments. You can write down questions you may have for the physicians that you do not want to forget! If you do not receive one, please ask and it will be provided.

We hope the information in this booklet will not only help you learn about our CF Center and Children's Hospital of The Kings Daughters but enable you to better understand your child's hospitalization and treatment. If you have questions at any time, please ask one of the CF team members.

We encourage you to read through this guide and ask questions if there is something you do not understand. We have provided resources available for CF patients and families, information about the services offered at the hospital, and practical tips for packing. Good communication is key for a comfortable hospital stay and transition home. Should you have questions pertaining to specific services not covered in this guide, feel free to contact a member of the CF team.

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## WHAT TO EXPECT

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Sometimes your child is ill or has had a decline in pulmonary function that has not been able to be treated by outpatient therapy. Your CF doctor may recommend that they be admitted for a "tune up". They may require IV antibiotics, increased airway clearance therapy, oxygen, a medical procedure or closer observation of symptoms and treatment.

A CF clinic staff member will start your admission to the hospital by contacting the hospital nursing supervisor to locate a bed for your child. If one is not located while you are at clinic then you will be contacted at home by the admitting office when a bed placement has been made.

Hospital admissions can be scary for both you and your child. You are welcome to stay with your child in their room as long as you like and also spend the night with them. Your child's room is equipped with a chair or sofa that converts to a bed. Sheets and towels will be provided for you by the nursing staff. Don't forget that the staff is working around the clock to treat your child so they will be coming in the room during the night.

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### YOUR CHILD'S ROOM TYPICALLY INCLUDES

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- A bed (or crib) for your child, pillow, sheets and a blanket
- A chair bed for one adult, pillow, sheets and a blanket
- A bathroom with sink and shower
- Storage space for personal belongings
- a rolling table
- Cable television and DVD player with remote control. There is capability for video game connection if they bring their own system
- Phone
- Wireless Internet connection

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### PROVIDED BY THE HOSPITAL

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- All hospital **approved** prescription and over the counter medications and medical equipment, such as nebulizers and vest (Best to bring your child's vest)
- meals, drinks, snacks and nutritional supplements
- hospital gowns
- masks
- diapers and wipes
- highchair
- toiletries (toothbrush, toothpaste, lotion, soap, shampoo)

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### RESOURCES FOR PARENTS WITHIN THE HOSPITAL

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- CHKD cafeteria to purchase meals
- A cafeteria at Sentara Norfolk General (next door)
- Coffee shop
- Vending machines
- ATM located on first floor

- Laundry facilities
- Ice and water
- Chapel located on first floor
- Gift shop located on first floor (can purchase snacks, drinks, toiletries)
- A microwave available on each floor

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### WHAT TO PACK

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- ✓ Insurance cards, medication lists, custody documents (if appropriate)
- ✓ Notebook and pen to write down what happens during your child's stay (doctors seen, what was prescribed, etc.)
- ✓ Several days change of comfy clothes for your child and yourself if you are staying
- ✓ Favorite toy, animal, blanket or pillow
- ✓ Personal hygiene items
- ✓ Electronic devices: such as I-Pod, handheld electronic games, computer, cell phones and chargers etc.
- ✓ Books, puzzle books, magazines
- ✓ Board games, coloring pencils (or crayons)
- ✓ DVDs
- ✓ Some home medications may not be available. Bring in their original containers for the hospital pharmacy to approve for use.
- ✓ Extra snacks, if desired
- ✓ School books, homework
- ✓ Airway clearance devices
- ✓ Vest-(there are some available in the hospital for patient use, but best to bring garment and machine if you have a small one )
- ✓ G-tube connector (most types are available in the hospital)

***Personal items of significant value should be left home as items can be misplaced.***

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### PARKING

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## GENERAL PARKING

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The parking garages are open 24 hours a day, seven days a week. Parking lot A is the closest visitors' lot to the main hospital entrance. Be sure to carry your parking ticket in with you; security at the front desk will validate it using the pink parking voucher that comes in your admission packet. The voucher is good for 1 free validation per day. Other family or visitors will be required to pay the posted hourly rate.

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## EMERGENCY ROOM PARKING

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You will be directed to park in a designated area of the staff parking garage. Tell the gate attendant you are there for the emergency room and he will give you a pass to place in your windshield. There is no fee. If your child is admitted, then you will need to move your car to the general parking areas.

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## VISITING HOURS

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Hospital visiting hours are from 10am until 8pm. Immediate family members are given more flexibility with visiting. One parent is allowed to sleep overnight with your child. A fold out chair or window bed is available for sleeping and sheets, blankets and towels are provided by the hospital for parents use.

