

# Becoming a CF Manager



For Parents of Children  
with Cystic Fibrosis





**PROGRAM DEVELOPED BY:**

The CF Family Education Project  
Baylor College of Medicine  
and Texas Children's Hospital



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## Becoming a CF Manager



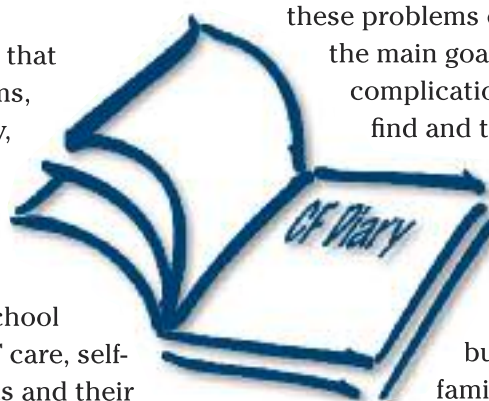
## INTRODUCTION

**M**anaging **cystic fibrosis\*** (CF\*) well requires you and your child to have many skills. The CF FAMILY EDUCATION PROGRAM (CF FEP) was developed to help give parents the knowledge and skills to manage CF as a **chronic\*** disease, to work with the CF health care team, and to help their children learn to manage CF as they get older. This module is about the skills parents need to become good CF self-managers.<sup>†</sup> In turn, parents will learn skills to help their children with CF become good managers. Good management skills will help parents and their child with CF work toward the goal of keeping the child as healthy as possible and doing the things that all children do.

### WHAT IS SELF-MANAGEMENT?

**Self-management\*** is behaviors that people learn to prevent problems, find and manage problems early, and make everyday life successful as possible. Self-management is applied to many areas of life. For example, parents and children manage school schedules and homework. In CF care, self-management means that parents and their children with CF are responsible for day-to-day CF care. CF is a disease that requires many daily tasks to manage it. The doctor and CF health care team cannot do these tasks for your child. Becoming a **CF manager\*** may require you to shift your thinking about what to expect from health care. Here is how most of us look at illness: we feel sick; we go to the doctor; the doctor makes a **diagnosis\*** and prescribes a treatment and/or medicine; we do what is prescribed and the illness goes away.

In CF, the body has several basic problems (see the CF FEP modules *Managing Lung and Other Respiratory Problems* and *Managing Nutrition and Digestive Problems*) that increase the chances of your child getting certain illnesses and **complications\***, especially **lung infections\*** and **malnutrition\***. At this time,



these problems cannot be cured. Therefore, the main goals of CF care are to prevent complications when possible and to find and treat **symptoms\*** of illness early. Preventing problems and noticing symptoms of CF early will be done not just in the clinic or in the hospital, but also at home by the family as CF managers. Families will use self-management skills to care for their children with CF and prevent or treat CF health problems.

### Managing Health Problems

**Prevention\*** is a very important goal of CF management. In CF, prevention means managing CF to slow down the worsening of the disease and its complications. CF is a chronic disease (a condition that lasts a long time and often cannot be cured). Families and their CF health care team work together to find and prevent problems related to CF.

### Managing Quality-of-Life Problems

Any chronic disease such as CF can affect the **quality of life\*** of the person with the disease and his or her family. Good CF managers have to learn how to live with CF, but not let the disease rule their lives. On the other hand, they

<sup>†</sup> In the CF FEP, we have shortened the term *CF self-manager* to *CF manager*.

\*See [CF Words to Know Glossary](#).



cannot ignore CF. Ignoring CF, even when there are few symptoms and the disease seems to be mild, is very risky. Complications can happen before you see symptoms. People who try to ignore CF and CF care usually end up with complications that might have been prevented or treated before they became big problems.

The CF FEP teaches you to think not just about health problems, but also about quality-of-life problems. When we talk about quality of life, it's really about balance. Do not allow one aspect of your life to take over everything else. Every family is different, but the overall goal is the same. We want to make sure every person with CF is able to live a full and active life. If CF is causing problems and stress in your family or in your life, you can use problem-solving skills to better manage these health and quality-of-life conflicts and reduce stress.

Keeping yourself healthy is important to you and to your child. Think about how you take care of yourself. Being a parent often means taking care of your child's needs but not your own. Here are some things to think about.

- Work on preventing stress from overwhelming you.
- Learn ways to counter stress in your life.
- Figure out which worries you can let go.
- Think about others who can help you. Do they need training to be a CF manager? Bring them to a CF clinic visit.
- Ask your CF health care team for help in training others who can support you and your child.

You can find more information about managing stress and solving problems in “MANAGING STRESS,” Appendix 1.

## SELF-MANAGEMENT SKILLS

- Set **GOALS** for health and life.
- **WATCH AND DISCOVER\*** a problem that keeps you from your goals, such as early symptoms or **signs\*** of a change in your child's health.
- **THINK AND ACT\*** to prevent or manage problems including:
  - Using CF **therapies\*** regularly to prevent symptoms
  - Treating episodes of **acute\*** illness
- Work with the CF health care team to figure out how well the **CF action plan\*** and treatments are working.
- Assess how CF and CF care fit into the rest of your child's and your family's life.

Through this program, and with help from your CF health care team, you will learn how to become an expert manager of your child's CF care. You can then teach your child how to manage his or her daily CF care.

## WHAT DOES A GOOD CF MANAGER NEED TO LEARN?

Learning to manage your child's CF care does not happen overnight. But, you do have a head start—you already have some of the skills from other areas in your life. These are the skills of watching and problem solving. Being a good CF manager involves learning and practicing these skills in three areas:

1. Preventing complications
2. Treating complications
3. Communicating with the CF health care team

**CF is a disease that can have many complications.** Most people with CF do have lung and **digestive\*** problems. But not everyone who has CF has the same complications. CF can affect other organs in people who have the disease. CF can also vary over time.

For these reasons, it is important that you become an expert in how CF affects your child. You will help your CF health care team learn how the disease and its complications affect your child. If, for example, your child normally





has a **cough\*** every day, but you notice that his or her cough gets worse or occurs more often, you know there may be a problem. Once you notice the change in cough, you can then work with your CF health care team who will gather more information, and together you will come up with a solution.

**Watching for and treating health problems quickly is important.** Your CF center and the CF Foundation recommend that your child have quarterly visits (CF “well visits” or checkups). During those visits the CF health care team can check for problems that are not easy for you to find. When you see a change or think there is a problem, contact your CF health care team right away. Watching your child closely, noticing and taking action if there are changes, communicating with the CF health care team, and bringing your child to well visits are all part of being a good CF manager.

### 1. Preventing Complications

As a CF manager you will learn skills to prevent complications. You and your CF health care team will design a daily care plan or CF action plan for your child. Most of the time this plan will include treatments to prevent lung and digestive problems from CF. Your child’s CF care plan is based on what you and the CF health care team know about your child’s CF and what the team knows about CF, including the latest **research.\*** Remember, prevention in CF means managing CF so that digestive problems, lung infections, and other complications are slowed or do not get worse. As a CF manager, you will need to practice good skills to watch for any change in symptoms and to organize your family’s day so that you can take action and complete your child’s CF care plan. Your child’s CF action plan outlines what you and your child can do at home to manage CF. For more information about using a CF action plan, see p. 18. Sample action plans are in the back pocket of this module.

### How Do I Know if the Preventive Care Is Working?

With CF, knowing if the preventive care is working can be difficult. People with an illness think getting better or getting worse is a way to know whether their care is working. Sometimes success can mean a person with CF stays the same. Having no digestive problems, the same **lung function,\*** or the same amount of cough can mean CF management is working. Even though there is no cure for CF at this time, we can slow down damage to the lungs by managing the disease as much as possible. Having goals for your child’s health and quality of life helps you decide how well preventive care is working.

### 2. Treating Complications

What happens if you notice that your child has a symptom that is getting worse even when you have been following the CF action plan? Watching for and treating complications is a large part of managing CF. Changes in CF can happen within a short time. For example, your child’s cough might increase if he or she has a **viral\*** infection. Other changes can happen more slowly—over several weeks or months—such as changes related to nutrition. Sometimes symptoms are easy to see, but sometimes there are no symptoms, or they are hard to see. Talk with your CF health care team about your child’s **baseline symptoms\*** or the symptoms your child has when he or she is well. You can use the worksheets “My Child’s Usual Respiratory Symptoms” and “My Child’s Usual Gastrointestinal (GI) Symptoms” in the back pocket of this module to record your child’s baseline symptoms. Make it a routine to compare these baseline symptoms to your child’s current state of health to see if a complication is beginning. For those changes that are not easy to see, watching your child closely, along with getting the results of your child’s tests (such as growth measures, chest **X-rays,\*** or **lung function tests\***) from the CF center, may show a need for a change in treatment or in your child’s CF action plan.

\*See CF Words to Know Glossary.



#### TO TREAT COMPLICATIONS:

- **WATCH AND DISCOVER** to see if there is a change or problem.
- **THINK** about possible solutions and talk with your CF health care team.
- **ACT** to make and try out plans for possible solutions.
- **WATCH** to see if your plans work.

### 3. Communicating With the CF Health Care Team

Being a CF manager does not mean that you are on your own with CF care. The best CF care occurs when the CF health care team and families work together to prevent, find, and treat problems. Good communication is another key part of successful CF management. Communicating well with your whole CF health care team may help your child have the best possible health and help your family have the best possible quality of life. (See p. 14 for more information about the CF health care team.)

#### WAYS TO COMMUNICATE

The CF FEP includes ways to talk about CF with your family, your CF health care team, and others who are important to your child's care. In this module, you will learn how to:

- Choose a focus for your communication: What do you want to be able to do and why? Who do you need to talk to?
- Give and get information in the best way
- Give feedback to your CF health care team
- Talk about your feelings and ways to improve communication

#### HOW CAN I HELP MY CHILD BECOME A GOOD CF MANAGER?

As your child with CF gets older, he or she will learn to become a manager, too—with your help. Children, as young as 3 or 4 years old, can tell you about symptoms in their own words, such as “My tummy hurts.” Young children also learn to cooperate with treatments. As they

grow older, they can do more of their treatments and handle other aspects of CF care. For example, middle-school children may help find a solution to fitting treatments into their families' busy schedules or talk with the CF health care team about how their treatments are going. Children who watch their parents and learn skills to be CF managers will be able to take responsibility for their own care later with more skill and confidence. (The CF FEP module *Working With Your Child* will provide more information and ways to help you guide your child to become a CF manager.)

#### NOTE TO PARENTS:

##### The CF FEP: Basics of Care

The CF FEP covers the basics of CF care. When additional problems come up, your CF health care team will help you learn to manage them. In addition to *Becoming a CF Manager*, the CF FEP contains four parent modules on managing CF.

- *Beginning CF Care*
- *Managing Lung and Other Respiratory Problems*
- *Managing Nutrition and Digestive Problems*
- *Working With Your Child*

Each module describes how to manage CF to prevent complications. As you work through the program and learn to manage your child's care, the skills you need to be a CF manager will become second nature. To help you see how manager skills are used in CF, we have included stories about other families. They will talk about how they **Watch and Discover**, and **Think and Act** to solve problems related to both CF care and their quality of life. The CF FEP worksheets will help guide you through these skills for your child's health and quality of life.

Some of the information in this module may be familiar to you or seem like common sense—if so, that's good! Look at the Table of Contents and talk to your CF health care team about what you might want to focus on first. Look for anything that can help you be the best CF manager and partner with your CF health care team.



## LEARNING SELF-MANAGEMENT SKILLS

**T**o prevent and treat complications of CF, the CF FEP describes important self-management skills as setting health and life goals and using the cycle of **WATCH AND DISCOVER, THINK AND ACT**.

### SETTING GOALS

To be successful with CF management, people must always be aware of what they are trying to achieve—what their goals for health and life are. Goals help you decide what you want to achieve.

