

A Hospital Guide for Parents of CHILDREN with CYSTIC FIBROSIS



Dear Parents and Guardians,

It is never easy when your child is admitted to the hospital. We know that sometimes, despite all you do to keep your child healthy, Cystic Fibrosis (CF) symptoms can get worse. Taking care of CF is a constant battle against germs that can settle in the lungs and cause infections. Worsening CF symptoms are signs that more treatment is needed.

The main purpose of this guide is to help you and your child feel less anxious and more prepared when getting ready for a hospital stay. In this guide, you will find information about how to prepare your child for their hospital stay, what the hospital provides for you and your child, and how your child can stay as healthy as possible. Remember that every child with CF is different and every hospital stay is unique. We hope to empower you with information to make your child's hospital stay a manageable and successful one. As the Kaiser Permanente CF Team, we put your child's health as our first priority and we believe this guide will help you continue to play a vital role in your child's health in the hospital as you do in the home.

Best wishes to you and your family for a bright and healthy future.

Sincerely,

The Kaiser Permanente CF Team
Los Angeles Medical Center (LAMC)





Introduction

Your child is being admitted to the hospital. This is one of the toughest parts about living with CF. The average stay in the hospital is 2 to 3 weeks. We know that it is not easy when a family must put their daily activities on hold to spend days or weeks away from home and in the hospital. The good news is that the Kaiser Permanente hospital staff does its best to help make your child's stay as pleasant and healthy as possible. You also have a great influence in what kind of hospital experience your child will have.

Should you have any questions about the services provided by the hospital and its staff, please feel free to ask a hospital staff member or a member of the CF team.



Reasons for an admission to the hospital

Pulmonary exacerbations (worsening lung infection) are the most common reason for hospitalization in children with CF. The Kaiser Permanente CF team believes that prompt treatment of pulmonary exacerbations leads to better long-term results. Treatment for a mild pulmonary exacerbation includes an increase in breathing and airway clearance (CPT/Vest) treatments and antibiotics (oral, sometimes IV) at home. However, if your child does not improve with home treatment or if the exacerbation is severe, then an admission to the hospital may be needed to get your child healthy again.

Pay attention for signs of a pulmonary exacerbation:

- Any change in frequency or severity of cough
- Any change in mucus production
- Coughing up blood, even a small amount in streaks or flecks in the mucus
- New noises made by the lungs (wheezes, crackles, “chest congestion”)
- Shortness of breath while sitting, walking, climbing stairs, or with exercise
- Feeling tired or “just not feeling well”
- Not eating well or not feeling hungry
- Losing weight or not gaining weight in between clinic visits
- Fevers, even slight fevers
- Small decreases in lung function over 3-6 months
- New findings on chest x-ray





Admissions

Depending on the severity of the pulmonary exacerbation, your CF doctor can make a decision to admit your child during a visit to the CF clinic, through the emergency room, or directly from home. Sometimes, families will be advised to go to the emergency room in order to start treatment promptly. Once a room is assigned, you will be provided the room number. The first number in the room number is the floor that the room can be found on. For example, room 5541 is on the fifth floor. Each room has a telephone, bathroom, and other amenities. Every room also has a Welcome Book Guide to the Los Angeles Medical Center that will give you more detailed information on the hospital and its policies.

General treatment plan in the hospital

The hospital stay is a time for your child to get more intensive treatment, good nutrition and rest.

Treatment

When you arrive in the hospital, an IV (small plastic tube inserted in a vein) may be placed

to give your child intravenous (IV) antibiotics. These are antibiotics given through the IV into the blood stream that might better fight infection your child's lung infection. Soon after your child's admission, a PICC line (Peripherally Inserted Central Catheter) might be placed. This is a long IV that is useful in children with CF who need longer courses of antibiotics because it lasts longer than the small IV you might be familiar with. Also, blood that may be needed for blood tests can often be drawn from these PICC lines, so your child may not need to be poked with a needle for blood tests after the PICC line is placed.

Your child will continue on all of the usual medications taken at home. However, some of the nebulized medications (like Albuterol) will be increased along with chest physiotherapy (CPT, like the Vest). Some children may need oxygen when they are sick with a pulmonary exacerbation. In certain situations, your child may be able to go home with IV antibiotics through a PICC line. If this will be part of your child's treatment plan, you will be trained on how to provide IV antibiotics in the home.

Nutrition

Maintaining a healthy weight goes hand-in-hand with lung function. Your child's meals are planned and served by the hospital food service under the supervision of a Registered Dietitian. Meals, snacks, drinks, and nutritional supplements (like Carnation Instant Breakfast, Ensure, Boost) will be delivered to your room

Every day, your child will be able to select their meals from a menu. The menu your child receives each morning is for making choices for meals served the next day. Three meals and three snacks may be selected each day. Be aware of the hours of operation and wait times for orders you have placed with the food service.

