Q: Parenting resources –

Parenting Children with Health Issues by Foster Cline, MD, and Lisa Greene (this book is available in our clinic, please ask for one if you are interested)

Teleclass: Winning with CF: Tools, Tips and Tactics for Raising Healthier Kids
https://www.happyheartfamilies.com/catalog/item/6705091/6585301.htm?desktop=true

Q: Weekend trips: what do I need to take, what can I leave at home?

When traveling, it is important to have all of your child's CF medicine with you. It is best if you have the amount you need for each day of your trip, plus a little extra in case your trip gets extended for some unforeseen reason. Depending on the length of your trip and whether or not you use a mail-order pharmacy, you may need to order refills in advance to make sure that you have enough of your child's medications. Share your trip plans with your CF care team. Your CF physician can give you a written prescription for your medications to carry with you if you are ever in need of more. If something happens to your child's medications while traveling or you need more, you can call your CF care team to send a prescription to a local pharmacy (if traveling within the United States). Please be aware that this does not mean insurance will cover additional medications for the month.

If your travel plans involve flying, you should carry your child's medications onto the plane – do not check them in. This will ensure that you have them available and that they do not get lost or delayed on your way to your destination. Carrying medications onto the plane allows you to be in control of the temperature at which they are kept. Enzymes need to be kept at room temperature - keeping them with you prevents them from getting too hot or too cold while flying. For medications that need to be refrigerated, bring a cooler bag with ice packs in it. The temperature requirements of each medicine can be found on their drug packaging. Keep your medications in their original containers when traveling. This helps you make sure that you are taking the right drugs at the right time, and can help prove to security that the medicines belong to you.

For the medicines that need to be refrigerated, you can call your hotel ahead of time to request that a refrigerator be in your room for your use. If your hotel does not offer in-room refrigerators, label your medicines with your name, hotel room number, and phone number. Ask the hotel staff to use the hotel refrigerator and freezer to keep your medications and re-freeze your ice packs.

Don't forget to keep your child's calorie intake high while traveling. Pack some high calorie snacks to take while you are on the road and remember enzymes.

You will need to continue your airway clearance techniques and nebulizer treatments while traveling. You should bring whatever equipment you use at home with you for this. This also means that you will need to have the necessary tools to properly clean your nebulizer equipment. The place you're staying may have a microwave so that you can disinfect your nebulizer parts between uses. If this is not an option, you could pack your own sterilizer device. Like your medications, you should carry your nebulizer and other CF treatment equipment onto planes with you. This helps make sure that it doesn't get lost or damaged in

the checked luggage. If you're traveling by car, you can look into getting a car adapter so that you can do nebulizer treatments on the road.

It is a good idea to look up CF centers that are near your destination. In the case where you need to seek care, you will already know where you need to go. If you're traveling within the U.S., you can find a list of CF centers on CFF.org. If you're traveling internationally, you can find a list of CF centers on CFWW.org. You should have a copy of your insurance card and information with you in case you need to receive medical care.

Please ask your CF care team ahead of time for a note from your doctor that explains Cystic Fibrosis and your child's need for the medications and treatment supplies that you will need to carry with you. This can help smooth over processes like airport security. You'll also want to bring a copy of the instructions for your treatment supplies in case they stop working while you are traveling.

Infection prevention is a main concern while traveling as well. Make sure you have plenty of alcohol-based hand sanitizer and/or wipes so that you can clean your hands and surfaces you touch often. Try to stay 6 feet away from anyone who appears to be sick. If you are on a plane and the person next to you is sneezing or coughing, ask to be moved to a different seat. People without CF will be able to handle getting sick better than someone with CF. In people with CF, minor illnesses can become more serious infections.

Q: What foods should I give enzymes with?

Enzymes should be given with every meal and snack that contains fat, protein, or carbohydrates. This includes breast milk, formula, nutritional supplements and tube feedings. Remember: without the help of enzymes, your child is not able to get the energy from food that they require to grow and be healthy.

There are certain foods that don't require enzymes because they contain only "simple carbohydrates" (sugar). These foods are easy for the body to digest without the help of pancreatic enzymes, and include fruit juice, flavored ice, hard candy, tea, fruit snacks, etc.

If your child cannot swallow pills, open the capsule and pour the enzyme beads onto a spoonful of a soft, acidic food. The most common suggestion is applesauce, but you can also use different pureed baby fruits, tomato paste, jelly or even ketchup. We use an acidic food because the enzyme beads are covered in a coating that dissolves away in basic/alkaline environments. This is helpful because the small intestine is basic/alkaline and will dissolve/melt the coating so that the enzymes can work. We do not want the coating to dissolve until it reaches the small intestine. Therefore, the enzymes should be given with acidic food.