Goals are important in the cycle of Watch and Discover, Think and Act. Sometimes we know that we have a problem because something bad happens. With CF that would mean a child has a symptom, such as an increased cough or a fever. Not meeting a health goal, however, is another important way to notice that there is a problem. For example, if a child's weight falls below the health goal set with the CF health care team, the parent will recognize that there is a problem and can work with the health care team to Discover why or where there is a problem.

***Some goals or health standards are recommended by the CF Foundation or the CF health care team.*** Be sure that you know what they are. Research into the best care helps provide some health goals for all people with CF. For example, the CF Foundation recommends that children with CF have a **body mass index (BMI)\*** that is at or above the 50th **percentile\*** because at that level or above, lung health is best. A 50th percentile BMI, therefore, is a good weight goal for your child. Other goals may be to treat lung infections until the child's lung function has

returned to his or her personal best level. With this goal, the CF health care team and family know to increase **airway clearance\*** not just for 10 to 14 days, but until the child's lung function has reached the goal level. Ask your CF health care team what other health goals may apply to your child.

The CF health care team has goals for your child based upon best practices, but setting your own health and life goals is also very important. Some of your goals will have much in common with and help meet the health care team's goals. For example, your goal might be to provide daily **supplements\*** to help your child get to 50th percentile BMI. Other goals may be personal, such as eating dinner together three times a week as a family, or taking a family vacation.

The process of goal setting helps people make changes in behavior. Goal setting starts with asking yourself what is important to reach. Then you set a time frame to meet your goal. Research studies have shown that active goal setting leads to improvement in many areas including management of chronic illnesses. Goal setting often helps people make more of an effort, keep going, stick with and concentrate on each of their tasks, and, when necessary, try different ways to do the behavior or task.

\*See CF Words to Know Glossary.



## TIPS: Setting and Meeting Goals

Here are some important points that will help you set and meet goals as you manage CF:

**Make each goal as specific as possible.** You might have a big goal of trying to make your child be as healthy as possible. This is not a helpful goal to set because you will not know when it is reached. Big goals, such as *make my child healthy*, need to be broken into smaller goals with more specific behaviors or actions. For example, to help your child stay healthy, you might set a smaller goal to have her eat an extra 200 calories every day in an afternoon snack, or have her use her **high-frequency chest wall oscillation\*** (HFCWD) airway clearance twice every day. You could decide to do each of these goals for the next 3 months. Then you could watch to see what health benefits your child gets with her weight gain or lung function when you go to the CF clinic.

**Goals should be big enough to make a change or improvement, but not so big that they cannot be reached.** For example, parents who decide to double the number of calories that their toddler eats every day may find that this is not a helpful goal to set. Meeting this goal may not be possible and could leave the parents feeling frustrated and that they had failed. Planning a series of goals—making a smaller goal and meeting it, then making a little bigger goal—is often a way to success.

**Just as smaller and larger goals are important, both long-term and short-term goals are needed.** Long-term goals set a target for where you are going, whereas short-term goals are the steps along the way. For example, if a young teen with CF has the long-term goal of going away to college, he will need to set and meet smaller goals first to reach this long-term goal. He knows that he will need to be healthy for college. His short-term goals might be to do daily treatments without reminders from parents or to drink one nutrition supplement a day to keep his weight in a healthy range.

**People can have goals for health and goals for other parts of life.** Sometimes these goals will go together well; sometimes they won't. For example, if your child has a goal to become a starter on the middle-school soccer team, he will have to practice soccer and become as fit as possible. In this case, his goals to eat well and do regular **breathing treatments\*** to keep his lungs healthy and his goal to go to soccer practice daily can work well together. On the other hand, the extra calories expended in soccer may result in a problem maintaining the best weight for CF. In this case the goal of highly competitive soccer and maintaining the healthiest weight for CF will be at odds. Recognizing this conflict will help you, your child, and your health care team come up with potential solutions.



### THE CYCLE OF WATCH AND DISCOVER, THINK AND ACT

This cycle describes how to work to reach and maintain goals for your child's health and quality of life. You will likely find that the steps make sense, but it takes practice to learn what to watch for and what action steps to take to solve problems. Work with your CF health care team to develop these skills.



#### WATCH AND DISCOVER

**Watch** means to notice signs of a change in symptoms or a problem related to your child's health, CF treatments, or quality of life. Think about the goals for health and life that you have set with your CF health care team and your family. Pay attention every day to catch problems early. Watch over time to see if a solution or treatment helps.

**Discover** means to use the information you learn from watching and decide what the problem is and what may be causing it. Describing a problem and finding the cause often lead to solving the problem. Asking the question "What exactly is going on here?" may be the most important step in solving a problem. Discovering often involves getting more information from your child, family members, or the CF health care team to find and understand a problem. Although you will be doing much of the day-to-day watching, the CF health care team will add information from tests and exams. You and your family will have the most information about other types of problems, such as stress caused by trying to fit CF care into family life.



#### THINK AND ACT

**Think** is figuring out what actions are possible. Think of different ways to solve problems. Think about what is in your child's CF action plan. Members of the CF health care team may help

you come up with possible actions. Think of old and new ideas. People who handle problems well think up and try many different options. They think about the pros (the benefits) and cons (the problems) of each option before they choose the one that they feel is best for them. For example, a pro could be: "If we do Jake's breathing treatment later in the evening, he can go to his extra swim practices." A con could be: "If we do Jake's treatment at 10 p.m., he won't get the sleep he needs."

**Act** is choosing and doing one of the options or actions that you came up with in the Think process. Make a problem-solving plan that is as specific as possible and do it.

Look at Watch and Discover, Think and Act as a cycle. Once you have gone through the cycle of management skills, go back to Watch and see if your problem-solving plan is working. To find out if an action plan is working, consider these questions:

- What am I looking for so that I can tell if the problem is solved? For example, should I see my child coughing less?
- What is my goal and how do I know when I reach it? Am I keeping a problem that cannot be fully solved from getting worse? For example, is my child coughing more, or less, or about the same?
- Am I managing treatments so that some other aspect of life is better? Have I reduced my stress or eased my negative feelings?
- Has the solution caused another problem?

If your problem-solving plan does not seem to be working, you may need to go through the cycle again and Think of more options to try and make new plans to Act. Then you can once again Watch to see if your new plan works. At times, you may decide that you need to refine your goal or make a new one.



#### NOTE TO PARENTS

##### Getting the Facts About CF: To Know or Not to Know

As you manage CF, you will have to learn more about CF and CF care. One key to solving a problem is to get enough information—get the facts. For some people, getting information comes easily. They naturally seek information from people and other sources, see changes in symptoms, and feel best when they are learning all they can about a problem. For these people, getting more facts and information often helps reduce their stress. For other people, getting information is not what they do first to solve a problem. The idea of getting more information may even make them anxious. They feel calmer and less stressed when they don't know as much. For people who need to be CF managers, however, not having enough information is a problem. People who avoid information may not have all the facts that they need to solve problems.

Here's how one parent handled needing information and not wanting to know scary information about CF.

### LEARNING FROM OTHER FAMILIES

## Alan

"Do I really want to know?" (Mrs. Kramer, mother of 4-year-old Alan)

I really didn't want to know about children who were sicker than my child and about new symptoms to watch for. I felt like I could manage only 1 day at a time. My husband convinced me that I should learn more about CF and see if getting more information made me feel better or worse. Since I've learned more about CF, I notice changes in Alan's symptoms and I know what steps I need to take. I've even prevented some problems from getting more serious. I also feel better because I can explain some things about CF to Alan. Now every bit of new information doesn't seem so scary. But it took time for me to get used to learning about CF.



#### WATCH AND DISCOVER

##### HEALTH PROBLEMS

As a CF manager, you will be watching for health problems in your child by looking for changes in physical symptoms. You will be able to find changes by looking at what symptoms your child has now and comparing them with your child's normal or baseline symptoms. The modules on *Managing Lung*

*and Other Respiratory Problems* and *Managing Nutrition and Digestive Problems* will help you learn what to watch for.

After you have watched enough to discover what the problem is, you can move on to the next steps Think and Act to figure out solutions, set goals, and take action to solve the problem.

Let's see how Jennifer's and Jose's mothers put all of the steps together to stop CF health problems from becoming more serious.





## LEARNING FROM OTHER FAMILIES

# Jennifer

"Jennifer hasn't been growing." (Mrs. Moore, mother of 3½-year-old Jennifer)

Jennifer Moore was diagnosed with CF when she was 2 months old. Since her diagnosis, Jennifer has been taking **pancreatic enzymes\*** and **vitamins\***. Her parents do **postural drainage and percussion\*** therapy on her twice a day. She has been on **oral\* antibiotics\*** a few times, but has never been in the hospital.

Now Mrs. Moore is a little concerned. She is very good at watching and she discovers that this year Jennifer is not growing out of her clothes as quickly as she has in the past. In fact, she has been wearing the same size for the past 6 months.

Mrs. Moore has been encouraging Jennifer to eat more. Jennifer refuses. Many mealtimes now end with yelling and crying. Mrs. Moore decides that she needs to stop and learn what the problem really is. She needs to discover

whether there is a problem and, if so, what the cause is. Does Jennifer have an eating problem, or a growing problem, or no problem at all?

Mrs. Moore thinks about what she knows about children with CF and growth. She then gathers information about Jennifer's growth. She looks at Jennifer's **growth chart\*** with her **pediatrician\*** and

finds that while Jennifer grew along the 50th percentile of height over the past year, she has dropped from the 50th percentile to the 25th percentile for weight.

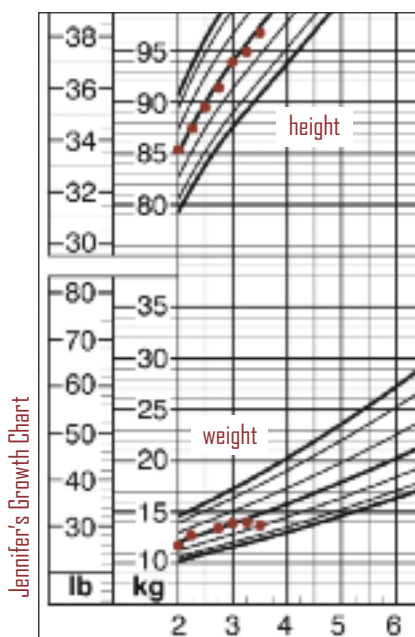
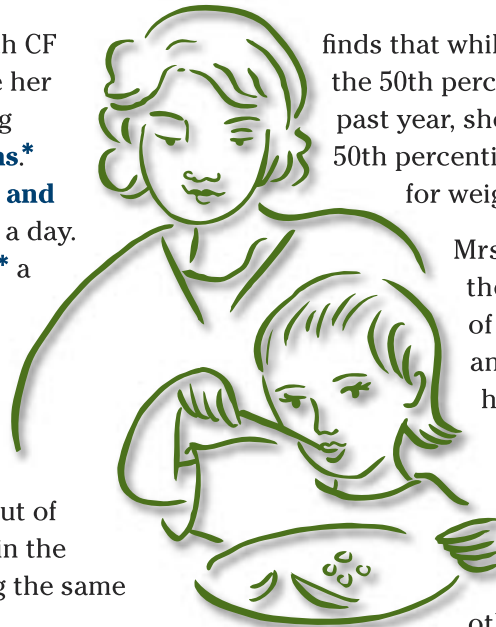
Mrs. Moore thinks about the kinds and the amount of foods that Jennifer eats and looks at what some of her 3-year-old friends eat. She thinks that Jennifer has eaten a bit more than the other children most of the time. She asks other parents who know

Jennifer. They agree that Jennifer seems to eat well.

Mrs. Moore decides to check Jennifer's stools for signs of **malabsorption\***. Since Jennifer was toilet trained just before she turned 3 years old, she has wanted to go to the potty alone "like a big girl." Mrs. Moore asks Jennifer to let her see her stool when she goes. Jennifer calls her mom to the potty three times in a day. Mrs. Moore is surprised—the stools are floating and appear greasy.