A cafeteria is available on site if you would like to purchase other food. Your child is not allowed to go to the cafeteria, regardless of if you will be accompanying them or not. Cafeteria "passes" or discounts are not available for patients or their family members. Unless you have specific instructions from your doctor, your child can also eat foods not served by the hospital. Feel free to bring his/her favorite foods to the hospital. Any food you bring in from your home or purchased outside the hospital should be labeled with your child's name.

Rest

Rest plays a key role in getting well and is an important part of the recovery process. During the hospitalization, every effort will be made to make sure your child has adequate time to rest. The schedule may seem busy in order to get in all of the respiratory treatments, meals, and medications but your child should try to rest when

they are able. Therefore, we advise that all children try to be in bed and asleep by 10pm because the hospital day starts early. Medications will be given and treatments will be performed as scheduled. They will not be delayed despite late bedtimes.



Your child's hospital care team

Each day your child is in the hospital, there will be visits from various doctors, nurses, respiratory therapists, and other members of the hospital care team. Your child will see different team members in the hospital than in the clinic. But, a CF clinic doctor is always part of the hospital team. The hospital care team also communicates frequently with the CF clinic care team whenever necessary.

Nurses

Your child's nurse is responsible for providing daily nursing care and education to your child and your family during the hospital stay. The nurse will do a complete assessment when your child is first admitted by asking you questions about your child's health and medical problems. It will be helpful if you have a complete list of current medications.

During the hospital stay, the nurse will perform a daily assessment. He or she will take vital signs (including temperature, heart rate, and breathing rate) regularly, administer oral and IV medications, and, most importantly, coordinate your child's

care with other members of the care team. At the time of discharge, the nurse will review discharge medications, schedule your child's follow-up visit with the CF Center, and provide you with a "Discharge Summary" with instructions to continue care at home.



Doctors

Kaiser Permanente LAMC is a teaching hospital, so you can expect your child to be seen by a team of physicians each day. This hospital team includes medical students and in-training doctors (like interns and residents), which are closely supervised by an attending pediatric doctor. The CF physicians (Dr. Saeed and Dr. Sohn) work with the hospital team to direct your care. Different members of your team will be present in the hospital during the day and evening times. There is always a doctor present in the hospital who is part of your care team. If you have any questions or concerns about your child's CF care, please speak to the CF doctor who visits your child in the hospital.

Respiratory Care Practitioner

The Respiratory Care Practitioner (RCP) is responsible for giving your child nebulized medications and CPT or Vest treatments. This RCP may be someone you are unfamiliar with, but the CF RCP is always available for any questions you might have. The Respiratory Care Service operates all day and night in the hospital. Patients are

expected to be awake and ready to participate at least 4 times a day, along with CPT or the Vest. Bedside pulmonary function tests may be done periodically to assess response to therapy.



Dietitian

It may be a challenge to find foods on the hospital nutrition menu that your child likes to eat. Many children with CF have a decreased appetite when they are sick. You can seek help from your CF clinic Dietitian or the hospital Dietitian if your child is struggling to eat well and maintain his/her weight, you have any special food requests, or you have any questions or concerns about your child's nutrition. Often, a nurse or physician will also be able to help you with these concerns.

Medical Social Worker

Medical social workers are specially trained and are available to help you and your family deal with emotional, social, or financial issues that may be affected by your child's hospital stay. This can include brief counseling to help you, your child, and your family cope with and manage changes in your child's CF care. The social worker can also help if there are challenges with your child following the treatment plan. Social workers coordinate community resources for home, school,

or work and link you to programs within Kaiser Permanente as well.

Your Pediatric Social Worker is available from 8am - 5pm, Monday - Friday. If you need help from a social worker outside of regular business hours, please ask your nurse.

Child Life Specialists

The main role of the child life specialist is to help children cope with being sick and being in the hospital. The child life specialist will, among other things, help your child manage pain during medical procedures and provide pediatric patients with toys or art supplies. The child life specialist will inform you about various activities based on the age of your child that are available in the hospital to help fill free time. They also encourage patients' families to bring toys, movies, favorite blanket, or video games to help comfort your child during their hospital stay.



Visitors

- All patients have a right to privacy however, any patient who engages in intimate behavior with a significant other will be asked to stop immediately as this will not be tolerated in the hospital. The visitor will be asked to leave if a patient does not follow this rule.
- Parents have the right to restrict any visitor from the hospital if desired. However, both parents are allowed to visit the patient unless legal documentation is presented to staff to state otherwise.

- Visits are discouraged after 8pm (this does not include the parents of a patient).
- No one under the age of 14 years of age may visit during the flu season or if they show signs of infectious illness.
- No one under the age of 14 years of age may visit unless they are accompanied by an adult at all times. You may not leave a child visitor in a patient's room unsupervised by an adult.