It is best for the enzymes to first contact the food substance right before it is swallowed; do not pre-mix the enzyme beads with the food ahead of time. The enzymes should be swallowed whole and not chewed. If the enzyme beads are crushed, there is a risk that the enzymes will not function well or that they will cause irritation to your child's mouth. Have your child drink something after taking enzymes to make sure that their mouth is clear.

Older children and adults with CF can take the enzymes in capsule form. Enzymes may also be taken with tube feedings. There are many ways to accomplish this, so work with your CF care team to figure out what works best for you.

Q: What is a PFT? When do we start PFTs?

Pulmonary function tests (PFTs) are an important tool to understanding the health of your child's lungs. A Respiratory Therapist will use a spirometer to measure while your child breathes in as much air as possible, and then blows out forcefully for an extended amount of time. Your child's nose will be clipped shut and they will have to perform this task a few times. Performing a PFT requires that your child be able to follow instructions. Typically, PFTs are started around the age of 5 at each clinic visit. It is common for it to take a few visits to learn how to perform this test properly. The PFTs can give information about the state of your child's lungs at the time of the visit, as well as provide a data point to map out your child's lung function over time.

Some important values that are obtained from PFTs are:

Forced expiratory volume (FEV1): FEV1 is measured during the portion of the PFT when you are breathing air out (exhalation). It is a measure of the volume of air that exits your lungs during the first second of forced exhalation. This is an important value because if it decreases, it can mean that lung function is declining. The FEV1 can decline gradually over time due to progressive CF lung damage that may not be reversible. FEV1 can also decline quickly in the setting of a lung infection (illness) and come back up to pre-illness levels after antibiotics. When a FEV1 is lower than it should be in a CF patient, it suggests that some of the airways are blocked– likely by mucus. Removing mucus is an important part of treating CF and keeping the lungs functioning as well as possible for as long as possible.

Forced vital capacity (FVC): FVC is the measure of how much air can be forced out of your lungs in one breath after a maximum inhalation (breath in) was taken.

Forced expiratory flow (FEF 25/75%): This measures the flow of air out of your lungs between the times that 25% of the air has been exhaled and 75% of the air has been exhaled. If this value is lower than it should be, it suggests that small airways in your lungs are blocked or obstructed. In a CF patient, this is likely by mucus.

Q: Is there anything I can do to help my child learn breathing maneuvers?

You can start playing blowing games with your preschooler like:

- fogging up a mirror

- taking a big breath in, holding it for two seconds, and then blowing a cotton ball or tissue across a table

- spinning a pinwheel

Q: What options are there if my child is not meeting weight goals?

If your child is struggling to meet their daily calorie goals, nutritional supplements can be used in addition to meals and snacks. These nutritional supplements include Carnation instant breakfast, Ensure, Boost, Pediasure, etc. You can get them in liquid milk-based drinks or powders that you add to milk or milkshakes on your own. Your CF dietician will have suggestions for what is best for your child. These supplements should not be used in place of meals and snacks, but in addition to them.

Getting a child with CF to eat as much food as they should to maintain a healthy weight can be a big stressor for parents and families. There are various reasons why a child with CF may not be able to get the nutrients they need to grow. These include nausea and vomiting, a respiratory illness, or even just a small appetite. If your child is having trouble consuming the larger amount of food they need, it can make mealtimes difficult and unpleasant. Please let us know. We can provide families with referrals to feeding teams or other specialist who can help. Not being able to meet nutritional demands on a consistent basis is stressful and your child may benefit from tube feedings. It should not be an end-of-the-line option. Many families who have used tube feeding to help their child get to their healthy goal weight have found that it improved their child's life and the life of their family in major ways. Not only can tube feeding help make your child more healthy, energetic, and robust, but by lifting the stress of getting your child to eat enough calories, you have more time to spend on activities that the whole family can enjoy.

There are different options to choose from when it comes to selecting a feeding tube. One of the most common is the gastrostomy tube (G-tube). To get a G-tube, your child will have to undergo a surgical procedure that places the tube through your child's abdominal wall and connects it directly to the stomach. Tube feeds can then be given directly into the stomach. Feeds are commonly done overnight while the child is sleeping so that they can move freely and eat by mouth during the day.

It is also important to check with your child's insurance ahead of time to determine if the formula for the g-tube and g-tube supplies are a covered benefit.

Q: What do I need to tell my preschool teacher? Is there information to give to other caretakers?