From what she discovered, Mrs. Moore believes that a very likely reason for Jennifer's lack of weight gain is malabsorption. Now Mrs. Moore can move on to think about reasons for the malabsorption and act with the CF health care team to fix the problem.

[**Note:** To learn more about managing problems of malabsorption, see the CF FEP module *Managing Nutrition and Digestive Problems.*]



\*See CF Words to Know Glossary.



## LEARNING FROM OTHER FAMILIES

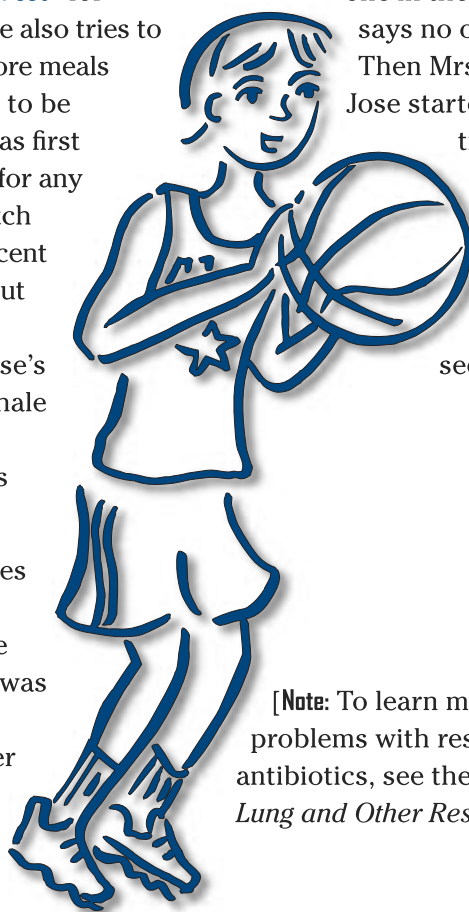
### Jose

"Jose sounds hoarse—why?" (Mrs. Garza, mother of 8-year-old Jose)

Jose Garza was diagnosed with CF when he was 3 months old. Since starting school 2 years ago, Jose has had more lung infections. He has been hospitalized twice in the past two winters. Jose's daily care for his lungs includes inhaling albuterol twice a day, inhaling Pulmozyme® once a day, and using the **percussive vest\*** for airway clearance twice a day. Jose also tries to remember to wash his hands before meals and treatments. Mrs. Garza used to be worried all the time when Jose was first diagnosed, but now she watches for any change in Jose's symptoms to catch problems early. At Jose's most recent CF clinic visit, Mrs. Garza found out that his **sputum culture\*** grew ***Pseudomonas\** bacteria\*** and Jose's doctor recommended that he inhale TOBI® (an antibiotic) twice a day every other month along with his other medicines.

One week later, Mrs. Garza notices that Jose sounds hoarse. Mrs. Garza tries to figure out why. She thinks back on times when Jose was getting sick. At those times, he coughed more, but she had never noticed hoarseness. She thinks about whether Jose has done anything with his voice to

change it recently—like yelling and cheering at his team's basketball game, but that has not happened. She wonders whether he has been around anyone who is hoarse from an infection such as **laryngitis\*** (usually from a **virus\*** causing **inflammation\*** of the throat). But no one in the family is ill and the teacher says no one else at school is hoarse. Then Mrs. Garza remembers that Jose started his TOBI® breathing treatments last week. She calls the **pharmacist\*** who tells her that hoarseness can be a side effect of TOBI®. Mrs. Garza makes a call to Jose's CF doctor to see what can be done.



[**Note:** To learn more about managing problems with respiratory infections and antibiotics, see the CF FEP module *Managing Lung and Other Respiratory Problems*.]





### QUALITY-OF-LIFE PROBLEMS

There are many kinds of problems a family will need to watch for and take action to manage and resolve. Problems can include disease complications, such as Jennifer's malabsorption, or a side effect of treatment, as in the case of Jose's hoarseness. At times, the

problem is that CF and its treatments interfere with a person's and his or her family's life. Quality-of-life issues can also be addressed by using the same problem-solving skills.

Let's see how Seth and his parents work through a problem with CF management that is affecting Seth's quality of life.

## LEARNING FROM OTHER FAMILIES

### Seth

"Our family has always prided itself on not letting CF interfere with Seth's life, but now that our son is 15, things seem to be falling apart. What's going on?" (Mr. and Mrs. Reiser, parents of 15-year-old Seth)

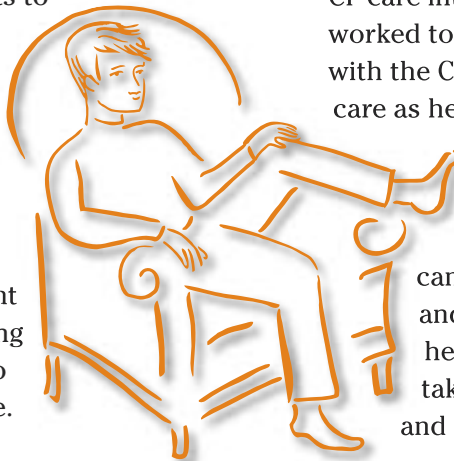
Seth Reiser has always been an outgoing child. He is very involved in theatre and school. His parents notice that recently Seth is withdrawn and grouchy. He says he hates CF and he hates doing his treatments. In fact, he is not doing them often enough to keep himself as healthy as possible. Seth's parents realize that the demands and pressures of his illness and school have built up for him over the past year. Seth was diagnosed with CF in his first year of life, but he needed antibiotics only a few times and was never hospitalized until he was 13. In the past year Seth has been in the hospital twice, but his parents don't think that is the only reason for the problem.

When they sit down with Seth to really answer the question, "What is going on here?" they discover some other parts to the picture. Seth and his parents have always prided themselves on not letting CF interfere with Seth's life. Now it is interfering in a big way. Seth even had to give up his part in the most recent play because he had a lung infection. CF is starting to affect Seth's quality of life.

Seth's parents realize that they have CF management problems. They know that because Seth did not require much medical care when he was young, he has not learned to make CF care a daily part of his life. He has not begun to take responsibility for his own CF care. What is also adding to the problem is that Seth does not talk much during clinic visits. He does not tell the health care team about his symptoms. He does not talk about how CF treatments are stopping him from doing what he wants nor does he try to solve the problem.

Seth and his parents are overwhelmed with how complex this problem has become. In the past year, Seth has needed more treatment for his lungs. But now the biggest problem seems to be that they have not changed how they fit CF care into their daily lives and they have not worked together to set goals to help Seth talk with the CF health care team and manage his care as he has gotten older.

Seth and his parents are hopeful that by having a better picture of the different issues going on, they can talk more about problems, goals, and possible solutions with the CF health care team. Together they can take actions so Seth can manage CF and improve his quality of life.





## MAKING IT WORK FOR YOU



### WATCH AND DISCOVER

As a CF manager, ask, “What is going on?”

- Do you know what to look for to tell if your child has an early sign of a health problem?
- Do you know what to look for to tell whether there is a problem with treatments and/or with the schedule for treatments?
- What might be a sign that your child’s quality of life is not at its best?

Based on your answers to these questions, write down one or more questions you would like to ask your CF health care team on the “Making It Work for You: Watch and Discover” worksheet in the back pocket of this module.

#### Identifying a Problem

**Think about a recent CF-related problem you tried to solve.** It might be a problem having to do with preventive care, an increase in symptoms, or another problem related to your child’s CF or CF care. Choose a problem that was concerning, but not earth-shattering. You can write a description of the problem on the “Making It Work for You: Watch and Discover” worksheet in the back pocket of this module. The worksheet includes questions to help you rate how you used Watch and Discover to notice a recent problem. What made you notice that there was a problem? How did you figure out or discover what the problem was?

Repeat this activity from time to time as you work through problems with your child who has CF, your family, and your CF health care team. Part of being a good CF manager is learning from your experiences and looking at how you are doing. You may be surprised at how much easier it will be for you to Watch and Discover, Think and Act on new problems.



### WATCH AND DISCOVER

#### PREVENTING COMPLICATIONS: WORKING WITH YOUR CF HEALTH CARE TEAM

When your child has an increase in respiratory symptoms, you will follow your CF action plan and adjust treatments. Call the nurse to discuss your plan and decide if a clinic visit is needed. When you find new symptoms or a change in symptoms that is not in your action plan, talk with your CF health care team to figure out what to do. Regular CF clinic visits for checkups are important to prevent problems and to find and treat changes as early as possible.

#### Quarterly Visits

The CF Foundation recommends that every person with CF, at any age, visit a CF center at least quarterly or every 3 months. People who have quarterly visits tend to have better health outcomes because the CF health care team members are experts in CF care. They know what CF complications to watch for, what treatments are needed, and how to help you and your family manage the disease at home. Specific tests are done at quarterly visits (depending on the person’s age), such as measuring the child’s growth in height and weight, lung function tests, blood tests, sputum cultures, and chest X-rays. These tests can help the CF health care team find health problems from CF and treat small changes early.



You can do your part to make sure your quarterly visits are as useful as possible. Talk about goals that you have for your child and family. See what health goals the team suggests for your child. Let your CF health care team know:

- Symptoms you have noticed when you used Watch and Discover
- Questions you have and find out which team members can help you
- Your ideas for actions you can take as you Think and Act
- Medicines you need to have refilled
- How you think your child's CF treatments are working
- Any concerns that you have about your child, treatments, and/or quality of life

Work with your child to help him or her take an active role in the visit (appropriate for his or her age). Help your child learn to talk with the doctor and other team members. Encourage your child to ask the CF health care team his or her questions. For more information about helping your child communicate with the CF health care team, see the CF FEP module *Working With Your Child*.

CF quarterly clinic visits will take some time. One of these visits each year may take longer because your child may have more tests or you and your child may see more team members. This is sometimes called an annual visit and may happen once a year. Ask your CF team how much time the visit will take so that you don't feel rushed and can make changes in your schedule ahead of time. Check to see if you should bring your child early to have a lung function test or other tests done before meeting with the doctor and other CF team members.

### **The CF Travel Folder**

The CF Travel Folder is a folder or notebook that has information about your child's CF care and treatment. Some call it a travel folder because it should travel with you between the clinic and home. The folder is used to gather

and store information that is important to your child's CF care. Items to include in your CF Travel Folder are:

- Information about your child's CF diagnosis and history. You'll find a sample worksheet "Key Facts About My Child's Cystic Fibrosis" in the back pocket of this module.
- Your child's CF action plan. (CF action plans are described more under THINK AND ACT—TREATING COMPLICATIONS: YOUR CHILD'S CF ACTION PLAN on p. 18 of this module. A sample CF action plan is in the back pocket of this module.)
- A list of your child's current medicines. (Include all over-the-counter, nonprescription medicines, and herbal or alternative products.) See "My Child's Current Medications" worksheet in the back pocket of this module.
- Your child's baseline symptom forms. (Baseline or usual symptom forms are described in the modules *Managing Lung and Other Respiratory Problems* and *Managing Nutrition and Digestive Problems*. See the baseline worksheets "My Child's Usual Respiratory Symptoms" and "My Child's Usual Gastrointestinal [GI] Symptoms" in the back pocket of this module.)
- Copies of lung function tests or lab results. (Include tests and labs that may be done outside your CF center.)
- A copy of your child's growth charts. The CF health care team can update the charts at clinic visits. You may want to write down the foods your child ate for 3 days before his or her visit. (See the worksheet "My Child's Food Diary" in the back pocket of this module.)
- A list of your CF team members and their phone numbers. (See the worksheet "My Child's CF Health Care Team" in the back pocket of this module.)
- Any school, insurance, or other forms that you need completed or signed by the doctor.
- A list of questions you want to ask and things that you want to report to the team, along with a place to write the answers. (See the worksheet "Planning My Child's CF Quarterly Visit Communication" worksheet in the back pocket of this module.)



