

CYSTIC FIBROSIS IN THE WORKPLACE

- The Questions
- The Needs
- The Solutions

Authors:

- Marianne Ferrin, CRNP
- Karen Cianci, RN, MHA
- Maureen Finnerty, RN, MN
- Gwen McDonald, RN, MS
- Thomas Smith, MD
- Staci Thrasher, MSW, LGSW

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Thanks to all,

A handwritten signature in black ink that reads "Marianne Ferrin". The signature is written in a cursive, flowing style with a long horizontal stroke at the end.

Marianne Ferrin, CRNP
Project Coordinator

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Introduction

People with CF are now living much longer and healthier lives than in years past. People with CF can now look forward to completing college or a technical training program, finding a job and developing a career. However, people with CF in the workforce have some unique issues and concerns. What issues should you consider when thinking about a job or career? Should you take a job or develop a career? What legislation is in place to help you? What should or shouldn't you say in an interview?

The purpose of this booklet is to present some of the issues pertaining to your employment.

Section 1: Issues Affecting Your Job or Career

Career choices should be based primarily on each individual's intellect, ability, interests and life goals. People with CF are not limited in choice of employment and enjoy success in a wide variety of professional, technical, clerical and blue collar jobs.

a. Job vs. Career

There may be times in your life when all you want or need is a job. A job is something that helps pay the bills and provides spending money. It is not something you plan to do forever. A career, on the other hand, is work that you could see yourself doing in ten years and that helps you develop both professionally and personally. Ask yourself which of these two options is right for you.

b. Part-Time Work

Many factors will influence whether you choose to work part-time or full-time. Consider the following:

1. Your daily self-care routine: How much time does it take to complete your daily treatments?
2. Your overall health: How often do you have an infection that causes you to lose time from work? Do you have other problems related to CF that could affect your ability to work? Is your lung disease mild, moderate or severe? If you don't know, ask your CF care team.

3. Your energy level: Are you able to push yourself or do you tire easily and need to limit your activities?

4. Your "coping" abilities: Do you cope easily with life and with the challenges of managing your disease or do day to day stresses get you down?

5. Access to health insurance: Part-time work often provides no health insurance (if you have a spouse with coverage, this may not be a problem).

Talk to your family and your CF care team about your career goals and ideas. They can guide you in the right direction. Also, government-funded **Vocational Rehabilitation** resources are available in all states and can provide job training and help in finding suitable work. You can find these offices by contacting your state agency of rehabilitative services or searching the internet. Sometimes talking with your CF social worker or a mental health counselor can help you manage the stresses of living with a chronic illness. This can make it easier for you to manage your work.

c. Self-Employment

Many people with CF prefer being self-employed as this offers more flexibility in work hours, allowing one to take time off whenever necessary. Being self-employed may also allow you to work from home.

Possible disadvantages of working for yourself include:

- lack of benefits, especially sick time and medical insurance coverage.
- the higher cost, and generally poorer coverage, of individually purchased medical plans (compared to group plans).
- no one to cover for you when you are ill, thus you may get behind in your work.
- no income during periods when you can't work.
- the tendency of people who are self-employed to work harder, longer hours than those who work for an employer.



Before deciding if working for yourself is best for you, consider the positives and negatives, and make sure to plan for times when you are ill.

d. Environmental Concerns

Whether you are applying for your first job, are a recent graduate of vocational school or college or are considering a career change, consider your work environment.

1. Look for work that will not expose you to irritants that could harm your lungs (e.g. smoke, fumes, dust, paints, allergens, volatile chemicals, auto exhaust). If you do choose a career that involves exposure to toxic fumes, make sure you use appropriate OSHA-approved respirators at all times. Avoid working in places that are frequented by people who smoke (e.g. bars, nightclubs).

2. Work involving toddlers and school-age children (e.g. day care workers, elementary school teachers) increases your exposure to upper respiratory viruses and may increase the frequency of CF infections. Similarly, some healthcare settings may expose you to potentially harmful bacteria that could infect your lungs.

3. Work requiring heavy manual labor (e.g. construction, landscaping) may have health benefits at first because physical work increases fitness and helps with airway clearance. But as pulmonary function decreases over time, such jobs may become too physically difficult. If you wish to pursue such a trade, look for a company that has the option of changing to a less physically demanding job in the future (e.g. moving to a desk job or supervisory position). This option is usually found in larger firms that are more likely to have job re-training programs and that are subject to federal protections such as the Americans with Disabilities Act. (See Section 5.)

4. Know your tolerance for stress. Jobs vary in their stress levels. For many people with CF, just managing the day to day demands of self-care can be a challenge. Careers that are fast-paced (e.g. Wall Street brokers), that require intense energy and concentration (e.g. air traffic controllers) or that have elements of danger (e.g. police work) may have more stress than you want.

5. Look for work that allows flexibility in hours, reduced hours, flexible use of vacation and sick leave benefits, additional paid or unpaid sick time and the option of working from home. For example, careers in computer technology lend themselves well to this kind of a flexible work schedule and alternative work setting.

6. Work involving close contact with others who may be at risk for cross infection (e.g. others with CF, people whose immune systems are damaged) is usually not recommended for people with CF because the organisms you carry in your lungs could be harmful to such people (e.g. working in a hospital).

7. With severe lung disease you will want to avoid high altitude work (e.g. airline pilots, flight attendants). Low oxygen in the air at high altitudes will cause the oxygen levels in your blood to drop too low.

8. Unless you have no lung disease at all, avoid jobs or activities that expose you to changing atmospheric pressures (e.g. flying airplanes, scuba diving). This is because people with CF may have **blebs** on their lungs, which can pop with changing air pressure, causing a dangerous air leak into the lining of the lung.