Your child's teacher should know that CF is a genetic disease that cannot be spread to other people and does not affect your child's ability to learn. The common illnesses that other children have can cause worse illnesses in children with CF, so sick children should be encouraged to stay home from school. If the preschool allows sick children to attend, ask to be notified if there are sick children in your child's room. Infection control is important in keeping your child safe, so hand-washing with alcohol-based hand gel and/or soap and water should happen very frequently for all students throughout the day. Students should wash hands especially after coughing, sneezing, or blowing their nose, and after touching classroom items that are common to all children. After a cough or sneeze, germs can hang in the air and be transmitted to other people. To combat this, children should be taught the proper cough technique of using their elbow to cover their cough whenever tissues are not available.

Your child might also need to go to the bathroom more frequently than other children. Forming a plan with the teacher ahead of time will help them be more understanding when this occurs. Your child also

might need to stay inside when the air quality outside is poor. They also might need to eat more snacks throughout the day to be able to meet calorie goals. The teacher should know about the pancreatic enzymes that your child has to take, and the importance of giving them with appropriate meals and snacks. Additionally, your child might need to have increased flexibility with the attendance policy; they might miss extra days due to their CF.

Please discuss your child's healthcare needs at school with your CF team members. Letters and forms as well as information can be provided to the school to help your child get what they need while at school.

Q: What if other children are sick at school?

Illnesses like colds and the flu may more intense for a child with CF. To avoid spreading sicknesses to children with CF, any child who becomes ill should stay home from school. If the sick child does come to school, frequent hand hygiene should be performed. The child should use tissues whenever they cough, sneeze, or blow their noses. If tissues aren't available, they should use their sleeve to avoid transferring the droplets into the air.

Partner with your child's teacher to let them know about your concerns. You could form a plan with the teacher that if a child is sick in the class, your child with CF will be seated on the other side of the room. You also may want to ask the teacher to tell you if he or she notices that a particularly bad illness is being passed around so that you may decide whether or not to keep your child home from school. The CF care team can provide you with educational handouts to give to your child's teacher.

Q: Can my child participate in sports?

Being active is an important aspect in the health and development of all children, including those with CF. Any physical activity that your child is interested in should be encouraged, whether that is their physical education class, a sport, or another activity. It is important to understand that your child with CF might get worn out more quickly than other children, particularly when they are coughing more. If this happens, they should be encouraged to take a break for a bit and rejoin the activity when they have energy. This is a good thing to communicate with teachers and coaches to ensure that they know your child's possible limitations. It is also important to remember that people with CF lose more salt in their sweat than others. To balance this salt loss, salty foods may need to be eaten before or after physical activity.

If you are unsure about a new activity that your child is starting, talk to your CF care team. They can help give you some suggestions on how to keep your child safe while they're exploring the new found interest.

Exercise is also a good way to keep the lungs clear and healthy but should not replace prescribed airway clearance.

Q: Helpful tips for packing lunch and snack

Enzymes will need to be taken at lunch time if your child is pancreatic insufficient. You will want to work with your school nurse/teacher to figure out what the school's policy is on students taking medicine. It is a good idea to walk through the process before starting school so you can make sure medication is being

stored properly and that the process is not overly cumbersome for your child or the administrator. Some kids will avoid eating to increase their play time and is something to ask the teacher to watch for. In addition, if possible, whatever is not eaten should be sent back home so you know what is being consumed at school. Children with CF have increased energy needs, so their lunches can look different than their friends. This can make your child feel different than their classmates, which may be difficult for them. This is something you can talk about before starting school.

There are a lot of ways to get more calories into your child's meals without increasing the amount of food that they have to eat in front of their friends. Here is a collection of some things that have worked for other parents of children with CF.

- Include dips *(bean, humus, sour cream) or dressings for vegetables and add extra butter or oil
- Add extra mayo, bacon, or avocado to sandwiches!
- Grill sandwiches in butter or margarine
- Make options that come with gravy or a creamy sauce
- Add extra cheese whenever possible
- Add extra butter or margarine whenever possible
- Add nuts and seeds to desserts or salads
- Include high-calorie desserts
- Include high calorie beverages (flavored milk, oral supplements)

Q: School forms for medication?

You should become familiar with your child's school policy on medications. There will likely be a medication authorization form that you can get from the school. Take this form to your CF care team to have them complete the information about the medications that your child may need to take during school. This will include information about the medication, how often it needs to be taken and the dose. It will also include the CF care team contact information if the school has questions about the medicine or its administration. If you would like your CF care team to communicate directly with the school, you will need to sign a release of information. You can ask your CF care team for this form.