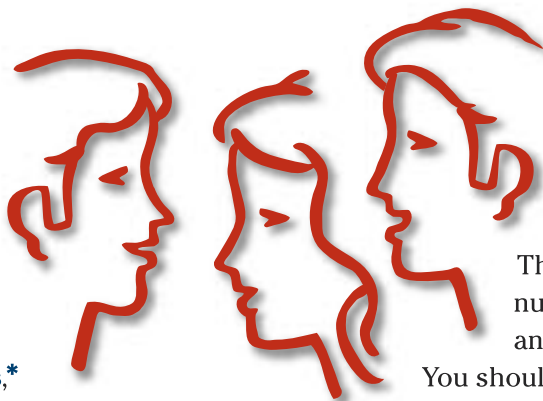
### Home and Health Care Teams

You have two CF teams, your CF home team and your CF health care team. Depending upon the problem, you and several other members of the team will Watch and Discover and/or Think and Act to describe the problem and find the best solution. Who is on your CF team?

**Your CF home team** includes your child, you and other family members, or regular caregivers. The home team can also include school and day-care personnel, babysitters, and friends. You can list your CF home team members on the back of the worksheet “My Child’s CF Health Care Team” in the pocket of this module and put it in your CF Travel Folder.

**Your CF health care team** includes a number of health care professionals. Know who each member of the health care team is and what role he or she plays.

For your child’s CF care, your doctor may be a **pulmonary\*** or lung **specialist\*** in CF care. The CF center team usually includes nurses, **social workers\*, dietitians\*, and respiratory therapists\*.** Other specialists may include doctors who take care of specific problems, such as **gastroenterologists\*** (GI doctors) for nutrition and **liver\*** problems, or **endocrinologists\*** for **CF-related diabetes (CFRD)\*.** Your team could also include **physical therapists\*, a child life specialist\*, a child psychologist\*, and a genetic counselor\*.**



### Your Primary Care Physician

Even though your child will be followed closely by the CF health care team, he or she also needs to have a **primary care physician\*** (a pediatrician or family doctor). This doctor provides well-child **immunizations\*** and treats health problems that are not related to CF, such as sore throats, earaches, or sports injuries. The CF health care team will work together with your primary care doctor. Talk with the CF health care team and your primary care doctor about the best way to communicate about your child’s care with all of the health care team members. When you are not sure whom you should call, check with your CF health care team first and they will direct you. You may find it helpful to use the worksheet “Who to Call/Who to Visit” in the back pocket of this module.

### CF Health Care Team Contact List

Keep a list of your CF health care team members with their phone numbers in your CF Travel Folder. (See the worksheet “My Child’s CF Health Care Team” in the back pocket of this module.)

The list should also have CF-related numbers, such as your pharmacy and emergency contact numbers.

You should feel comfortable about calling your CF health care team or asking for an appointment for an urgent or sick clinic visit to discuss a concern or change in symptoms. You may have other questions or concerns that are not urgent, but are important for your child’s care, such as calling the pharmacy to refill a medicine. The CF health care team can help you with CF management questions and/or concerns before your child’s next clinic visit. If you are not sure whom you should talk to, call the CF nurse and ask. Sometimes the nurse may direct you to another team member. If the problem does not seem to be CF-related, the nurse may suggest you talk with your child’s primary care doctor.



### BRAINSTORMING AND CHOOSING A PROBLEM-SOLVING PLAN

After you discover a problem, you need to take steps to solve the problem—you will need to Think and Act.

- Think about possible solutions and weigh their pros (the benefits) and cons (the problems).
- Act and make a problem-solving plan to try out a solution and reach your goals.

**Think of different ways to solve problems and meet your goals.** There may be more than one way to reach a goal and avoid or overcome problems that get in your way. Be energetic about problem solving—maybe even a little daring. Think of or brainstorm old and new ideas. Don't reject ideas because you "have never done it that way before" or because "it seems silly" or because "Aunt Fanny would never approve." People who are able to deal well with problems think up and try many different options or solutions. Even though they may not always be successful, people who solve problems well don't throw out an option without thinking about its pros and cons.

**Remember to make your action plan as specific as possible and to set a time to meet your goal.** The CF health care team can help you think about plans and action steps to meet a goal. They can also help you learn to Watch and Discover and see if a goal is met. Later, you can go back to Watch and Discover to see how well an action works to solve a problem. As a CF manager, with the help of the CF health care team, you can make use of Watch and Discover, Think and Act to meet your goals.

### REMEMBER:

**Practice making specific plans and action steps to reach your goals.** Break down a big goal into smaller goals with actions that can be done. Set a deadline to meet your goal. Once you take action, go back to Watch and Discover how you are doing. Watch to see if you reach your goal.

If you find that the goal was too big or your actions didn't work well, try again. Talk with others who can help you make a smaller goal and think of other action steps. Perfect solutions do not exist for many problems and finding the best solution does not always happen the first time that you try. Just like you often need to try a different antibiotic to clear up a respiratory infection, you often have to try different solutions to problems before you find the best one for you, your child, and your family.

And, remember the old saying, "If at first you don't succeed, try, try again!"







## LEARNING FROM OTHER FAMILIES

### Mary

"I've had to take Mary to the doctor almost every week for a month. She's been so cranky. It's completely wearing me out." (Mrs. Gill, mother of 6-year-old Mary)

Mary Gill has been sick for the past month and now is prescribed an antibiotic for a lung infection that requires blood tests to check for side effects. Her mother has had to take Mary to the doctor every week for a month. Mary is cranky. Mrs. Gill is tired. She wonders if all of these visits are really needed. She also wonders why Mary is making the visits so hard. She worries whether Mary is going to get well. Mrs. Gill complains to her friends that the doctor does not seem to know how hard all of these clinic visits and daily treatments have been on her and Mary. The CF health care team doesn't seem to notice her stress.

After two horrible visits, Mrs. Gill begins to problem solve. First she puts together what she has Watched and Discovered about the situation. Mary is both bored at the visits and scared about what the visits are about. Mrs. Gill has been annoyed with Mary and the situation and has not tried to make her time with Mary enjoyable. Mrs. Gill sets a goal to help Mary become less cranky at visits. She decides she is going to make a plan with Mary before the next visit. She talks with Mary when they are sitting on the back porch after dinner. She asks Mary what they can pack to keep her busy at the clinic. She also explains to Mary what the blood test is for. She tells her that so far the medicine is not having any bad effects—it is



working to make Mary better. Mary asks what will happen if they find "bad blood." Mrs. Gill realizes that Mary may have been worried, too. She explains that the medicine will not make Mary's blood bad. If the doctors find that the medicine is not helping or is hurting Mary, they will give her a new antibiotic. Already Mrs. Gill is Thinking and Acting to solve the problem.

At the next visit, Mrs. Gill acts to help Mary be less cranky. Mrs. Gill takes a deck of cards to the clinic as Mary had suggested. They play together while they wait. Less upset about her visits to the CF center, Mary becomes more cooperative. Mrs. Gill reduced her stress by first looking for and discovering the cause, then thinking about and choosing an action.



## LEARNING FROM OTHER FAMILIES

### Frank

"Frank has been throwing tantrums before we go to clinic visits, and I've been feeling more and more stressed by CF treatments. I'm feeling overwhelmed." (Mrs. Brown, mother of 7-year-old Frank)

Frank has had many infections this winter. He's had many antibiotics with only a couple of healthy weeks in between. Frank has begun to throw temper tantrums before treatments. Now each breathing treatment and airway clearance session is a struggle. Mrs. Brown is feeling stressed and overwhelmed. She wonders if her worries about Frank's health are making her stress much worse. The problem might not really be Frank's tantrums. As she begins to look at the problem, Mrs. Brown is surprised by what her *Watching and Discovering* turns up. She is worried that Frank's lungs are getting worse. What if he keeps having infections? Since Frank's most recent illness, Mrs. Brown is spending more time each day caring for him. She feels like she has a heavy load to carry on her own. She wonders if she is doing something wrong. Even when the doctor tells her that Frank is doing well, she finds it hard to believe.

Mrs. Brown thinks about these problems: One is Frank's tantrums and the other is her feelings. She decides to set a goal to solve her feeling problem first. She plans to talk with someone and share her feelings before the



end of the week. At first, she can't decide whom she should talk to. She realizes that there are really two parts to feeling overwhelmed. One is her concern and worry about Frank's lungs. She has talked to Frank's doctor who has assured her that Frank is recovering well now that the right antibiotic has been identified, but Frank will need treatments more often for a while longer. She realizes that her main stress now is that she needs a break. She calls the mother of another child with CF, and they plan to go out to dinner. Frank's father agrees to do the evening treatments and to put Frank to bed. Taking action to talk about her feelings and have a night out helped Mrs. Brown manage her feelings.

She was better prepared for Frank's next tantrum and it was minor. She made a plan with him to read during treatments from a new book that he picked out as long as he was not throwing a tantrum. Within a couple of days, Frank had no tantrums at all. Maybe Frank felt better when his mother did. Who knows? But, Mrs. Brown did feel better afterward. Talking to another mother who could understand what Mrs. Brown was going through helped her change her unhappy feelings, even though the situation wasn't changed.



## MAKING IT WORK FOR YOU

### PRACTICE PROBLEM SOLVING TO REACH A GOAL

Think about being a CF manager and use the worksheet “Making It Work for You: Think and Act” in the back pocket of this module to practice managing a problem that is preventing you from reaching your goal.

First, think of a goal you have related to your child’s health or quality of life that you have found difficult to reach. Outline the problem and work through it using the problem-solving skills that we have been reviewing in this module:

- **Watch and Discover.** What is the problem? Has one of your goals not been met? Do you need to gather any more information to understand what is happening? If so, what information and how will you get it? Do you need to break the goal into smaller ones?
- **Think and Act.** List a number of possible action plans to address the problem using the worksheet “Making It Work for You: Think and Act” in the back pocket of this module. Think of your usual ways to approach and solve the problem. This time come up with some new ideas. Think about all aspects of the problem. Talk with others—your child, family, friends, and/or the CF health care team—to come up with other possible solutions. List the pros and cons of each plan.
- **Make a plan to take action.** Put a check by the action plan that you expect to try first. Exactly what will it take to do this solution? How likely is it that this will fix your problem? Could the solution cause more problems? List the steps on the worksheet that you’ll need to take to carry out the action. How long will it take to see results? Try out the plan that you think will work best and that is doable.

- **Decide how well your plan of action worked.** What happened? Were there benefits (pros) that you had not expected? Were there any new problems (cons) that you found? If this plan takes longer to do, look for signs that things are improving. If things have not improved, do you want to continue with this action? Or do you want to try something else? Talk with others to figure out your next steps. How are you doing toward reaching your goal? Do you need to make a smaller goal? Get input from others to judge how you are doing. Remember to go back to Watch and Discover as you move forward to the next steps!

Repeat this activity from time to time as you work through problems with your family and CF health care team. Part of being a good CF manager is learning from your experiences and reviewing how you are doing. You may be surprised at how much more comfortable you will be when you Watch and Discover, Think and Act new problems.



### THINK AND ACT

### TREATING COMPLICATIONS: YOUR CHILD’S CF ACTION PLAN

#### CF Action Plan

Having a written CF action plan can help you know what needs to be done to manage CF and can help you share the treatment plan with others. An action plan can include how long to do airway clearance, **dosages\*** of medicines, and how often to give medicines every day. A CF action plan may include when and how to increase treatments or medicines with a change in symptoms. Ask your CF health care team to help you put a plan together. Don’t forget to update it every time treatments are changed. Plan to discuss how your CF action plan is working with the CF health care team at clinic visits. (See a sample of a CF action plan in the back pocket of this module.)