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## CARE FOR THE CAREGIVER

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Hospital days can be long, exhausting and stressful for parents. It is important for parents to take care of themselves so that they can keep their energy and spirits up so as to help maintain their child's spirits and optimism during their stay. Parents are pulled many different ways by responsibilities of jobs, other children and finances. We know that parents want to be by their child's side as much as possible, but each family has to develop a plan that works for them and their child. Parents who are spending long hours at the hospital will find it helpful to take small breaks or walks. Parents may feel comfortable leaving when their child is preoccupied with other activities such as the playroom or when they are receiving instruction from the hospital teacher. The child may also just enjoy having some down time to play videogames or watch movies.

CHKD is located in the beautiful Ghent section of Norfolk. This is a very eclectic area with many shops, restaurants and points of interest to visit. The following should help familiarize you with our immediate area:

- ✚ Botetourt Gardens is a park located nearby off Olney Road
- ✚ Colley Ave. ends nearby at historic Fort Norfolk
- ✚ If you turn left out of the hospital on Colley there are many shops and restaurants a short distance away.
- ✚ The Naro movie theater is located on Colley Avenue

- ✚ There are several yoga studios and a gym in the Ghent area.
- ✚ If you continue down Colley Ave. and turn right on 21st St. there are more shops and restaurants.
- ✚ Harris Teeter is several blocks away at 1320 Colonial Avenue
- ✚ Farm Fresh is on the corner of Colley and 21st St.
- ✚ The Chrysler Museum is a short walk down Olney Road
- ✚ A light rail station is located at Colley and Brambleton Avenue, a short walk from the hospital. The train will take you to downtown Norfolk to Macarthur Mall which contains many stores, movie theaters and places to eat
- ✚ Waterside, Nauticus, the Macarthur Memorial, Scope and Chrysler Hall and historic St. Paul's Church can also be reached by light rail.

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## KEY PLAYERS IN THE HOSPITAL

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Your **attending physician** is one of the CF doctors that you see regularly in CF clinic. They rotate who sees in-patients on a weekly basis. They will see your child daily and supervise their care throughout the hospital stay.

Your **resident** has completed medical school and is in his or her first year of pediatric residency. This is the physician you will see most frequently. He or she is responsible for writing orders and taking care of any medication changes that are required.

Your **senior resident** is in their last year of pediatric residency and will supervise the resident following your child's stay. They address any concerns that the resident may have questions about.

Your **nurses** will provide care and dispense medication around the clock. The nursing staff works 12-hour shifts starting at either 7am or 7pm. The nurse will help you settle in, collect history and current medication information and assess your child daily. There are specialized nurses for certain procedures.

Your **clinician** will assist the nurse during your hospital stay. They will take your vital signs and change your bed linens daily.

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## KEY PLAYERS IN THE HOSPITAL CONTINUED . . .

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Your **respiratory therapist** will administer your child's breathing treatments and do chest physiotherapy as ordered by your physician. Therapists typically stay in the room during the

course of each treatment. Your child may receive more frequent therapies during his or her stay in the hospital.

Your **physical therapist** will examine the child to evaluate the impact of cystic fibrosis on cardiovascular and pulmonary systems. They will develop a treatment plan of activities to encourage improved lung functioning. They will encourage regular physical activity in the hospital and at home.

Your **child life specialist** helps your child adjust to being in the hospital. This person will also teach your child about various procedures or therapies to help them better understand what to expect. At times, the child life specialist may even accompany your child to tests and procedures to offer support and provide distraction for coping. Due to all patients with Cystic Fibrosis being on isolation, your child life specialist will discuss play and distraction options with you when appropriate. Your child life specialist will meet you at the beginning of your admission to discuss support and available resources.

Your **social worker** can assist with specific problems related to your child's illness and hospitalization. They can help you communicate with other members of the care team, ensure that the needs of your child and the family are being met and help you locate community resources such as counseling or financial support if you need assistance. Connie Sigley is the CF care team social worker and will visit your child regularly. There are also social workers assigned to each unit in the hospital.

Your **registered dietitian** works with the care team to ensure your child receives proper nutrition during their stay. They can answer questions or concerns related to your child's vitamins, enzymes, and menu issues. All CF patients should receive a high calorie diet including snacks per their preference. Supplements are also available during hospitalization.

Your **pharmacist** reviews and dispenses all medications that your child will receive while in the hospital. They can answer any specific drug information questions you may have. You can talk with your attending physician or resident regarding the use of any specific home medications while in the hospital.

Your **discharge planner** is responsible for coordinating your child's transition home. They facilitate home antibiotics, durable medical equipment and any nursing services that may be required as your child returns home.

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## HOSPITAL ROUTINE

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## CONTACT WITH THE CF CLINIC

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One thing that may feel different about being admitted to the hospital is feeling disconnected from the CF team. Staff from the CF clinic will maintain regular contact with the inpatient CF physician. The CF team will stay informed about your child's progress.

