Having good health insurance is important but understanding or choosing your health insurance is not easy. This pamphlet gives you information and lists questions you can ask about your health insurance.

**Review Your Health Insurance Plan**

*Health insurance plans* change from year to year. Each year carefully review and be familiar with sections of your health insurance that are important to care for cystic fibrosis (CF). Highlighting the plan’s sections key to CF care, like *home healthcare* and *prescription drug coverage*, may help. Do not assume that your prescription drugs and health care coverage will be the same from year to year. Call your insurance company to get your questions answered and to find out more.

*Words that appear in bold italic are defined at the end of this pamphlet.*

Whether you or your child have been recently diagnosed with CF, you are getting married, changing jobs, or it is time for the *yearly re-enrollment* at your job, take time to find out what services your health insurance covers for CF care, as well as other illnesses that affect you or your family.

If you have a choice between two or more health insurance plans, review each one carefully. Compare benefits to find out which is best. When deciding between two insurance plans, find out if you have a choice of doctors or hospitals and how much you have to pay for clinic visits or prescriptions. You also may want to learn about coverage for dependent children over 18 years of age, transplants, and any *exclusions* from coverage.

---

**Review Your Health Insurance Plan**

- Obtain a copy of your health insurance plan description from your employee benefits office or call your insurance company.
- Carefully read and highlight the sections important to CF care, such as home healthcare and prescription drug coverage.
- Review coverage for other chronic illnesses.
Although there is no “best” insurance, there are some that will be better than others for you and your family. Insurance differs both in how much you have to pay and how easy it is to get the services you need. Although few insurance plans will pay all the costs of your health care, some will cover more costs than others. It also helps to know that choosing the health insurance plan with the lowest premium may not be in your best interest. Sometimes these plans pay much less for prescription drugs and health care and can cost you more money in the end.

The Six “ Cs” of Insurance can help you learn more about your insurance. They also can help you make a decision if you have more than one insurance plan to choose from.

**Six Cs of Insurance**

1. **Coverage:** Do the services covered match the services you need? Will the insurance provide the needed drugs and equipment? Are there any exclusions?

2. **Co-pays:** Few health insurance plans cover every expense. Out-of-pocket expenses are what you pay. They are called **co-pays** and **deductibles.** It is important to find out what these will be for CF care. Is your CF care team part of the insurance plan’s network? If the CF care team is outside the plan’s network, ask about the yearly deductible amount and any charges you must pay beyond your normal co-pay to go to your CF clinic. What will insurance pay after you meet the deductible? Also, find out your prescription drug co-pay. With some insurance, you pay for the cost of the drug first and then fill out the paperwork before insurance will pay you back for the drug. With other insurance, you pay a percentage of the drug’s cost. You may not be able to afford the drugs with these plans. (See Table 1.) Usually, there is a lower co-pay for a generic prescription drug, and a higher co-pay for a brand prescription drug. Know which brand drugs are covered by your insurance and what your co-pay is.

3. **Claim Payment:** Find out what you have to do before your insurance will pay the medical bill. Some insurance will not pay the bill until you fill out a form. With other insurance, you pay the bill first and then fill out a form before the insurance company pays you back.
4. Conditions That Affect Payment:
Do you need to call the insurance company to get *prior authorization* or approval before getting certain prescription drugs, tests, or before being admitted to the hospital? Check to see if the health insurance company has a set timeframe to submit a claim or paperwork after services have been provided. Some insurance will not pay for services if a claim has not been filed within a certain time period, such as 90 days or six months. Check the insurance coverage for *pre-existing conditions*. Does your insurance plan consider CF a pre-existing condition?

5. Caps on Benefits: Many health insurance plans will have dollar limits on the amount to be paid for medical equipment, physical therapy, or prescription drugs. Because CF requires a lifetime of expensive health care, see if the insurance plan has a yearly or lifetime *cap on the benefits* that they will pay.