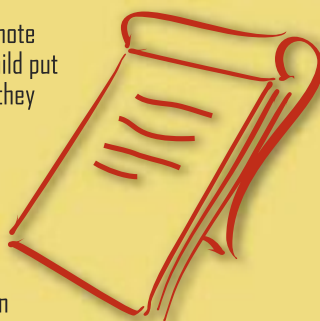




## TIPS: Getting Organized and Using Reminders

Keeping up with all the daily treatments your child needs takes time and planning. There are many things you can do to help yourself and your child be organized. Think of different solutions that will help you and your family. Here are some ideas used by other families.

- Make a list of tasks on note cards and have your child put them in the order that they need to be done.
- Make a family calendar to mark things such as clinic appointments, how many days of antibiotics to take, when to start an inhaled antibiotic, and when you want to meet your goal. Add special days including birthdays, holidays, and school events.
- Make a menu for the week to plan your grocery list. Include how to add more calories to meals.
- Put supplies for cleaning equipment in a basket in one place.
- Set alarms on the cell phone for treatment and snack times.



- Choose school clothes the night before and take showers at night.
- Set up a shelf for healthy, high-calorie snacks. Have the shelf where your child can reach and choose his or her own snacks.

There are many ways to remember medicines. Most people are better at remembering if they have a regular routine, such as doing things in the same order every time. Here are some other ideas.

- Have a pill box to store medicines by day for the morning and evening.
- Make a chart for your child to check off when things are done. Include treatments, daily chores, and homework.
- Set up a special place that is easy to see for medicines.





## COMMUNICATION AND CF CARE

**T**o be the best CF manager that you can be, you will need communication skills along with the self-management skills of goal setting and **WATCH AND DISCOVER, THINK AND ACT.**

Think about how many messages you give and get each day. You communicate with your spouse, your children, your babysitter, your boss, your dry cleaner, and your car mechanic. Most of your communication probably goes well. But sometimes messages become muddled, confused, or turn into a conflict. Communication is a two-way street. You have the sender of the message at one end and the receiver at the other end. The success of the communication depends on both.

### WHY TALK ABOUT COMMUNICATION IN CF?

Communication is everyone's task. But because you have a child with CF, you need to communicate very well. Here are some reasons why learning to communicate well is important in CF care.

**Communication is important to be a good CF manager.** You will need to get and give information many times as you manage CF. You will need to communicate well with your child, other family members, your CF health care team, and school personnel. Most people don't know about CF. You need good communication skills to explain these things to others so they can help you manage CF.

**Parents who set a good example of communicating well pass this skill on to their children.** As children grow older and manage more of their own care, they will need good communication skills.

### COMMUNICATING WITH THE CF HEALTH CARE TEAM

**How many times has one of these situations happened to you?**

- You have left the doctor's office or the CF center feeling that you did not understand some of what was said.
- You decided not to ask questions for fear of seeming stupid, or because there was not enough time, or simply because you forgot.
- You were upset when your child was sick and the CF health care team did not notice.
- You wished that you could explain to the CF health care team some of your other family concerns having to do with recreation, money, work, or school. But, you just did not know how and when to bring up your concerns.

It's not surprising that good communication with the CF health care team is hard. Think about what must happen during each visit:

- The child with CF and the parent must give information.
- The doctor and other health care team members must get information.
- The family and team may need to talk about emotional or quality-of-life issues that are affecting CF care.
- The doctor, the child with CF, and the parent must work together to make decisions about treatment.
- The child with CF and the parent must learn how to do treatments at home.

Good communication is central to having all of these tasks happen in a timely and effective way. Knowing what needs to be communicated, with whom to share it, and how to do it are important skills for both families and the health care team to work on.



### COMMUNICATING WITH FAMILY MEMBERS

You need good communication with family members to provide good CF care. Unfortunately, the pressures of having a child with CF may make communication harder.

#### Do any of these family problems sound familiar?

Do you sometimes feel that you and the people you live with are on different wavelengths? Perhaps you want to talk and your spouse does not. Perhaps each time you try to talk about how the CF treatments could get done, there is a fight or hurt feelings.

If you believe your communication with your family, CF health care team, or others who help out with CF care is less successful than you would like it to be, there are steps you can take. These steps will also help you even if you feel that the communication from other people is a big part of the problem. As you use the CF FEP, you will gain the knowledge and skills to use communication to become a better CF manager.

### CHOOSING A COMMUNICATION FOCUS: WHAT AND WHY?

Communication serves many purposes. Through communication we give and get information, share feelings, ask for a change in behavior, and build and maintain our relationships. But sometimes people aren't clear about what they want from communication. The lack of a goal or focus may cause the communication to fail and frustrate the sender and the receiver.

#### Example

As Peter Brown picks up his Sunday paper, he sees his neighbor do the same. He shouts out, "Hi Jack! How's it going?"

Jack responds, "Fine, Pete, how about you?"

"Just fine," says Peter Brown and takes his newspaper inside his home.

The goal of that interaction for Peter was to have a continued friendly relationship with his neighbor. No real information was exchanged, and that suited the situation.

But what if you had the same kind of conversation with members of your child's CF health care team?

#### Example

"How's it going, Mr. Smith?"

"Oh just fine, Dr. Jones. How about you?"

"Just fine. How's Johnny doing?"

"Okay, I guess."

Dr. Jones is not likely to be satisfied by the response of "Fine" to his question: "How's it going?" Although you may start a CF clinic visit this way, you want more than just a simple exchange with your child's doctor. You need to decide what you want the communication to accomplish. What would you like to communicate to the doctor to make the visit successful? If you have many goals you want to talk about, it's important to decide which ones you want to focus on. If you focus on your most important goals, you'll be more likely to talk about all of them with your child's doctor. During a visit, your child's doctor will also have goals for the communication.

### CHOOSING A COMMUNICATION PARTNER: WHOM?

After you've figured out why and what you want to communicate, choosing whom to communicate with is easier. Each communication goal can then be paired with the right communication partner.

For example, if you want to know why an unfamiliar antibiotic was prescribed for your child, you should ask the doctor who prescribed it. If you want a daily medication refilled, however, you do not need to speak to the doctor, but instead you probably need to call a refill line either at the pharmacy or at the doctor's office. If you want your spouse to help with CF tasks, you should talk to your spouse, not your coworker.



#### GIVING INFORMATION:

##### The CF Health Care Team

Often you will pass on information about your child to help you and the CF health care team make decisions about care. To do this well, you need to 1) observe your child, 2) know what information is important, and 3) give the information to the team so that it is clear.

Compare the ways that these two parents give information to the health care team. Which do you think is good communication? Which will lead more quickly to a treatment change, if it is needed?

Mrs. Smith calls the CF nurse and says, “Tommy is feeling really bad. He needs to see the doctor.”

Mrs. Jones calls the CF nurse and says, “For the last week Janie has been coughing up more mucus, which is getting darker. She has lost her appetite. She’s been taking 250 milligrams of amoxicillin three times a day for 1 week for bronchitis and does not seem to have improved much. I think that she needs to see her CF doctor.”

Mrs. Jones gave more complete information. Her communication will help the CF nurse decide more quickly what kind of medical care Janie needs and if the doctor needs to see her.

Most of the information that you share with the CF health care team is about your child’s respiratory care and nutrition. The CF FEP modules *Managing Lung and Other Respiratory Problems* and *Managing Nutrition and Digestive Problems* will help you figure out what the CF health care team needs to learn from you. In the back pocket of this module are the worksheets “My Child’s Usual Respiratory Symptoms” and “My Child’s Usual Gastrointestinal (GI) Symptoms.” These worksheets can help you figure out what

your child’s baseline symptoms are and what you and the CF health care team consider normal or usual for your child.

Communicating about your child’s symptoms and treatment is a key part of being a CF manager. Unlike the CF health care team, you see and talk with your child every day. You will Watch and Discover when your child’s symptoms are changing or when your child is having problems with treatments. Sharing what you notice about your child with the CF health care team can help pinpoint problems and improve care. Asking yourself questions (similar to the following questions) will help you to be prepared to give more complete information to the team. (See the worksheet “Planning my Child’s CF Quarterly Visit Communication” in the back pocket of this module.)

- What changes have you noticed in your child’s normal (baseline) respiratory or digestive symptoms? In what symptoms have you not seen a change?
- What did you do when you noticed symptoms getting worse?
- What symptoms are getting better?
- What treatments is your child doing at home? Is there anything that prevents you and your child from being able to follow your child’s CF action plan and do treatments?
- How does your child respond to treatments (for example, coughing up more mucus, gaining weight)? Do you think they are helping?
- What concerns do you have about your child’s CF or treatments?

#### GIVING INFORMATION:

##### CF Medical Words

Many situations and environments have their own language. This is true in the world of health care, too. If you take time to learn what the words mean that describe your child’s illness and treatments, you will be able to communicate more clearly with the CF health care team members.



For example: Your child is taking several kinds of medicine. Telling the doctor, “The medicine seems to upset his stomach,” doesn’t give the doctor the information he or she needs. Naming the medicine that seems to be causing the stomach upset, for example, would be more helpful.

The CF FEP has a glossary (“CF Words to Know”) that is a list of common CF words and what they mean. Another important way to learn new words is to ask what they mean any time that you hear or see words you do not know. CF health care team members will explain any words that you ask them. If you do not ask, they may assume that you know a word even if it sounds like a foreign language to you!

#### GIVING INFORMATION:

##### Feedback

Feedback means telling people how a certain communication has worked for you. Ideally you should give feedback when something has gone well and when it has not gone well. Feedback about a successful communication will help the person continue to do the things that you find helpful.

##### When communication has gone well:

You could tell the nurse, “Thanks for taking the time to explain how the clinic makes appointments. Now I’ll understand delays and I’ll know how to get an appointment quickly if Joey really needs it.”

You could tell the doctor, “Your summary of how Susie is doing well and what we can improve on was helpful to me. I sometimes get overwhelmed with the long visit, but now I understand better.”

##### When communication has not gone well:

When communication has not gone well, it is often a little harder to give feedback in a way that is helpful. Some people may feel uneasy making a

critical remark to a health care team member. Some people make these remarks in a way that sounds angry. Anger tends to turn the message into an emotional one. An emotional message may not be seen as trying to give feedback and to make a change in future behavior.

Feedback about communication that has not gone well works the best when it’s constructive and helpful. Constructive feedback will be easier for someone to hear. Here are ways to give helpful feedback.

- Use *I* statements. State the problem from your point of view, not from what you believe the other person is doing. For example, “You never give us enough time during these visits,” sounds like you are angry and blaming them. Now try: “So much happens during Susie’s visits. I need a little more time to understand how Susie is doing and what we need to do now. Is there a way I could schedule appointments to get that done?” The *I* statement is more likely to get a better response.
- Instead of just saying what is wrong, suggest what the person could do to communicate better with you. For example, instead of “Your explanation of how to adjust enzymes is confusing,” try “I am having a hard time understanding how to adjust enzymes. Can you suggest something for me to read more about that?”



#### MAKING IT WORK FOR YOU

##### GIVING INFORMATION

**Think of a time when you needed to give information and did not feel successful.**

Use the worksheet, “Making It Work for You: Reviewing Your Communication Skills,” in the back pocket of this module to answer questions about when communication didn’t feel successful.



### Talk, Text, or Tweet

There are lots of ways we communicate using technology. People are reaching out to others more and more by electronic mail (e-mail) and electronic text and Twitter messages. Find out the best way to communicate to each of the many people who take care of your child. Electronic mail may be a good way to communicate with your child's teacher who is not available most of the day to take phone calls. Electronic mail may not be the way to communicate with your CF health care team for several reasons. Your CF health care team

may not be able to accept some electronic messages because of privacy and security rules. E-mail messages may not be received in a timely way. Ask if it is possible to use electronic messages and if the messages are secure and received and checked regularly.

Phone messages are a useful way to reach CF health care team members. Phone messages (and e-mail and other electronic messages) will be most useful if you follow the tips for leaving messages for the CF health care team.



### TIPS for Parents: Messages for the CF Health Care Team

Here are ways to help make the most of your messages to the CF health care team.