Resources for families from out-of-town

Many resources are available to help patient families who are coming from out-of-town. You can get useful information in advance about the Kaiser Permanente Los Angeles Medical Center by visiting the hospital's website from www.kp.org. The medical social worker can also provide resources for: Overnight accommodations, catering to both long-term stays, such as the Ronald McDonald House, and shorter-term stays, such as hotels, as well as resources available to family members who are staying overnight in the hospital.



Parking

Parking is available to patient families and visitors in the parking area of your hospital. Hourly parking rates vary by location. If you are not able to pay for parking, speak with the medical social worker to see if you qualify for assistance.



Infection control

Kaiser Permanente has strict guidelines for infection control for children with CF. These guidelines are to prevent the spread of bacteria or other infectious diseases. It is widely understood in the CF community that people with CF should not be near each other because they might share harmful germs. While in the hospital, parents should ensure that their child avoids other children who have CF.

Certain children with drug resistant bacteria will not be allowed to leave their rooms. If your child leaves his/her room, he/she must wear a mask at all times and practice good hand hygiene. Be sure to let the nurse know where you are going with your child. Do not forget to respect appointment times with caregivers such as RCP's. Parents should be aware that Kaiser Permanente does not allow patients to leave the hospital grounds during a hospital stay (there are no "passes" to leave the hospital).

When any hospital staff enters your child's room, they must wear a gown and gloves. Any hospital staff who has contact with your child must also wear a mask.

If you believe someone has not put on the necessary protection before coming into your room, do not hesitate to remind them.

Playroom

The hospital has a playroom that many of the children admitted to the hospital use. While it provides a good service to many patients and families, please be aware of the high risk of passing along infections. Try to use the playroom when it is not crowded and there are no other children with CF there. If your child would like to use the playroom, please arrange it with the child life specialist. A good alternative to the playroom is to pay a visit to the outdoor spaces on hospital grounds. This will give you and your child the chance to stretch your legs and get some fresh air. Kaiser Permanente LAMC hospital has a garden, which provides a welcome change of scene from your child's hospital room. Just remember to ask the doctor if it is ok to go to one of those areas.

Hand Hygiene

You and your child should always practice good hand hygiene in the hospital. The same should apply for any visitors or family members. They should use the hand sanitizer to clean their hands or wash their hands with soap and water frequently, especially before touching your child or your child's things.





Discharge day

Once your child has finished his/her hospital treatment and the attending doctor says he/she can go home, your child will be discharged home from the hospital. You and your child may be anxious to leave right away, but please be patient. The hospital discharge is sometimes a long process.

If your child has new medications to pick up, please go to the 4700 Sunset Pharmacy. If you have any questions, please call the 4700 Sunset Pharmacy directly.

Hours: Mon – Fri: 8:30am – 9pm;
Sat, Sun, Holidays: 9am – 4pm
Phone Number: (323) 783-9078
Location: 4700 Sunset Blvd First Floor Pharmacy
(Corner of Vermont and Sunset)
Los Angeles, CA 90027

Before your child leaves, check for all of his/her and your belongings. Parents, remember to look in cabinets and drawers and take your personal items, including cell phone chargers. Your child will leave the hospital with specific discharge instructions. Before you leave the hospital, be sure that you have an appointment with your child's CF doctor for a follow-up visit.

Packing checklist

For Your Child

- Extra supplies of prescription medications, for the waiting times during admission and discharge.
- Comfortable clothes and pajamas; socks, slippers or easy slip-on shoes. Choose loose layers of clothes that slide easily over IV lines.
- Toiletries
- Special favorites like stuffed animals, blankets, pillows or pacifiers. Things to do, including small games and toys, arts & crafts supplies, books, DVD's, CD's, iPOD or school work.
- Room decorations like pictures of loved ones, cheerful posters, tape for hanging artwork and flowers.
- Nutritional supplements that are unusual and not likely to be provided by the hospital pharmacy or food service; favorite snacks.
- Your child's VEST from home (no need to bring the compressor with its cord and tubing).

For Parents

- Comfortable clothes, socks, slippers or easy slip-on shoes. Remember to dress appropriately for hospital staff who will be coming in and out of your child's room at all hours of the day and night.
- Toiletries and your own medications or supplements
- Things to do or use, including books and magazines, laptop computer, cell phone and charger. Favorite snacks and beverages.





Kaiser Permanente Cystic Fibrosis Center developed and made available this hospital guide as a resource for families having a child with Cystic Fibrosis and requiring trips to the hospital.

Your CF Team would like to thank you for your cooperation and for taking the time to read this booklet of information.

Working as a team will help your child get the best outcomes possible during his/her hospitalization.

Please let us know if you have any questions or concerns! The Kaiser Permanente CF Team

Los Angeles Medical Center (LAMC)