6. Cost of Insurance Premiums:
Be careful when changing to insurance with a lower premium. The insurance may have higher co-pays and deductibles. You could end up paying much more out of your own pocket in the long run. For example, insurance with a lower premium may only pay 50 percent of your prescription drugs. Think about what it would cost you if you had to pay for half of the total cost of your prescription drugs for one month. The better option may be to pay a slightly higher monthly premium for insurance that pays 80-100 percent of your prescription drug costs and/or one that requires a small co-pay.

<table>
<thead>
<tr>
<th>TABLE 1. HOW TO COMPARE HEALTH INSURANCE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>INSURANCE A</strong></td>
</tr>
<tr>
<td>Set co-pay vs. Percentage</td>
</tr>
<tr>
<td>You pay...</td>
</tr>
<tr>
<td>• $30 for brand drug</td>
</tr>
<tr>
<td>• $15 for generic drug</td>
</tr>
<tr>
<td>Low deductible vs. High deductible</td>
</tr>
<tr>
<td>You pay...</td>
</tr>
<tr>
<td>• $500/year deductible</td>
</tr>
<tr>
<td>• Co-pays for drugs, doctors visits, etc. do not apply to the deductible</td>
</tr>
<tr>
<td>Coverage of Services</td>
</tr>
<tr>
<td>You pay...</td>
</tr>
<tr>
<td>• A $15 co-pay for each visit</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

3

3
Health Insurance Coverage Laws
There are federal and state laws that affect health insurance coverage. The Consolidated Omnibus Budget Reconciliation Act (COBRA) is a federal law that can help you keep your group health insurance. All employers with 20 or more employees have to offer COBRA. It allows you to extend your group health insurance when you change jobs, if you go through a divorce, when your child turns 18 years old, or for other life events. The coverage can last up to three years depending on why you extend your coverage. For example, it helps a person keep health insurance for 29 months after approval and while waiting for Social Security Disability Insurance and Medicare to start. This law helps you keep your insurance during these life events, but you will have to pay all the premiums. Your CF care center team can tell you when COBRA will or will not help you and how long you can be covered.

Continuation of Coverage
States that do NOT have a law requiring continued health insurance coverage for disabled, dependent children:
- Alabama
- Alaska
- District of Columbia
- Kansas
- Maine
- Oklahoma
- Oregon

When your child turns 18 years old and is not in school full time, your health insurance may no longer cover your child. COBRA can help keep them covered for up to three years until their own health insurance starts. Most states have laws that require health insurance to continue coverage for children who turn 18 years old if they are unable to support themselves because of a physical or mental condition. This continued coverage lasts until they are able to support themselves. You will have to pay the premiums. You can request a Continuation of Coverage form from your health insurance company. Your CF care center social worker and care team can help to fill out this form. Some children cannot support themselves when they turn 18. It may be better to get insurance through a state program. Your CF care team can help you find out about your state’s programs.

Know Your Rights
Example: You have 10 months of coverage under a group health insurance plan. Then, you obtain a new job and insurance right away. Because of HIPAA, your new plan will give you credit for 10 months of coverage—creditable coverage—under the prior plan. Now, your new plan can only refuse to pay for two months of CF-related expenses instead of 12 months.

The Health Insurance Portability and Accountability Act (HIPAA) helps people who have group health insurance. Group insurance can refuse to pay for CF-related
expenses for the first 12 months of insurance if CF is listed as a pre-existing condition. Under HIPAA, you can get credit for the amount of time you had insurance under another health insurance plan. This is called creditable coverage.

If more than 63 days have passed without coverage, then your group insurance can refuse to pay for any pre-existing condition. This is one reason why it is important to always have insurance, especially when you change jobs or during a life event.

Remember, COBRA, through your employer, can help you avoid a gap in insurance greater than 63 days until you get a new job or health insurance. Your CF care center team has more information about COBRA, HIPAA, state programs and how to keep your insurance.

**Taking Action**

You will probably have some medical bills your insurance will not pay at first. This is called a denial of coverage. When this happens, you can appeal the decision. Call your insurance company and find out why there was a denial of coverage. Also, ask what you need to do to appeal the decision. Your CF care center team can help.