- Think about the purpose of your message, then plan what information you need to give to make sure your purpose is met.
- Include the most important information and do it as briefly as possible.
- Always give your child's full name, date of birth, and your name at the start of a message.
- Make your message brief and state your main question or concern. Sometimes you may want to give an update on how your child is doing. Sometimes you may be concerned about a new symptom. Give specific information on your child's new symptoms compared with his or her baseline symptoms. If you have started a new treatment following your child's action plan, report how long you have done that and how your child is responding to the treatment.

- Do not assume the nurse or team member has your correct contact information. Leave one or more phone numbers and repeat the number slowly and clearly, or let them know the best way to contact you.
- If you don't need a call back, you can say that, too.
- If you have not gotten a response within a day, you should contact the CF health care team. Many messages are received each day and the CF health care team does not want to overlook your message. Usually, even if a team member is out of the office, someone else will be checking messages.
- Make sure you have emergency phone numbers if you need to get help quickly.

**Note:** As your child gets older, help your child learn to leave a telephone message. Allow your child to practice leaving some simple messages so that he or she gets comfortable with this kind of communication. Calling for medicine refills is an easy way for your child to start.





## LEARNING FROM OTHER FAMILIES

### Carlos

"Now that Carlos is a little older, I'd like to have him talk with the doctor more and ask questions when we go for his next visit." (Mrs. Rodriguez, mother of 9-year-old Carlos)

Carlos's quarterly CF clinic visit is coming up next Monday. Mrs. Rodriguez starts to think about what she can do to be prepared and get the most out of the visit. She gets out Carlos's CF Travel Folder and looks through it. She puts his CF action plan in the folder and plans to review it at the visit. She gets out a notepad and puts it on the kitchen counter so that she can jot down questions. She knows that Carlos is getting to be old enough to participate more in visits. She talks with Carlos about what he can share with his CF doctor and health care team at the visit. She practices with Carlos so he is more comfortable talking about his cough and stools.

Carlos tells his mom that he is tired of the nutrition supplements he is supposed to drink. He doesn't like the vanilla flavor now. He wonders if he still needs to drink them. Mrs. Rodriguez says that that's a good question to ask the dietitian. It is also important to know how his weight is doing and what choices he has to get enough calories. Carlos and his mother add his question to the notepad so they don't forget.





## MAKING IT WORK FOR YOU

### GETTING INFORMATION: KNOW THE TYPE OF QUESTION TO ASK

To be a good CF manager, you will need to gather information from many sources, such as the CF health care team, school, and insurance personnel. In this section, we use examples from medical situations to show how to ask good questions. You can use these same skills in other situations you handle every day.

We covered how it is important to know why you need to give information in the previous section. It is also important to know why you are seeking information. What is the goal of your communication? If you know your goal, you will know how specific you want the information to be. Do you want a summary or details? If you know how much information you want to meet your communication goal, you can keep asking questions until you have the information you want.

There are two basic types of questions you can use to get information: open ended and close ended.

**Open-ended questions** often start with words such as *how*, *what*, *when*, *where*, or *who*, or with phrases such as *please explain*, *tell me more about*, *I don't understand*, *how do you mean*. The person asking such a question clearly expects a broad answer. This kind of question can't be answered with *yes* or *no*.

For example, if you ask, "How can I tell that my child is getting the right dose of enzymes?" you expect a full explanation. But if you ask, "Is my child's enzyme dose okay?" you are likely to get just a yes or no answer.

**Close-ended questions** typically start with words such as *are*, *did*, *do*, *is*, or *can*. These questions can be answered with one word—often *yes* or *no*. This type of question will usually not get you much information. But sometimes you may want a clear, simple answer—has something happened or not?

For example, if you ask, "Will you get the test results today?" you will get an answer to that single question. But if you want to know if or how you will hear about the test results, you will not find out what you really want to know. In that case, you would want to ask "How will I know if my child's test results are normal or not?" Many times, you may decide that a close-ended question is the best kind to ask. You might ask the respiratory therapist, "I was out of the hospital for a while. Did my daughter get her 12 o'clock treatment?" If the answer is yes, you may not want any other information or you may choose to ask how well the treatment went. If the answer is no, you may follow up with a different question.

### GETTING INFORMATION: REVIEW YOUR SKILLS

Think of a time when you tried to get more information about your child's health or a CF treatment. Use the worksheet "Making It Work for You: Reviewing Your Communication Skills" in the back pocket of this module to answer questions about what happened. Next, think about something related to your child's health or CF treatments that you would like to understand better. What question or questions do you want to ask? How will you plan to get the information that you need?





## Communication TIPS

### HOW TO GET THE INFORMATION YOU NEED

#### State the purpose of your question before you ask it.

Telling why you want the information (what is your goal) helps the other person understand what you plan to do with it. Then he or she may be able to answer your question more fully.

#### Example

"I want to increase Becky's weight. We've been trying different things to help her eat a high-calorie diet and I'm wondering if it's helping. What is her weight?" This may get you a more complete answer than if you ask, "How much does Becky weigh?" without telling why you want to know.

#### Keep questions as short and simple as possible.

#### Ask only one question at a time.

Asking many questions at once may confuse both you and the other person. It may also leave you with unanswered questions. Get the answer to one question and make sure that you understand the answer before moving on to the next one. Often the answer to one question leads you to the next question.

#### Be careful with *why* questions.

You may often want to know why, but asking questions that start with *why* may backfire. To your listener, using *why* questions may sound like you are blaming or aggressive. Asked why he or she did something you aren't happy about, your listener may feel defensive and have trouble communicating with you. Often you can get to the same question in a different, less-threatening way.

#### Example

Think about how your communication with the other person will feel if you ask, "Why did you change the antibiotics?" Now think how he or she might respond if the question was "Would you please help me understand your reason for changing the antibiotics?"

#### Plan ahead and write down your questions.

Using questions to get information from CF health care team members works best if you plan ahead. Take some time now to write down questions before you meet with a person or speak by phone. Bringing a list of questions to each visit will help you be organized and get all the information you need. Look at the types of questions you write and decide if they will give you the detailed information you want or need. Choose which of your questions will need to be open ended.

#### Play the message back.

One good way to make sure that you understand information you have been told is to rephrase and repeat the message back to the person who gave you the information. Repeat a message using only words you understand. Ask the other person to define words you don't know and to clarify messages. To "play back a message" you might say, "Let me see if I understand." Then repeat the message in your own words.

If the message is detailed or complex, you may want to write down the key points to review as you listen. Then you can repeat the information in your own words, using your notes. Or ask the other person to write it down for you. Be sure you read the notes to see that they are clear to you before you leave the clinic. Some people feel awkward doing this, especially in medical situations. But most health care team members will appreciate your effort to understand. When you see how much better it is to clear up misunderstandings right away, you will appreciate being able to use this skill.

Because you have a child with CF, you need to understand complex information well enough to pass it on to others who help with your child's care. By "playing back" the message, you can make sure you really understand it and can pass it on.



### TALKING ABOUT YOUR FEELINGS

Feelings are another important part of communication. This section will include how to name your feelings and why it is important. It's good to know when to talk about feelings so they don't interfere with another focus of your communication. Beginning a communication by stating your feelings can help the listener understand one reason for your communication. For example, "I'm worried Jamie is worse. Would you tell me the reason for changing Jamie's antibiotics?"

*Something to keep in mind when you talk about your feelings:* In some cases you do not expect or want the other person to do anything—except listen. Talking about an emotional experience can at times reduce your stress and help give you a feeling of support. Often, however, you will want to warn the other person that you do not expect or want any advice or solutions to your situation.

#### Examples

You might say:

"I just need to talk about my terrible day. I know there is nothing you can do about it. Listening is all I need now."

"I've been under a lot of stress lately trying to fit extra treatments for Jake's infection in with my work schedule. I appreciate your spending a few minutes with me and listening."

**Use I statements when you're talking about feelings.** This is another time where I statements are helpful, so that you do not sound like you are placing blame on the other person.

#### Examples

Instead of: "You make me angry when you won't talk to me," try "I wish you'd talk to me about this problem. I feel angry when you are silent."

Instead of: "You act like I don't even care about my child because we missed some treatments," try "I want you to understand that I care about my child's health. We are having problems doing so many treatments."

**Remember also to share your positive feelings when someone does something that helps you or makes you feel better.**

#### Examples

You could say to your spouse, "I want you to know how much it means to me that you're helping with Susan's treatment. Having a break makes me feel like a different person."

You could say to the CF nurse, "I really appreciate your taking extra time to talk to my mother-in-law at the hospital during Brian's admission. I think she understands better how hard I try to keep him well."

### When Should I Talk About My Feelings?

#### With the CF Health Care Team

Before you express your feelings, ask yourself, "What is the most important focus of my communication? Will talking about my feelings change my focus? Is this the person I need to talk to about these feelings?"

If now is not the right time, or the CF health care team member is not the right person, you may want to find another person with whom to communicate your feelings. Ask yourself, "Do I just want to talk about being upset or do I want to gather some information that may help me better manage the situation?"

The CF health care team knows that CF can cause a lot of strong feelings and stress at times. If you need to talk with someone about your feelings, think about talking with a social worker. The social worker can also help you decide if talking to a mental health professional (such as a psychologist) would be helpful for you.



### With My Family

In dealing with family members, it's easy to blurt out feelings when they are most intense. This backfires sometimes. When we are under stress and need to solve a problem, communicating about how to solve the problem may work better than expressing feelings.

### Example

Mrs. Black calls her husband and says, "I'm so frustrated with you! You just don't help enough with the kids. How can I pick up Jason from day care when I have to take Kim to the doctor?" Mr. Black feels attacked, and he argues that he does help.

Because Mrs. Black's goal was to arrange for Mr. Black to pick up Jason from day care, she probably should have skipped saying how she felt and simply asked him to pick up Jason. Her feelings could be expressed appropriately at another time, when the couple had time to talk.

"Tomorrow is a busy day—can you pick up Jason from day care while I take Kim to the doctor?"



### MAKING IT WORK FOR YOU

#### PLANNING TO TALK ABOUT FEELINGS

Describe something that happened, and why or how you need to tell someone about your feelings. Using the worksheet, "Making It Work for You: Reviewing Your Communication Skills" in the back pocket of this module, write some *I* statements using feeling words that fit the situation you just described. For example, "I feel sad when..."

To whom are you talking with the *I* statements you just wrote?

How is the person you want to tell likely to react to these statements?

#### GOALS TO IMPROVE MY COMMUNICATION

Here are examples of goals that may help improve your communication with the CF health care team and others.

#### Examples

**Goal:** Make a list of information I want and questions I have ahead of time.

Mrs. Thomas often leaves the office of her daughter's doctor without getting the information she wanted. Her communication goal was to come to the next visit with an organized list of information she wanted and questions to ask.

**Goal:** Phrase questions to get the information that I need without placing blame.

Mrs. Douglas thinks about what she wants to say to her son Kyle's CF doctor at his follow-up visit from the hospital. She wonders why she never saw him while Kyle was in the hospital. Instead of asking, "Why didn't I see you when Kyle was in the hospital?" she decided to ask, "Please help me understand how the CF center doctors work with patients in the hospital and the clinic. How does the doctor in the hospital know about my child?"

**Goal:** Keep my goal in mind.

Trudy Jacobs's doctor believes that her lung function can improve if she does airway clearance more often. He has asked her to increase her airway clearance treatments to three times a day. After several weeks, Mrs. Jacobs realizes that her daughter is not consistently doing her airway clearance after school. To get her 13-year-old daughter back on track, Mrs. Jacobs wants to set a goal of having Trudy be responsible for the treatment after school. She thinks about how she can ask Trudy about doing her afternoon treatment. She knows that if she makes Trudy feel bad that she has not done a treatment, it may not help them figure out how to reach her goal. So she tries to think of how to ask Trudy without starting the question with *why*. She is sure Trudy's answer will be "I don't know" or "I forgot." That answer would just make everyone frustrated. Instead of saying, "Why didn't you do airway clearance after school this week?" Trudy's mother asks, "What makes it hard for you to do your airway clearance after school?" Trudy replies that she's not sure if she really needs three treatments of airway clearance every day. They talk about how to ask Trudy's CF doctor this question. Rather than saying "Why does Trudy have to do airway clearance three times a day?" they ask "How flexible can we be in scheduling Trudy's airway clearance so that she has time for after-school activities?" and "How quickly would you expect to see Trudy's PFTs improve from doing airway clearance three times a day?"



