



WORKING WITH YOUR CF CENTER AND YOUR INSURANCE COMPANY

CYSTIC FIBROSIS SPECIALIZED CARE CENTERS

About 115 **cystic fibrosis*** (**CF***) centers are accredited by the CF Foundation in the United States. CF centers meet or exceed medical care standards that the CF medical community feels are necessary to care for this complex and serious **chronic*** disease.

The health care professionals who work in CF centers specialize in treating CF. Going to a CF center gives families access to a team of people who know how to take care of CF and have the right care plan for a child with CF. CF centers can help parents and their children:

- Manage the disease while living as normal a life as possible
- Prevent **complications*** or problems from CF
- Identify problems early
- Treat complications effectively
- Teach children with CF how to care for themselves and become independent when they are adults

The CF Foundation not only accredits pediatric (children's) CF centers, but also accredits adult CF centers. People with CF usually transition to adult CF center care late in their teen years or as young adults. To find out more about the CF Foundation's CF Care Center Network visit their Web site at <http://www.cff.org>.

VISITING THE CF CENTER

The CF Foundation recommends that every person with CF be seen four times a year (quarterly) by a CF health care team. The quarterly visits are important because the CF health care team can review how well treatments are working and identify problems early. A person with CF should still do quarterly visits even if he or she feels fine. If you have problems getting to the CF center, you may want to ask the CF center **social worker*** for help with transportation.

ROUTINE HEALTH CARE

Most centers want you to have a **primary care provider*** for your child's routine health care including **immunizations*** (shots); well-child visits; common illnesses or problems, such as ear **infections*** and rashes; and sports or school annual physical exams. Your primary care provider might be a **pediatrician***, family doctor, **physician assistant***, or **pediatric nurse practitioner.***

YOUR CHILD'S PRIMARY CARE PROVIDER AND CF CARE

Typically your child's primary care provider does the routine health care (for example, school physicals or shots). But, if you live a long way from your CF center, you may need to have your primary care provider help you in an emergency or work together with the CF center to carry out a treatment plan in between your child's CF center checkups. If a CF problem does not respond well to treatment, your next step would be to call or visit the CF center. Talk with your CF health care team about how to work together with your child's primary care provider.

MEDICAL INSURANCE RULES

Medical insurance providers include HMOs (Health Maintenance Organizations); PPOs (Preferred Provider Organizations); private insurance; military insurance, such as CHAMPUS; and state programs, such as Medicaid or CHIP (Children's Health Insurance Plan). Each insurance program can have different ways of providing access to **specialists*** including your CF health care specialists.

Many plans require people to use only certain doctors or hospitals, usually called the plan's "network" or "preferred" providers. The CF center and its doctors may or may not belong to your plan's network. Some plans may not allow the person to go outside the plan's network for help, even if a person needs special care. In some plans, people can go outside the network for care as long as they get approval first. Such plans usually have doctors, nurses, or case managers who review a person's situation before granting approval.

Talk with your medical insurance representatives or case manager about the doctors in the network and how you can make sure that CF specialists see your child. Find out what your plan's requirements are for your child to be seen at the CF center. If your health care plan wants your child only seen by doctors in its network, find out how you can request that the CF center doctor be added to the network.

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



Some health care plans may want you to see the CF center only once a year or when your child is having problems. Other plans may ask that you get approval before each CF center visit from your primary care provider. There are many possibilities. You may decide what your health plan requires is not in the best interest of your child. In that case, there are steps you can take.

- Work with your CF center to find a medical care plan that best matches the needs of your child and family.
- Don't be afraid to pursue matters with the insurance company and case manager until you feel comfortable that your child is getting the care he or she needs.

Keep in mind that you are your child's **advocate***. You are the one to plead for and speak in support of your child getting good CF care. You do not have to take 'no' for an answer. You may need to be more assertive or forceful than you have been in other situations. Every insurance company and health plan has a formal appeals process. An appeal is a way of asking for a new review of a decision usually by a higher authority. This process may be difficult and time-consuming, but it can be worthwhile. Families may not receive everything they want for their children's CF care, but they are often able to reach an acceptable compromise with their insurance companies.