There are many things you can do before you appeal a denial of coverage. Staying organized can help. Have a file with your insurance statements that show payment and match them to the medical bills. Remember to copy and date anything you send to your insurance company. Learn your insurance by highlighting the sections that apply to CF care. Review your medical bills and write down your clinic visits, prescription drugs, and the result of your treatments. Keep notes when you talk with your insurance company. Write down the date, time, first and last name of the person you spoke to, what you talked about and what you agreed to. Ask the person you spoke with to send you, by e-mail or U.S. mail, what you agreed upon in writing. Doing all of this will help if you have to appeal a denial of coverage.

Asking your insurance company for a case manager to assist you may be helpful. A case manager can act as your representative at the insurance company. You may need to tell your case manager about CF and what health care you or your child needs. The case manager and you can become a team to work toward meeting the costs of your health care.
Drug Formularies

A drug formulary is a list of prescription drugs that your insurance wants you to use. These may be dispensed through certain pharmacies. This list is reviewed and changed by health insurance regularly. Drug formularies are often used by health insurance to help manage drug costs and improve quality of care. Below is a list of the different types of formularies.

1. Open or “voluntary formularies.” These are simple lists of drugs that the insurance company would like providers to prescribe. Your doctor can prescribe anything and insurance will cover it. An open formulary pays for both formulary and non-formulary drugs.

2. Closed formularies. In a closed formulary, the insurance company chooses a limited number of drugs that it will cover and lists them as formulary drugs. Drugs not included on this list are considered non-formulary drugs and are not covered. If you need a non-formulary drug, you will have to work with your doctor to get an approval from your insurance company. This is called an exception process. These formularies are not common, but they do exist.

3. Tiered, or “preferred” formularies. (See Table 2.) All drugs are covered, but there are three or more different levels (tiers) of co-pays. For example, a generic drug might have a $5 co-pay, while a “preferred” brand drug would have a $20 co-pay, and a “non-preferred” brand drug would have a $35 co-pay.

In summary, health insurance is important to everyone. The type of coverage you need changes with every life event. Review the Six “C’s” of Insurance every year and if you change jobs, get a divorce or when your child becomes an adult. Take action and organize your insurance forms and bills. Do not take “no” for an answer when coverage of a health care cost is denied. Remember, you can appeal a denial of coverage. Knowing your health insurance can help you get and keep the best coverage for you and your family.

<table>
<thead>
<tr>
<th>TABLE 2. TIERED, PREFERRED FORMULARIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Classification</td>
</tr>
<tr>
<td>----------------</td>
</tr>
<tr>
<td>TIER 1</td>
</tr>
<tr>
<td>TIER 2</td>
</tr>
<tr>
<td>TIER 3</td>
</tr>
</tbody>
</table>

*if applicable
GLOSSARY

**Appeal:** When you ask your insurance company to review the decision not to pay for a drug or medical service.

**Caps on benefits:** The limit on the total dollar amount insurance will pay. The cap may be for a year or a lifetime.

**Case manager:** Often, registered nurses are hired by the insurance company or a hospital to decide the best treatment options available. They can help patients get their treatments. You may need to give them more information about CF.

**COBRA:** Consolidated Omnibus Budget Reconciliation Act is a federal law that extends group health insurance for a certain period of time during a life event, such as leaving a job, getting a divorce, or a child turning 18 years old. You pay the full monthly premiums. Employers with 20 or more employees must offer extended health insurance through COBRA.

**Co-pay:** A cost-sharing arrangement when you pay a specific charge for a specific service, such as $10 for a doctors visit. You are usually responsible for payment at the time of care or when getting a prescription filled. Typical co-pays are set amounts for doctor visits, prescriptions or hospital services. Sometimes they are a percentage of the cost of the drug or service.

**Creditable coverage:** Under HIPAA, this will reduce the amount of time your group health insurance can limit coverage based on a pre-existing condition. You get credit for each month you had coverage under another health insurance plan if you have not had more than 63 days without health insurance.

**Deductible:** Annual amount you have to pay before insurance pays your health care costs. This often applies to the total amount your family pays.

