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### Information for Adults with CF

Welcome to your Adult Guide to Cystic Fibrosis — your one-stop source for accurate information and practical advice on all aspects of living with CF.





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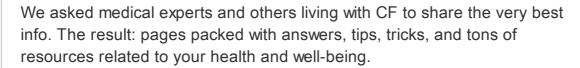
Care Center Network

Drug Development Pipeline

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Being an adult with CF includes some pretty distinct challenges. Finances, relationships, work — we cover all these topics, too.

If you have a great idea or a question of your own, we want to hear it. We're expanding the Guide all the time.

### In this Section

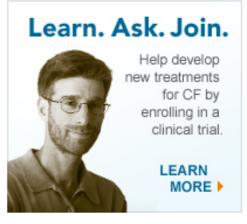
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Send your thoughts to us at info@cff.org.







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### Care Center Network

When the Cystic Fibrosis Foundation was established in 1955, most children did not live to attend elementary school. Today, the predicted median age of survival is in the late 30s, thanks — in large part — to the care provided though the national network of CF Foundation-accredited centers.

This network provides expert cystic fibrosis care for people living with the disease. In fact, the National Institutes of Health has cited the CF care center network as a model of effective and efficient health care delivery for a chronic disease.



The Foundation funds and accredits more than 110 cystic fibrosis care

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What's in the Pipeline?

Healthy Web Surfing
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In the Spotlight

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**Get Connected** 

centers nationwide. This means that there are more than 260 clinics where children or adults with CF can get care. All programs, however, are staffed by dedicated healthcare professionals who specialize in the treatment of cystic fibrosis.

Each center undergoes thorough review by the CF Foundation's Center Committee before it receives accreditation and funding. This review for accreditation occurs every year.

Besides taking care of people with cystic fibrosis, care centers also participate in CF clinical research and work to educate healthcare professionals about CF and the care people living with the disease require. Data from people with CF is collected in the national CF Foundation's Patient Registry, which is a rich resource for you, your CF health care professional and CF researchers to track the health of people living with CF in the United States.

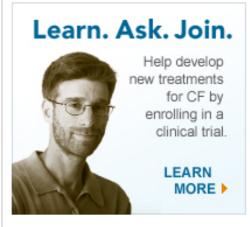
### **CF Care Centers**

- Find a Care Center
- Review Care Center Data

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Updated 01/26/12











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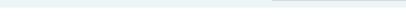
Speaking from Experience

Managing Home Care

Learn the Basics

Make Home Care Work

Home • Adults with CF • Daily Life • Managing Home Care • Manage Your Time



### Manage Your Time

### **Put Rest and Health First**

As with everything else involving CF, time management plays a big role in successful home care. Try these tips to help you focus on feeling well and balancing your medical schedule with everyday life.

- Take your IV medication out of the fridge an hour before your infusion. When you're going to sleep, place your IV into a cooler bag (with or without an ice pack, depending on how long until your infusion). It will warm up before it is time to infuse. This saves you a trip to the fridge.
- Set alarms. Try using a conventional alarm clock, cell phone alarms or kitchen timers to remind yourself when to start your IVs or flush your line.
- Try to stay on schedule with your medication. If your infusions are every 6 hours, a 6 a.m.—12 p.m.— 6 p.m.—12 a.m. schedule might work best. Or, if it's every 8 hours, a 7 a.m.— 3 p.m.—11 p.m. routine might work. Be flexible and rearrange all of the priorities in your schedule. Anything that's not health-related might have to wait.

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Work with Your CF Team

Manage Your Time

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Learn Helpful Tips

Maintain Your Health &

- Slow down. Errors happen when we rush. Talk yourself through medication or IV preparation so each step is clearly followed. Try to schedule your routine so you won't feel rushed, and stick to that schedule.
- If you can't be home for a delivery, ask if your home care agency can deliver your supplies to your work or a neighbor's home. Ask if you can place your oxygen tank outside your door and have it refilled when you're gone.

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**Updated 8/7/13** 







