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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.



- Volunteer
- Employment Opportunities
- Become an Advocate
- Find a Clinical Trial
- Care Center Network
- Drug Development Pipeline
- Make a Donation

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Enter zip code



We asked medical experts and others living with CF to share the very best info. The result: pages packed with answers, tips, tricks, and tons of resources related to your health and well-being.

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.



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 - Managing Home Care
 - Time Management
 - Traveling with CF
- **Other Health Issues**
 - Anxiety & Depression

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

What's in the Pipeline?



Check the progress and status of potential CF drugs and get details on clinical trials & news updates with a few clicks.

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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 through 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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Tomorrows.

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CF Cycle for Life

Help keep the
wheels in motion
to cure cystic
fibrosis.

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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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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.

Give today
for more
Tomorrows.

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CF Cycle for Life

Help keep the wheels in motion to cure cystic fibrosis.

FIND A RIDE ▶

What's in the Pipeline?



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Make Home Care Work

Work with Your CF Team

Manage Your Time

Get Help When You Need It

Give Yourself a Little Love

Speaking from Experience

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Time Management Tips

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Make Wise Decisions

Forgive Yourself

Get Help When You Need It

Speaking from Experience

• Traveling with CF

Basics of Traveling with CF

Work with Your CF Team

Traveling with Meds & CFRD

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

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