**Denial of coverage:** When insurance will not pay a medical bill, they “deny you coverage.” A denial of coverage can be appealed. Call your insurance company to find out how you can appeal.

**Drug formulary:** A list of drugs that health insurance plan prefers a doctor to use. In some cases, the doctor can only prescribe drugs from this list unless an exception is obtained.

**Exception process:** Process by which the doctor gets a letter from your insurance company stating that specific drugs or services will be covered. A release is usually needed to get coverage for a non-formulary drug. It may require your doctor to call or write the insurance company asking for the release and explaining why it should be given.

**Exclusion:** A service or product that is not paid for by insurance. Typical exclusions are cosmetic surgery, drugs to help quit smoking, or over-the-counter drugs.

**Group health insurance:** Insurance sponsored by your employer or by a large group or organization.

**Health insurance plan:** An insurance company, Health Maintenance Organization (HMO) or other company that pays for health care, such as doctors visits, and drugs, for people in the plan.

**Home healthcare:** Agency or organization that visits a patient’s home to provide services, such as IV therapy.

**Plan network:** A list of providers that have an agreement with a health insurance plan to provide services to patients covered by that insurance. Networks can include doctors, pharmacies and hospitals.

**Pre-existing condition:** Any medical condition that has been diagnosed or treated within a defined period of time before you start your new health insurance. A waiting period may be required. Some insurance may not pay for treatment of a pre-existing condition. With group insurance, the waiting period can be up to 12 months. Creditable coverage can shorten, or get rid of, the waiting period.

**Premium:** The amount of money you must pay, usually monthly, to your employer or insurance company to have health insurance coverage.

**Prescription drug coverage:** Defines the type of coverage for prescription drugs. For example, it will specify the co-pay, limits on coverage and the type of formulary used.

**Prior authorization:** You have to get the health insurance company’s approval before they will pay for certain services or drugs.

**Provider:** Someone who gives health care service to a patient. A “provider” can be a doctor, nurse, pharmacist or dietitian.

**Yearly re-enrollment:** The requirement to choose a health insurance plan and sign up for coverage every year. Depending on your employer, you may have the option to select from more than one health insurance plan.
Important Questions to Ask About Your Insurance

• Is a referral needed from my regular doctor every time I visit a CF Foundation-accredited care center?

• Are brand CF drugs covered such as TOBI®, Pulmozyme®, and pancreatic enzymes? If yes, how much will insurance pay? Is it a set amount or a percentage of the drug’s cost? If no, what is the cost to me?

• How much will this insurance cost each year?

• Are there any conditions or any services that are not covered?

Resources

Besides your CF social worker and care team, there are many resources to help you get the best health insurance for you and your family.

• Your CF Foundation-accredited care center has the Advocacy Manual: A Clinician’s Guide to the Legal Rights of People With Cystic Fibrosis as a guide.

• CF Services, Inc., a national mail-order pharmacy and subsidiary of the CF Foundation, can help you get prescription drugs. They will work with you and your insurance company. Call (800) 541-4959 or visit www.cfservicespharmacy.com to find out more.

• The Institute for Health Care Research and Policy at Georgetown University has A Consumer Guide for Getting and Keeping Health Insurance for each state on the Web at www.healthinsuranceinfo.net.

• For more information about federal government programs and laws affecting health insurance, visit www.firstgov.gov/.

• To contact the state insurance commissioner, obtain more information on health insurance, or file a complaint, go to www.naic.org/consumer.htm.

• If you have questions, contact the CF Foundation at (800) FIGHT CF or info@cff.org.

©2006 Cystic Fibrosis Foundation

Contributing Authors:

Leslie Hazle, M.S., R.N., C.P.N.
Director of Patient Resources
Cystic Fibrosis Foundation
Bethesda, MD

Beth Sufian, J.D.
Sufian & Passamano
Attorneys and Counselors at Law
Houston, TX

Suzanne R. Pattee, J.D.
Vice President of Public Policy and Patient Affairs
Cystic Fibrosis Foundation
Bethesda, MD