

# 5 WAYS TO PARTNER WITH YOUR CF CARE TEAM

## *For Families Managing Cystic Fibrosis*

Managing cystic fibrosis (CF) may feel like a balancing act where the demands of CF are just one part of a busy day. By sharing what matters most to your family, you can partner with your care team to help find balance.

Consider using these tips to help you prepare for your clinic visits.

1

### Ask for Help With Your Family's Care Plan

Share openly and honestly about your loved one's needs so your team can work with you.

- ◆ You are experts in what does and doesn't work in your loved one's life.
- ◆ If something's not working, share that with your team so you can come up with solutions together. Your team is there to help you.

2

### Share What's Going on in Your Life

When life changes, your family's care plan may need to change too.

- ◆ Life can sometimes get in the way of doing daily CF care — and vice versa.
- ◆ Your team knows that things come up that impact how you are able to manage CF. Share what else is going on at home so your team can help you make positive changes.

3

### Communicate Outside of Clinic

Your family manages CF every day, so why wait until clinic to ask questions?

- ◆ CF care happens in real time, so think about how you can reach out to your care team with new ideas or questions when something comes up.
- ◆ If something urgent is going on, connect with your team for advice and next steps.

4

### Invite Other People Into Your Family's Care Planning

Managing CF doesn't have to be a solo activity.

- ◆ Managing CF can often be a family affair, so think about a team approach to care.
- ◆ Think about who else in your life can join the journey of managing CF and invite them to participate in care discussions at clinic.

5

### Approach Difficult Conversations with Respect

You and your team are motivated by a shared goal: improving your loved one's health.

- ◆ Your team is there to help you manage CF, but it's not always easy to work together.
- ◆ Even when it might be difficult, think about how you all can work with your team to find a plan that works for your loved one's life and that will help them meet their medical goals.

# Stories of Partnership: What's Yours?

Now that you know the 5 Ways to Partner, here's what it looks like in your community. What's your story?



## 1. Ask for Help With Your Family's Care Plan

My daughter had been on a feeding tube for years. One day, she decided that she wanted to stop the tube feedings because she was working really hard on gaining weight in other ways. So, in preparation for our next clinic visit, I had her email the team to tell them about her decision. At the visit, the team was receptive. We talked about our options, and together, with my daughter, we decided on how to proceed. —*Mother of teen with CF*

## 2. Share What's Going on in Your Life

My son is a Boy Scout and wanted to go on a 12-day trek with his troop. We were reluctant to let him go but worked with the team to develop a plan. We brainstormed how he could take care of himself without electricity, and after much discussion, we decided that a 7-day trek would work better for him. It was a true partnering conversation where they were willing to work with us but also help us stay realistic about his treatments and therapies. The trip went well and my son had a memorable experience. — *Father of son with CF*



## 3. Communicate Outside of Clinic

My daughter knows when something's up with her body. One time she had a PICC line in and felt like she had a blood clot. So, I encouraged her to reach out to her team right away, even though her visit was the next week. The team worked with us to get her in sooner, and after my daughter described her symptoms, even though they weren't typical of a blood clot, the doctor listened. Sure enough, they found a clot in her shoulder and were able to treat it. They trusted that she knew her body well, and they responded when she reached out. — *Mother of teen with CF*

## 4. Invite Other People Into Your Family's Care Planning

Ever since I was little, my dad has always been the one to drive me the two hours to and from clinic. Even now, in my 20s, I still want him to come with me because going alone is a bit stressful. I know as an adult I should be doing things on my own, but just having my dad there really makes a big difference. It would be weird if he wasn't there. I value his company and sometimes talk about my plan for whatever is going on with my CF on the way home. It feels very comforting just having my dad around. — *Young man with CF*



## 5. Approach Difficult Conversations with Respect

CF was very new for us and our 2-year-old son, and the rest of us hadn't spent much time with doctors. Several of our lifestyle choices didn't quite fit with managing CF, and initially we caught our care team off-guard with that. But, through several meetings, we connected and they respected our choices, understanding that what mattered most to us was to find alternatives for his diet without resorting to animal products or sugary foods and making sure that we used medications only when necessary. They've helped us make this transition into life with CF as a family. — *Father of son with CF*