## LEARNING FROM OTHER FAMILIES

### Seth

"Seth's getting ready to go to scout camp, and since the camp will be the middle of July, we want to make sure he's prepared for the heat and the problem of losing more salt and fluids than the other kids who don't have CF. We need to get more information before camp." (Mrs. Reiser, mother of 15-year-old Seth)

Seth and his family are making plans for summer. They have a goal for Seth to go away to a resident camp for 2 weeks with his Boy Scout troop. They have some information about the camp already. They know that the cabins are air conditioned so he will be able to sleep well. They also know that he can set up his equipment for his daily breathing treatments and airway clearance. He will be involved in a lot of outdoor activities including swimming, hiking, and rock climbing. One possible problem they want to avoid is **dehydration\***. The camp is in July.

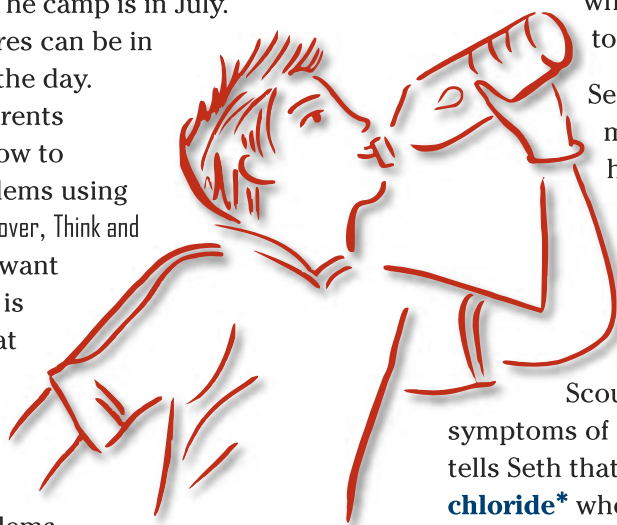
The temperatures can be in the 90s during the day. Seth and his parents have learned how to approach problems using the Watch and Discover, Think and Act steps. They want to be sure Seth is prepared so that he can enjoy camp, be as active as possible, and avoid any problems from CF.



#### WATCH AND DISCOVER

Mrs. Reiser reminds Seth that he loses more salt and fluid when he sweats than boys without CF. This makes Seth more prone to **heat stroke/heat exhaustion\*** and dehydration. Seth has used **electrolyte\*** sports drinks in the past when he has gone to the beach or during tennis matches, but he has not gone to camp before where there are all-day outdoor activities and no parental supervision. He's not sure how much to drink or what symptoms he should watch for to tell if he is having a problem.

Seth and his parents decide to get more information from his CF health care team. He has an appointment to get a checkup before camp. He makes a list of questions to ask his doctor and the CF dietitian. He shares with them his goal to attend the Boy Scout camp. The doctor tells Seth the symptoms of dehydration to watch out for. He tells Seth that he will lose more **sodium\*** and **chloride\*** when he sweats (the electrolyte salts in the blood and sweat). Seth's doctor makes the point that anyone can get overheated on a very hot day, especially during exercise. He suggests that Seth talk to the scout leader about having his troop talk as a group about signs of dehydration, heat exhaustion, and heat stroke.





Seth meets with the dietitian. He asks her if eating salty snacks will prevent him from losing too much salt. The dietitian tells him that eating salty snacks at camp is a good idea, but reminds him that the snacks alone will not be enough salt if he is sweating a lot. She then talks about various electrolyte and fluid drinks and how Seth can make his own if he needs to. She also tells him how much water or fluid he should drink each day to prevent dehydration. She reminds him that a person can't tell how much to drink by how thirsty he feels. Most people tend not to take in enough fluid and stop drinking too soon even if their bodies are getting dehydrated. Seth should drink fluids all through the day, not just when symptoms start or at the end of an activity. He needs to plan how he will get fluids during the day and how he can take breaks to cool off if he needs to. She gives him a note with instructions that he can share with his troop leader and the camp staff.



### THINK AND ACT

Seth contacts his troop leader to find out whether he can bring extra electrolyte solution to camp and how it can be stored. The Reisers also contact the camp director and make a plan so that he can store fluids and get assistance from the counselors to have the drinks available at different areas of camp, such as the ropes climbing course, hiking trail, or pool.

The Reisers make a copy of Seth's CF action plan for the camp, as well as emergency numbers for his doctors. Before camp, Seth decides to plan a day trip to a local beach with some friends to try out his plan. He brings the fluids he needs for the day. He realizes that he has to remind his friends to keep drinking water, too. He didn't really think about how much he needed before he started to make his camp plan. He makes a goal to drink at least 8 ounces of sports drink every hour during his 6 hours on the beach. After he gets back from the beach, his parents are relieved to know he can handle this. They figure out that drinking 8 ounces of sports drink every hour about 10 hours a day for 14 days means he needs to take about 9 gallons of sports drink to camp. He decides which flavors to bring so he doesn't get tired of the same one.

Seth goes to scout camp and has a great time. When he comes home, he talks with his parents about how he managed the heat. He says he did try to get in the shade more than some of the other boys. He was the champion drinker of the camp and his goal worked well. He calls his CF dietitian to tell her how well their plan went.

### COMMUNICATION: PUTTING IT ALL TOGETHER

You can practice your communication skills by using the worksheet, "Putting It All Together: Communication" in the back pocket of this module. Read the two stories in the worksheet and think about the goal or focus of each parent's communication. How do you think he or she should approach the situation using specific communication skills?



## SUMMARY – BECOMING A CF MANAGER

**R**emember, becoming a CF manager takes both skills and practice. Give yourself time to read the CF FEP modules. Use the worksheets to help you gain knowledge and skills that you need to be a CF manager. You will continue to be a better CF manager as you work with your CF health care team and learn about your child's CF. Practice the skills of **Watch and Discover** and **Think and Act**, and work with others—over time you will find there is a lot you can do to become a good CF manager.

### SETTING GOALS FOR HEALTH AND LIFE

Talk with your child, the CF health care team, and your family about goals for your child's health. Think about what is important for your family's quality of life. Some goals may only be reached in the future, and others may be reached now. Keep in mind that big goals often need to be reached by breaking them down into a number of smaller goals. Use **Watch and Discover**, **Think and Act** to check and see if you are reaching and maintaining your goals.

### PREVENTING COMPLICATIONS

- Watch and Discover signs and symptoms to find problems early.
- Take action to prevent infections by getting immunizations, washing hands often, and avoiding contact with people who are sick.
- Make quarterly visits to your CF center and know who is on your CF health care team.
- Do CF treatments correctly on the schedule you and your CF health care team worked out.
- Look with the CF health care team at how well the treatments are working and how well they are fitting into and affecting the quality of life of your child and your family.

### TREATING COMPLICATIONS



#### WATCH AND DISCOVER

- Be aware of the goals for your child's health. Make goals to reach things you value for your child's health and your child's and family's quality of life.
- Know your child's baseline symptoms. What symptoms are normal for your child?
- Watch actively for any new symptoms or a change in symptoms that may be a problem. This includes health problems or problems that affect your family's quality of life. What is keeping you or your child from reaching a goal?
- Try to figure out possible causes for the problem.
- Talk with others about what they observe and what they think the problem might be.
- Decide if you need more information and how you can get it.





- **Think** about possible solutions for the problem that you have discovered. Be flexible and think about many solutions.
- **Think** about what resources and help you need to address the problem.
- **Think and Act** to choose a solution and make a plan of action.
- Set a time frame to carry out your plan and decide if it is working.
- Talk to everyone who needs to be part of carrying out the plan. Be a good communicator.
- Take action and watch to see what happens. Did it work? Do you need to go back and come up with another solution?
- If you are successful in solving the problem, congratulate yourself and those who helped you. You deserve a reward—even if it is a small one! Celebrate your successes.
- If you are still having problems, think about other solutions and talk with others about what to try next. Don't give up—just find another way! If you find a goal is too hard, change the goal or break it down into smaller steps.

Remember, this is a cycle. Whatever actions you take, you need to watch and see what happens. Keep going back to Watch and Discover.

#### COMMUNICATING WITH THE CF HEALTH CARE TEAM

Communicate regularly with your child, family, and friends to see how they think things are going. Decide with whom you need to talk when you are working on a problem. Plan your questions and decide what the focus or goal of your communication is.

Stay in regular contact with your CF health care team. Make quarterly visits (every 3 months) to the CF center even if you do not see health problems in your child. Talk with CF health care team members when you have

questions, discover a problem or change, or need help in coming up with goals or solutions to problems. They want to be a resource for you and your child.

Keep a CF Travel Folder with important information about your child's CF care and treatment. Be sure to review and share this information with others on your CF home team and the CF health care team. Remember to bring this folder to CF clinic visits. Put your list of questions in it to help you with communication.

#### BECOMING A CF SELF-MANAGER:

##### GETTING MORE INFORMATION AND BUILDING SKILLS

##### The CF FEP Modules

You have learned the basics of becoming a CF manager in this module. You will find information about preventing and managing CF problems in other CF FEP modules. Choose the module(s) that best matches your needs or the current CF problems your child is having. It's a good idea to plan on reading each of the modules over time. You will want to share them with others in your child's life who are part of your CF home team and who help you with CF care. Review the modules again as you experience problems or have questions.

The module *Working With Your Child* covers three major developmental stages: the young child, middle childhood, and adolescence. You will want to use this module over time as your child moves through each of these developmental stages.

Use the glossary "CF Words to Know" when you read the CF FEP modules or when you hear CF words while managing your child's CF. Be sure you understand the words you need to know to manage CF with your child and the CF health care team. Ask your CF health care team for help if you do not understand a word or information that they give you.



### **Other CF Resources**

The CF FEP covers the most common lung and digestive system problems in CF and is designed to give you basic information and skills to be a good CF manager. If you need more information on less common CF problems, there are other resources that you can use. Ask your CF health care team for help in finding the information that you need.

### **The CF Foundation**

The CF Foundation has a wealth of information that is available to you by a number of different means. The CF Foundation's Web site, [www.cff.org](http://www.cff.org), is updated often with electronic versions of pamphlets, information sheets, and Web casts that focus on many CF-related issues from nutrition to research. You can also find information about current clinical research, CF Foundation-accredited care centers, and chapter activities. Please e-mail [info@cff.org](mailto:info@cff.org) or call 1-800-FIGHT CF for more information.





## BECOMING A CF MANAGER APPENDIX

Appendix I: MANAGING STRESS ..... A-3

### WORKSHEETS

(Located in back pocket)

MY CHILD'S USUAL RESPIRATORY SYMPTOMS

MY CHILD'S USUAL GASTROINTESTINAL (GI) SYMPTOMS

MAKING IT WORK FOR YOU: WATCH AND DISCOVER

KEY FACTS ABOUT MY CHILD'S CYSTIC FIBROSIS

CF ACTION PLAN SAMPLES:

MY CHILD'S CF ACTION PLAN — MANAGING LUNG PROBLEMS

MY CHILD'S CF ACTION PLAN — RESPIRATORY AND GASTROINTESTINAL (GI) / NUTRITION

MY CHILD'S CURRENT MEDICATIONS

MY CHILD'S FOOD DIARY

MY CHILD'S CF HEALTH CARE TEAM / MY CHILD'S CF HOME CARE TEAM (on back)

PLANNING MY CHILD'S CF QUARTERLY VISIT COMMUNICATION

WHO TO CALL / WHO TO VISIT

MAKING IT WORK FOR YOU: THINK AND ACT

MAKING IT WORK FOR YOU: REVIEWING YOUR COMMUNICATION SKILLS

PUTTING IT ALL TOGETHER: COMMUNICATION



## APPENDIX I: MANAGING STRESS

Stress is a common part of our lives. People often experience stress when they are in new situations or when they are in situations that seem to be too much for them to manage. Having a child with a **chronic\*** disease, such as **cystic fibrosis\*** (CF\*), can put you in many stressful situations.