MANAGING PROBLEMS WITH HEALTH INSURANCE COVERAGE

Here are tips for managing your insurance coverage on a daily basis and when special problems arise.

- **Talk with a CF team member if you feel you are not getting what you need from your child's health care plan.** Team members may be able to tell you what has worked for other families in similar situations. The center can also be an advocate for your child's receiving the most appropriate care. You can learn more about health insurance coverage from the brochure *Day-to-Day: Know Your Health Insurance Coverage* available on the CF Foundation Web site: <http://www.cff.org>. The CF Foundation also has a free CF Legal Hotline service that can help provide legal information about medical insurance, government benefits, and other legal rights of people with CF. You can also learn more about this service on the CF Foundation Web site. To reach the CF Legal Hotline call 1-800-622-0385 or e-mail CFLegal@cff.org.
- **Know your health care plan's requirements.** Know about what is needed to get pre-approval for a clinic visit, hospitalization, or surgery. Know how many days ahead of time an approval is needed or when a claim must be filed. Bring your insurance card with you to clinic visits.
- **Get to know your child's insurance case manager.** Most insurance companies have case managers who can work with individuals and their families over time. Request a case manager if you have not yet been assigned one. Talk with your child's case
- manager to help him or her get to know your child's health problems and needs for CF care.
- **Be careful when considering a change in insurance coverage.** Plans may have a pre-existing condition clause. With a pre-existing clause, you could have a waiting period before your child's CF care is covered or there may be different charges because your child has a known chronic disease. Some states have laws to protect against this.
- **If your employer changes plans or you consider a change in insurance providers, see if your CF center doctor is in the network for the new plan.** Doctors in the network have agreed to accept the insurance plan's allowed amount for payment—non-network health care providers have not. If you use a non-network health care provider, you may be billed for charges over the insurance company's allowed amount in addition to your usual deductible and co-pay.
- **Check out whether there is any limit on how much a plan will pay.** Most have a limit on the amount of lifetime coverage for a person—this is called a cap. Compare insurance plans and what caps they may have. If you have questions or concerns, talk to a social worker or financial counselor for more help.
- **Do not let your child's health insurance expire.** Make sure you keep up with payments and renewals. Find out how often you have to renew your child's coverage even if you are in the state Medicaid plan that you do not pay for. A lapse in insurance coverage may make it more difficult to get coverage later.



HEALTH CARE COSTS AND TESTING RULES

Health care plans vary in the way they provide coverage for CF care. You may feel pressure to arrange your child's CF care in a certain way to get insurance coverage for the costs involved.

Some health plans may ask that any tests or **X-rays*** be done at a specific hospital or lab that is different from the one your CF center usually uses. Sometimes this works out without a problem. Sometimes it can be a hassle, but the results of the tests are still accurate and available to your CF health care team.

Sometimes the CF center, however, needs a certain kind or quality of test that the average lab cannot provide. Talk with your CF center about your health plan's requirements. One approach is to go with the health plan lab on a trial basis and let your CF center see if the results are acceptable. If there is a problem, you can talk with your health plan case manager or administrator. If a test, such as a **sputum culture*** requires a special lab to get the best results, your

CF health care team can help you talk with the health plan about why this special testing is needed. Ask the CF health care team for a letter about the test to send to your health plan.

Some medical plans have mail-order pharmacy services that are less expensive if you order 90-day supplies. If your co-payment will be less, ask your CF center if you can have mail-order prescriptions. Some people work with the mail-order CF Services Pharmacy because it may have lower prices as well. The CF Services Pharmacy can also provide information about patient assistance programs available from some drug companies. You can find out whether your insurance works with CF Services Pharmacy and how the costs compare by calling 1-800-541-4959 or by going to its Web site at <http://www.cfservicespharmacy.com>. You can also access it through the CF Foundation Web site at <http://wwwcff.org>.

*See **CF Words to Know Glossary**.