

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. This guide was written in conjunction with parents of children with CF to provide 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 therapists, pharmacists and other hospital staff. We all work together toward the goal of improving your child's health.

We hope the information in this booklet will not only help you learn about our CF Center and Children's Hospital of The King's Daughters, but enable you to better understand your child's hospitalization and treatment.

We encourage you to read through this guide. We have included 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. If there is anything you don't understand, or you have questions pertaining to services not covered in this guide, please contact any of the CF team members.

CHKD will also 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 for the physicians that you don't want to forget. If you do not receive one, please ask and it will be provided.

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## WHAT TO EXPECT

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Sometimes your child is ill or has a decline in pulmonary function that can't be treated by outpatient therapy. Your CF doctor may recommend they be admitted for a "tune up." This may include 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 by contacting the hospital nursing supervisor to locate a bed. If one is not located while you are at clinic, you will be contacted at home by the admitting office when bed placement has been made.

Hospital admissions can be scary for both you and your child. You are welcome to stay in your child's room as long as you like or even spend the night. The 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 works around the clock to treat your child, so they will be coming into 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 PS2 with remote control
- 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
- High chairs
- 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
- CF clinic staff can loan you a computer during your stay if needed

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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 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 iPod, 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 medications in their original containers for the hospital pharmacy to approve for use.
- ✓ Extra snacks, if desired
- ✓ School books for 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 visitor's lot to the main hospital entrance. Be sure to bring 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 one free validation per day. Other family or visitors will be required to pay the posted hourly rates.

### 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 you will need to move your car to the general parking area.

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## VISITING HOURS

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Hospital visiting hours are from 10 a.m. to 8 p.m. Immediate family members are given more flexibility with visiting. One parent is allowed to stay overnight with the child. A fold-out chair or window bed is available for sleeping. Sheets, blankets and towels are provided by the hospital for parents.

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## CARE FOR THE CAREGIVER

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Hospital days can be long, exhausting and stressful. It is important for parents to take care of themselves so they can keep their energy and spirits up. This will help you maintain your child's spirits and optimism during their stay. Parents are pulled in many different directions by responsibilities of their jobs, other children and finances. We know parents want to be by their child's side as much as possible, but each family must develop a plan that works for them. Parents who are spending long hours at the hospital will find it helpful to take small breaks or walks. You may feel most comfortable leaving when your child is preoccupied with other activities such as the playroom or when receiving instruction from the hospital teacher. The child may also enjoy having some down time to just play video games 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 Avenue ends at nearby historic Fort Norfolk.
- ✚ If you turn left out of the hospital on Colley Avenue 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 Avenue and turn right on 21st Street there are more shops and restaurants.
- ✚ Harris Teeter is several blocks away at 1320 Colonial Avenue.
- ✚ Farm Fresh is on the corner of Colley Avenue and 21st Street.
- ✚ The Chrysler Museum is a short walk down Olney Road.
- ✚ A light rail station is located at Colley and Brambleton Avenues, a short walk from the hospital. The train will take you downtown Norfolk to MacArthur Center which contains many stores, movie theaters and places to eat.
- ✚ Waterside, Nauticus, MacArthur Memorial, Scope, 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 visit 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 the last year of pediatric residency and will supervise the resident following your child's stay. They address any questions or concerns the resident may have.

Your **nurses** provide care and dispense medication around the clock. The nursing staff works 12 hour shifts starting at either 7 a.m. or 7 p.m. 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. They will take vital signs and change the bed linens daily.

Your **respiratory therapist** will administer 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 and will encourage regular physical activity in the hospital and at home.

The **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. There are playrooms available on both the 7th and 8th floors for your child to enjoy. If your child is on isolation precautions, the child life specialist can bring fun things right to the room. Your child life specialist will meet you at the beginning of your admission to discuss available resources.

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## KEY PLAYERS IN THE HOSPITAL CONTINUED . . .

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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 family are being met and help you locate community resources such as counseling or financial support if needed. Connie Sigley is the CF care team social worker who 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 vitamins, enzymes, and menu issues. All CF patients should receive a high calorie diet including snacks per their preference. Supplements are also available.

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 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.

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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 being 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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## HOSPITAL ROUTINE CONTINUED...