Stress may be experienced in the body, in the mind, and/or in the emotions. Examples of common responses to stress include:

- Responses in the body, such as muscle tension, stomach upset, insomnia (not being able to sleep), and feeling tired
- Mind problems, such as having trouble concentrating and memory lapses (forgetfulness)
- Emotions, such as anxiety, fear, frustration, irritability, and, over time, depression

Sometimes you can take action to avoid stress or to resolve or control a problem that is causing stress. The CF Family Education Program (CF FEP) module *Becoming a CF Manager* teaches problem-solving skills you can use to prevent or resolve some stressful situations. Not all problems, however, can be resolved. You will experience stress at times. But you can take action to reduce your feelings of stress. Benefits of controlling stress include:

- Improving your **quality of life\***
- Being better able to interact with and take care of your family
- Improving your problem solving by helping you think more clearly

Here are some strategies you can use to reduce and control your stress. These three practices have been found to help other people reduce the stress that they feel:

1. Change your thoughts.
2. Get support from others.
3. Relax your body.

You will find that different strategies work for different stress situations. Many times you will use several strategies for one situation.

### THINGS TO DO TO RELIEVE STRESS

#### 1. Change Your Thoughts

The way that you think about something can affect the way that you feel. When your thoughts are very negative, your feelings will be negative too.

Consider three thoughts that a parent might have after learning that his or her child has CF.

*This is bad that my child has a serious chronic illness.*

*This is terrible that my child has a serious chronic illness, and I will never be able to be happy again.*

*This is bad that my child has a serious chronic illness, but at least we know how to keep him as healthy as possible by working with the CF health care team.*

How do you think each of these statements would affect the way that you adjust to the stress of learning about your child's CF **diagnosis\***?

Negative thinking can make you feel bad and discouraged. Positive thinking can make you feel better. You have the ability to have both negative and positive thoughts and feelings. It is your choice. You may not be sure that you can change your thoughts. You may believe that thoughts just happen. But research has shown that a person's negative thoughts can be changed, and, by doing so, a person can improve his or her feelings. Here are some pointers for changing negative thoughts.

- **Be realistic and slightly optimistic.** Try to balance your negative thought by adding a positive thought. For example: *This is a bad situation. I wish it wasn't happening, but it is. I've handled bad situations before, and I can get through this one.* Try to think of a cup as at least half full instead of half empty.
- **Avoid words such as "never," "always," "worst," and "must."** These words make it seem that things are final and absolute. Most things in life are not that way. For example, instead of thinking, *I'll never be happy unless this happens*, try thinking, *I wish everything was going my way. But that's not happening now. I can still enjoy \_\_\_\_.*
- **Avoid catastrophizing.** Catastrophizing means thinking about the very worst aspects of a situation, and expecting the very worst thing to happen. People who catastrophize in stressful situations become overwhelmed and cannot use good strategies to solve the problem and make the situation better. Most people may feel

\*See CF Words to Know Glossary.



overwhelmed at times. Some find that being overwhelmed brings others running to help them. In the long run, however, using strategies to stop catastrophizing is a much more useful way to decrease stress and begin to resolve a problem or adjust to a situation.

- **Don't expect to be perfect. Don't expect the rest of the world to be perfect.** For example, instead of thinking, *These clinic visits are so long. No one respects my time, try thinking, I wish these visits were shorter. I'll ask if there is something I can do to make the appointment go faster or with less waiting. I want to make the most of our clinic visit and what our CF health care team has to help us.*
- **Avoid generalizing.** Just because things did not go well in a situation or you were not able to do something right, do not think that means nothing will ever go right or that you are unable to do anything right. Focus on the situation and how to resolve it. For example, instead of thinking, *I shouldn't have come to the grocery store. I should have known he would get tired. Now he's screaming. I'm a bad mother, try, He's so tired he's screaming. He needs to nap. He's not the first child to scream in a grocery store. Maybe he'll calm down if I let him play with my keys.*

### Stop Your Thoughts

Sometimes it makes sense just to stop thinking about something. More thinking is not going to help with problem solving and it is going to add to your feelings of stress. Some people feel guilty when they decide to stop thinking about a situation. Stopping your thoughts to decrease your stress, however, is often a wise idea and one that will lead to better coping in the long run.

Here are two ways to stop thinking about a problem:

- **Do something else.** A distraction will help you put unhelpful, negative thoughts out of your mind. A distraction can be anything that you find pleasant, or at least not troubling. It is something that involves you so much you can't think about the problem. Something as boring as counting sheep helps people fall asleep because it replaces stressful thoughts with boring thoughts. Other less boring examples of distractions include reading a good book, working on a hobby, doing physical exercise, working hard at your job, talking to someone (not about the problem), praying, or watching TV or a movie.
- **Plan your worry time.** Instead of thinking about the problem all day, choose a time to think about it for a short time, about 15 to 30 minutes. During that time, think about all aspects of the problem. Some people write in a journal for their worry time. It's okay to allow yourself to get upset about the problem during this time. When the time for thinking about the problem is over, let go or stop thinking about the problem and move on with your day.

### 2. Get Support From Others

People who have others who will help them with various aspects of their lives often do better managing stress. Therefore, it is important to stay connected to people and feel that you have a support system. Sometimes just knowing that you are connected to others is positive and can help you cope with stress. At other times, your support system will provide help with solving problems or managing feelings.

Most of us rely on spouses, relatives, or friends for support. But many other people can offer some kind of support. Another person does not have to be involved with or understand all aspects of your life to offer you valuable information and support. You may also be able to give some support back that will help make you feel more positive. Support from others can help you solve problems and deal with your feelings about a stressful situation.

- **Solve Problems**  
Even if their children do not have CF, other parents have worries and problems. They may be able to suggest ways to solve problems. Parents of other children with CF may be able to give you some ideas based upon their experience with CF. By talking to another parent, you can learn that others have been able to get through difficult times. You can ask your CF clinic if there is another parent you could talk with.



### • Deal With Your Feelings

Negative feelings can seem even worse when a person feels that he or she is the only one who has had these experiences or feelings. Some parents of children with chronic problems find that talking to others who have similar experiences helps. Being with people can also be a distraction—a chance to talk and laugh and plan activities outside the stressful part of your life. Spending time around other people may make you feel less alone and less overwhelmed by your feelings.

**NOTE:** When getting support from others, avoid people who catastrophize. Sometimes people who want to be supportive of you become overwhelmed themselves with your situation or believe they are supporting you by dwelling on how bad things are. Although they may mean well, they are not going to help you get away from negative thoughts and feelings. If you cannot get them to see that catastrophizing is not helping you, you may have to avoid these people in times of stress.

### 3. Relax Your Body

Here are some physical ways that you can relieve stress.

#### • Get Some Exercise

Exercise helps release your body's tension. When you have less tension in your body, you will feel less stressed. If you already exercise, you probably know this feeling. Exercising regularly is a good way to help keep feelings of stress under control. Exercise also has been found to help with mild depression. For most of us, the daily chores we do are not physical exercise. Too often chores leave us feeling tired, whereas brisk walking or other **aerobic\*** exercise can leave us feeling less stress and energized. Exercise will often

leave you feeling more refreshed than a nap or a snack.

Getting in the habit of exercising may be hard. You may say, *I don't have time to exercise. I don't need one more thing to do. I'm under enough stress already.* But remember that exercise reduces stress and can help you be more productive with your time. If you don't already exercise regularly, one easy way to start is with fast walking. Try it first for 20 to 25 minutes. Exercise programs on TV or DVDs are another way to start exercising. Or check out a local gym or exercise class. Having the instructor talk as you exercise will keep you motivated and distract you from stressful thoughts.

#### PROGRESSIVE MUSCLE RELAXATION

Another physical way to reduce stress is to practice progressive muscle relaxation. When your mind is full of stressful thoughts and feelings, your body becomes tense. Signs of muscle tension are tight shoulders, a sore jaw, or a headache. Often when you decrease the tension in your body's muscles, your feelings of stress also decrease. Progressive muscle relaxation is one way to relieve tension in the body. It may be difficult to imagine "just relaxing your body," but, if you try to relax one part at a time, the task becomes easier, and with practice you can learn to relax your body quickly. In this technique, you tense, and then relax muscles in different parts of your body.

For many people, the easiest muscle groups to tense and relax are the hands. We'll walk you through progressive muscle relaxation using the hands as an example. Following these instructions, you'll find a list of muscle groups you can relax using the same technique.

- Lie down on your back, or sit with all of your body parts well supported (i.e., sit in a chair with arms).
- Tense your hands first by making fists for 5 to 7 seconds.

- Unclassp your hands and relax them completely for 20 to 30 seconds.
- Repeat this at least twice with your hands before moving on to the next muscle group. Once you have relaxed your hands, do not move them. Notice the different sensations when the muscles are tensed and when they are relaxed.

After your hands are relaxed, move on to the other muscle groups in this order:

- Forearms
- Upper arm muscles (biceps, etc.)
- Forehead, cheeks, and jaw
- Neck and shoulders
- Chest, upper back, and **abdomen\***
- Feet, legs, and buttocks

After you have relaxed your entire body, stay relaxed for about 5 to 10 more minutes. During this time many people like to imagine a relaxing scene or just listen to their own calm breathing and think of nothing at all!

**Suggestion:** You can get audiotapes or CDs of progressive muscle relaxation that will talk you through the process and may contain soothing music as well.

\*See CF Words to Know Glossary.



- **Deep Breathing**

From public speakers to women in labor to Little League pitchers, many people have discovered that taking controlled deep breaths is a good way to become calmer quickly. People who practice yoga use breathing to calm the body and relax. If you pay attention to your body when you are stressed, you will notice that, among other changes, you don't take deep breaths. You can change your breathing to calm yourself.

#### How to Use Deep Breathing to Relieve Stress

- Focus on taking from four to eight long, slow, deep breaths.
- Breathe deeply so that your abdomen (not your upper chest) expands. To practice deep breathing, you can lie on your back and put your hand or a book on your abdomen. Your abdomen should rise up when you **inhale\*** and go down when you **exhale\***.
- Inhale slowly through your nose only.
- Exhale slowly through your nose or through your mouth while pursing your lips so

that you make a slight wind sound as you blow out.

- To keep your breathing slow and even, count to yourself while you inhale and then exhale for the same count. Inhale 1, 2, 3, 4 ... exhale 1, 2, 3, 4.

*Caution— Do not take so many long, deep breaths that you make yourself dizzy.*

Use these breaths whenever you find yourself in a stressful situation. Consider taking long, slow breaths several times a day to prevent tension from building in your body.

#### SUMMARY

Stress is a common part of life. A chronic disease, such as CF, can cause stressful situations for families. You can improve your quality of life and become a better **CF manager\*** if you learn to manage your stress.

Don't put off dealing with stress. Be aware of current or potential problems and try to resolve or prevent them to reduce the amount of stress you have. For stresses that can't be changed, practice changing your thoughts, getting social support, and relaxing your body in the ways that you have learned about from this appendix.

How well you can manage CF depends upon you being able to handle stress well. If you are feeling overwhelmed despite trying these things to help reduce stress, ask for help. Talk with your CF health care team. They can give you support and ideas, resolve your stress, or help you find a mental health professional (such as a **psychologist\*** or **social worker\***) who can work with you. Remember that good communication and problem solving can help you avoid and reduce stress. See the CF FEP module *Becoming a CF Manager* for more information about these skills.

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