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## DAILY SCHEDULE

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Your resident and medical students are early risers! They will begin visiting your child as early as 6:00-7:00am to complete their daily assessments. The nursing staff will follow to complete their assessment as well, dispense morning meds. and check on your needs for the day. Your attending physician will examine your child daily as well. If any x-rays are ordered your clinician will take your child down to radiology and bring them back to their room.

Sleep is very important for healing & feeling better. You can discuss options with your doctor & nurses for overnight vitals and breathing treatments, decreasing their frequency. Be flexible and expect occasional sleep interruptions. Working with the staff, you and your child should be able to find a happy medium that allows for much needed healing rest.

Dining associates will visit you throughout the day to take your meal orders and provide guidance with the ordering process. Please tell us about any food preferences or allergies. Our dining associates will also provide their contact information to ensure great customer service. Meal Service Times: Breakfast: 7:30 a.m.-9:00 a.m. Lunch: 11:30 a.m.-1:00 p.m. Dinner: 4:30 p.m.-6:00 p.m. Between meal times: Ask your nurse about snacks or boxed meals

The respiratory therapist will come to your child's room several times a day to administer aerosol medications and chest physiotherapy per physician's orders. Any other therapies ordered will be scheduled in your child's day.

The hospital teacher will either work with your child in their room or may take them to a classroom. Their sessions may last up to 90 minutes. The teachers follow Norfolk Public Schools schedule for holidays and summer vacation.

Due to the special isolation needs of your child, in some circumstances, private sessions can be arranged in the playrooms, or a child life specialist will come to the room to bring games or craft supplies. Visitors under the age of 18 are not allowed in the playroom. You may accompany your child if you choose.

The hospital attempts to follow your home treatment schedule as much as possible but remember that there are often times emergencies or other priorities may cause interruption. This could disrupt treatment schedules or result in a change of room assignment. If your child's room needs to be changed suddenly due to hospital issues a nurse will try to provide you with as much notice as possible. Sometimes this can seem abrupt and may worry your child.

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## HOSPITAL ROUTINE CONTINUED...

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The staff will take responsibility with moving your child and his personal belongings in the event you are not present. It may be helpful to discuss this possibility with your child upon their admission in case it occurs. Let them know that it is not their fault and reassure them that you will be able to find them easily when you return to the hospital.

Your child's nurse is the most accessible staff member for you. CHKD has well trained nurses who try to make your child's stay as pleasant and comfortable as possible. You can ask them questions and if they do not know the answer or if it is not in their area of decision-making, they will help direct you to those who can help. Let your nurse know where you can be reached while away from the hospital so if unexpected things happen, such as room changes, etc., they will be able to reach you.

There is a folder in your room with a list of movies and PlayStation games available to your child during their stay. Simply call the number listed and leave the names of the desired games/movies on the recording. Staff has scheduled times when they will be delivered to your child's room.

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### INPATIENT PFT

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Patients old enough to perform **PFTs** in CF Clinic will also perform **PFTs** before discharge. One of the respiratory therapists from CF clinic will come to your child's room and perform the test at the bedside. The results will be given to both the inpatient team and the CF clinic team.

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### HOSPITAL TEACHER

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There are certified teachers from Norfolk Public Schools on staff at CHKD (hospital teachers) who will ensure that your child's educational needs are met. With the parents signed consent, they will contact your child's teacher to obtain work so as to keep your child up to date, as much as possible, with their schoolwork. Your child is withdrawn temporarily from their home school and enrolled on the NPS school program. They are counted as present in school for each day they are enrolled, and this will be applied to their regular school attendance.

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### INFECTION CONTROL

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Proper hand washing is important for the safety health of your child as well as other patients in the hospital. There are hand sanitizer stations throughout the hospital as well as by the door to your child's hospital room. Feel free to request any hospital staff member to wash their hands with either soap and water or hand sanitizer prior to entering your child's room. The hospital staff will also wear gowns, gloves, and a mask to ensure that no cross infection occurs with other patients. Patients and visitors are required to wear a mask over their nose and mouth.

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### INTRAVENOUS (IV) LINES

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While in the hospital, your child may require IV antibiotics to treat lung infections. There are different types of IV lines that may be used or discussed with you:

- ☞ **Peripheral line**--short catheter and quickly inserted just under the skin on the back of the hand or forearm which can be placed by various trained staff that have to be replaced frequently
- ☞ **PICC** (peripherally inserted catheter) --longer catheter inserted by specialized team of nurses (vascular access team or VAT) which is placed in a large vein that leads directly to the heart. This line can be used for longer periods of time
- ☞ **Mediport** (Port-a-cath) -- a surgically placed central line, long-term port providing frequent IV access, placed surgically under anesthesia by our pediatric surgeons.