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### DAILY SCHEDULE

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Your resident and medical students are early risers. They will begin visiting as early as 6:00 to 7:00 a.m. to complete daily assessments. The nursing staff will follow to complete their assessments, dispense morning medications and check on your needs for the day. The 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 the room.

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

Breakfast, lunch and dinner are delivered by food service staff to the room. Ordering is done through a "room service" method and your child may pick what they want to eat for each meal. You will call 668-6368 (8 – MENU) between 6 a.m. and 6 p.m. to give food choices from a menu in the room. Please talk with your nurse if the menu is not in the room or you would like more details about room service. Meals must be ordered by the stated timeframe to ensure your choices. If no choice is made, the dietitian will provide a healthy selection. Snack packs are also available for patients and parents.

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

A hospital teacher will 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.

If not on any contact precautions, your child may go to the playroom during regular scheduled hours. Please be sure to check with your nurse first. You may accompany them if you choose, but no visitors under the age of 18 are allowed. Toys and games may be checked out and brought back to the room. If your child is on contact precautions, a child life specialist will come to the room to bring games or crafts. In some circumstances, private sessions can be arranged in the playrooms.

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 deliver these to your room.

The hospital attempts to follow your home treatment schedule as much as possible but 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 provide you with as much notice as possible. Sometimes this may seem abrupt and could worry your child.

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## HOSPITAL ROUTINE - DAILY SCHEDULE CONTINUED. . .

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The staff will take responsibility for 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 in case it occurs. Let them know that it isn't their fault and reassure them you will be able to find them easily when you return. Let your nurse know where you can be reached while away from the hospital so they will be able to notify you if unexpected things happen.

Your child's nurse is the most accessible staff member to 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. If they don't know the answers, or if it is not in their area of decision-making, they will direct you to those who can help.

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## INPATIENT PULMONARY FUNCTION TESTING (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 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 ensure that your child's educational needs are met. With a parent's signed consent, they will contact your child's teacher to obtain work to keep them as up to date with their schoolwork as possible. Your child is withdrawn temporarily from their regular school and enrolled in the Norfolk Public Schools' 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 and health of your child as well as other patients in the hospital. There are hand sanitizer stations throughout the hospital and by the door to your child's room. If your child may have acquired a particular virus or bacteria that could be passed to other children in the hospital, they may be placed on contact precautions, droplet or isolation. The hospital staff may wear gowns, gloves and a mask to ensure that no cross infection occurs with other patients.

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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 (PIV)** - Short catheter quickly inserted just under the skin on the back of the hand or forearm. Can be placed by various trained staff. This line must be replaced frequently.
- ☞ **PICC (peripherally inserted catheter)** - Longer catheter placed in a large vein that leads directly to the heart. Inserted by a specialized team of nurses (vascular access team or VAT). 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 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 line.

The **PICC** placement requires that the child's arm be carefully cleaned and draped with special sterile covers to prevent infection. The team can do this in a special VAT procedure room. The child will receive medication by mouth or by the PIV to calm them prior to the insertion. They will also receive a topical numbing medication. Some children who are anxious about the PICC placement may be given a combination of medications to calm them and will need to go to the ICU (intensive care unit) for a short stay to receive these 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 your child will be on IV antibiotics in the hospital or at home. When using the PICC at home it must 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 a general surgeon. 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. 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 with heparin to maintain proper functioning. This can be done by a home health nurse or a parent who has received training. 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 during some sporting activities. The child's physician should be consulted prior to any sports. Airway clearance with the vest is normally able to be done with a port in place. 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 often 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 medication levels. 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 a change in your child's health status prevents 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 leaving the hospital. Be sure you understand the instructions and feel comfortable following them. Do not hesitate to ask questions. You should call the 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 determine limitations of your plan regarding home equipment, nursing or financial caps for service. Remember, the home health nurse will usually only come on your **first** day home to complete an assessment and assist you with understanding equipment and/or 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

- ☞ Farm Fresh pharmacy
- ☞ 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 a.m. to 10:30 a.m., 11a.m. to 3:30 p.m., 4:30p.m. to 3:30 a.m.
- ☞ BB&T ATM
- ☞ Coffee shop