

5 WAYS TO PARTNER WITH YOUR CF CARE TEAM

For Individuals Living with Cystic Fibrosis

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

1

Be Open and Ask for Help With Your Care Plan

Share openly and honestly about your care needs so your team can work with you.

- You are an expert in your care and know what works and doesn't work for you.
- 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 care plan may need to change too.

- Sometimes, life can get in the way of your daily care — and vice versa.
- Your team knows that CF is just one part of your life. Share celebrations and challenges in your life with them so they know what else is going on.

3

Communicate Outside of Clinic

You manage CF every day, so why wait until clinic to ask questions?

- CF care happens in real time; reach out to your care team with ideas or questions.
- If something urgent is going on, connect with your team for advice and next steps.

4

Invite Other People Into Your Care Planning

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

- You are the one managing your CF, but you don't have to do it alone.
- Think about who else in your life can join you on your journey of managing CF and invite them to participate in your care discussions in a way that works for you.

5

Approach Difficult Conversations with Respect

You and your care team are motivated by a shared goal: improving your 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 can work with your team to find a plan that works for your life and that will help you meet your 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. Be Open and Ask for Help with Your Care Plan

In high school, I got a port and had two IVs every night. I couldn't play sports or hang out with my friends. I got sicker and sicker and ended up in the hospital more. I had less time at school and for doing the activities I enjoyed. I told the care team that this wasn't working. So, my doctor and I decided to come up with a plan that would work for me. We were able to negotiate a deal so that I was doing more treatments than I had been but that I wasn't just sitting at home hooked up to machines.
— *Young woman living with CF*

2. Share What's Going on in Your Life

When I had my son, I started skipping therapies, missing meals, and opting out of treatments if they posed any risk to my milk supply. Reality hit hard at one of my appointments after my son turned one and my PFTs were unrecognizable. Finding balance at this new stage of life took time and practice, but my care team worked with me to develop strategies I could use to incorporate my CF care into work and time spent with my son, and ultimately carve out the time for myself that my health so desperately needed.
— *Woman living with CF*



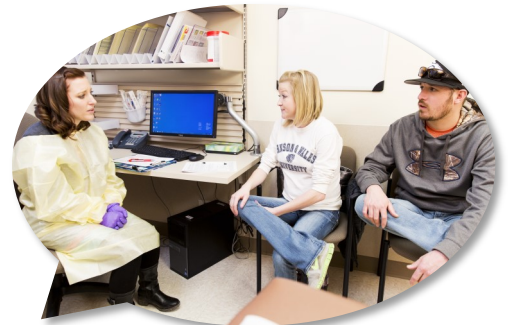
3. Communicate Outside of Clinic

Outside of CF clinic, I reach out to my care team about ongoing needs and questions, like getting and using new equipment, working with insurance, and coughing up blood for the first time. Email or phone calls work, depending on what the issue is. I know it's important for me to reach out to them if something's not working because it can't wait until the next appointment.
— *Man living with CF*



4. Invite Other People Into Your Care Planning

My wife has CF and I've attended clinic with her, but I usually sit back and take it all in. I was afraid to communicate with her team. But, I realize that it is important for me to speak up. So I did. The team was so appreciative of that and said that they wished that I would be more a part of the conversation. They said I didn't need to be an expert like them, but that my insights were valuable and welcome. Realizing I had a voice meant that I could help my wife even more when making important decisions about her care.
— *Husband of wife living with CF*



5. Approach Difficult Conversations with Respect

Some of the best experiences I have with my team is when they listen to my input and work with me to develop a treatment plan. When my FEV₁ is down but all other symptoms don't reflect that, instead of throwing me on antibiotics, my team listens to me when I tell them about my symptoms. We agree to monitor my health more closely, come to clinic sooner, and do some extra breathing treatments.
— *Man living with CF*