The **peripheral line (PIV)** is generally inserted at the bedside. This is usually an easy procedure performed by your VAT team member. This line is useful for short courses of IV medications or for quick access to the vein. The VAT team member will offer some type of topical numbing medication before starting the child's peripheral line (PIV).

The **PICC** placement requires that the child's arm it will be placed in is carefully cleaned and draped with a special sterile cover to prevent infection. The VAT team can do this in a special VAT procedure room with the use of equipment there. The child will receive a medication by mouth or by the PIV to calm them prior to the insertion. They will receive a numbing medication prior to the PICC placement. Some children who are anxious about the PICC placement may have a combination of medication to calm them and will need to go to the ICU (intensive care unit) for a short stay to receive the medications. Once the PICC is in place they will return to their room. The advantage of the PICC is that it can be used for the entire time that your child will be on IV antibiotics in the hospital or at home. While using the PICC at home it does need to be kept dry when bathing.

The **Mediport** may be required if the child has difficulty with placing and maintaining PICC lines. These lines are only placed under anesthesia by general surgeons. The procedure requires a separate consultation with the surgeon and scheduling with the operating room. This small circular port is placed under the skin, usually in the upper chest. It requires a monthly flush with heparin to ensure its proper functioning. The advantage of this port is that it generally lasts for years. It is accessed with a special needle whenever your child requires IV antibiotics. The port will require monthly flushing either by a home health nurse or a parent who has received training to flush the port. Unless the port is accessed for receiving IV antibiotics the child may swim, shower and take part in normal activities. There is a padded device that may be ordered to protect the area of the port during some sport activities. The child's physician would need to be consulted about any sport activities. Airway clearance with the Vest is normally able to be done with the port. The Vest Company will provide padding for the port area. It is also helpful to discuss port placement with the surgeon prior to surgery to discuss location choices that may provide better access.

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## LABORATORY TESTING

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Your child will get lab testing done at the beginning of the hospital stay. This will most likely be drawn when the IV is placed. They will also likely need a lab drawn 2-3 days after the IV

medications have been started to check on an IV medication level. This lab will need to be drawn from a vein, not from the IV line.

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## DISCHARGE DAY

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Your child's length of stay is determined by their medical needs and treatment. Your hospital inpatient team will discuss your child's progress and timeframe for discharge. There are times when discharge appears soon and then a change in your child's health status could prevent this from occurring. These concerns should be discussed with the physician. The CF in-patient physician will use your child's PFT's along with other clinical measures to determine their readiness to go home.

It is helpful to anticipate any specific discharge needs and bring them up early in the admission.

The inpatient team will provide you with detailed discharge instructions before you leave the hospital. Be sure you understand the instructions and feel comfortable following them. Do not hesitate to ask questions before you leave the hospital. You should call CF clinic if a question comes up after you get home.

### **Before you leave the hospital:**

- ✓ Check for all personal belongings. Remember to check cabinets and drawers
- ✓ Check for cell phone chargers
- ✓ Schedule follow-up appointment at CF clinic
- ✓ Make necessary home health arrangements
- ✓ Get prescriptions for any new medications
- ✓ Get any home medications you brought from the nurse

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## HOME HEALTH

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If your child requires any special medical equipment or IV medications, the discharge planner will facilitate this. Your insurance plan will indicate companies that are appropriate, and the discharge planner can assist with providing options. The discharge planner will check with your insurance provider to find out any limitations of your plan regarding home equipment, nursing or financial caps for service. Remember, the home health nurse will usually only come on the **first** day to complete an assessment and assist you with understanding equipment and/or your medications. They will be available by phone 24 hours a day for questions or concerns.

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## RESOURCES

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CHKD CF CENTER-[WWW.CHKD.ORG./SERVICES/CF/RESOURCES.ASPX](http://WWW.CHKD.ORG./SERVICES/CF/RESOURCES.ASPX)

RONALD MCDONALD HOUSE-[WWW.RMHCNORFOLK.COM](http://WWW.RMHCNORFOLK.COM) (757-627-5386)

- ☞ Parents can make reservations to stay in this house located across the street from CHKD.
- ☞ Parents may also use this facility as a place to rest, do laundry or cook hot meals for themselves- staff would like you to call ahead if possible

LOCATED IN LOBBY OF CHKD

- ☞ Hague pharmacy 757-881-1126
- ☞ Grand Grounds coffee shop
- ☞ CHKD Cafe
- ☞ CHKD gift shop
- ☞ Bank of America ATM

LOCATED IN LOBBY OF SENTARA NORFOLK GENERAL (NEXT DOOR)

- ☞ Gift Shop
- ☞ Cafeteria hours: 6:30 am to 10:30 am, 11am to 3:30 pm, 4:30pm to 3:30 am
- ☞ BB&T ATM
- ☞ Coffee shop