In summary, do not let CF prevent you from pursuing the career you want. Set career goals that will challenge you, make the most of your talents and make you happy, but use common sense and know your limits. Life is always changing, so be ready for changes in your career as your health changes. At each stage of CF, be the best that you can be, doing the work you want to do.

Section 2: The Interview

The day has finally arrived for your interview and you are prepared. You have evaluated the position and believe the job may be the right one for you. You are rested, have performed good mucous clearance, have eaten well and taken your enzymes. If you wear a medical alert bracelet you may consider taping it up on your arm or removing it. If you are particularly congested or not feeling well on the day of the interview, you may want to reschedule.

Put your best foot forward and be yourself. You know what questions need to be asked. Be confident about your abilities and be prepared to answer questions about yourself. Know the state and federal laws related to questions that can legally be asked of you (www.ada.gov or www.eeoc.gov). Once you have been offered the job, but before accepting, you should ask about the benefit package, sick/leave time and the possibility of working flexible hours.

Should you share your CF diagnosis at the interview? Generally, the answer is no. Sharing this information at the interview can put you and the company in a difficult

position. If you feel you can do the job as it is presented to you, your diagnosis should have no bearing. Most jobs have job descriptions which specify the physical requirements of the position. The decision to hire you should be based on your ability to perform the physical tasks of the job, not the diagnosis you carry.

If you need to provide references, make sure those persons do not mention that you have CF.

Be knowledgeable. Express confidence that you are the right person for the job. Good luck!

Section 3:

If or When to Tell Your Employer

To tell or not to tell? That is the question.

Now that you have been offered the job you must decide if you will disclose your diagnosis to your prospective employer. This is a very personal and important decision. You may want to talk through this decision with your CF care team, family and friends, and other patients who are already employed.

Three things to consider are:

1. Legally, you do not have to share your diagnosis with your employer. Most would discourage disclosure, especially throughout the interview process. For more information about your legal rights visit www.ada.gov or www.eeoc.gov.

2. Consider the severity of your illness. If you think you will need **accommodations** in order to perform your job responsibilities, you will need to disclose that you have CF after you are offered the job.



3. Timing is everything. Once you are offered the job you may disclose your medical condition should you choose to do so. If you disclose your CF during the interview and you do not receive an offer, it will be difficult to prove discrimination.

Section 4: Choosing Medical Coverage

Health insurance, including prescription benefits, is an important part of choosing a job. At the same time, it can be a confusing choice. When choosing a job, find out if there are choices between two or more health insurance plans. If so, you will want to get a copy of the plans (the Human Resources office may have a summary sheet for comparison). When deciding if a plan is right for you, consider the following:

- Does the plan allow you to see the doctor you want to see? You may need to ask your doctors if they participate with the plan: if they are “**in network**” or “**out of network**”? Your part of the payment (called a “**co-pay**”) for each visit may vary depending on this. (*See page seven for more about “co-pays”.*)
- Does the plan allow you to be hospitalized at the hospital of your choice? Once again, is your hospital “in” or “out” of network?
- Does the plan require a referral for specialist appointments? If so, you will need to choose a Primary Care Physician (PCP) who is “in network” and willing to give you these referrals for each visit to your CF team.
- Think about the health services you use. Does the health plan cover these things?



Make sure the plan covers drug benefits, equipment benefits (nebulizers, oxygen), and home intravenous antibiotic services. Find out what your co-pay is for each one.

- Find out what your responsibility is for the services you need and what the plan covers. Your responsibility is called a “co-pay” and “deductible”. Is there a yearly deductible that must be paid before the plan starts to help you with costs? Is that deductible a set dollar amount (and how much) or is it a percentage of charges?
- There is a big difference between a \$10 co-pay every month for a service and a 30% co-pay for a service that may be quite expensive. For example, if you are on a medicine that costs \$2000 a month, and your plan covers 70% of that cost, will you have to pay the other 30% (\$600) every month? Is there a maximum amount (“cap”) you are responsible for each year? Once you meet the cap, your insurance should pay 100% of the bill.

Ask about the co-pay for these services:

- Primary Care Physician visit
- Emergency room visit
- Hospitalization
- Prescriptions
- Specialist (CF team) visit
- Outpatient surgery
- Home IV Antibiotics

• Claims: Some insurance plans require that you submit paperwork to them in order for a service to be paid by the plan. Ask what you have to do in order for a medical bill to be paid by the insurance plan.

• Authorization for services: Some plans will only pay for services that have been authorized ahead of time (“prior authorization”). This will require that either you or your doctor call or fax a request for services before you get those services. For example, a hospital stay may not be paid unless the plan authorized that service ahead of time. Find out what the process is for this “prior authorization” to occur. Is it your responsibility or the doctor’s/hospital’s to get this approval?

• Limits: Many insurance plans will cover the services you need up to a certain lifetime dollar amount. Find out if there is a “cap” on what the plan will pay for the services you need. Is it a lifetime limit or a yearly limit?

• Cost: What will you have to pay for this plan? You will notice, as you compare plans, that the more things that are covered by the plan, the more the plan will cost you. You will want to compare the cost of participating in the plan (for example, a monthly payment to have this coverage) against the cost of the services you are getting. It often is in your favor to pay a higher monthly amount to receive more coverage.

Your Prescription Drug Coverage

Many employers offer a separate drug plan. Ask for the drug plan's formulary, or list of covered medications. You may find this on the plan's web site. Also, you will want to find out if there is a procedure for asking the plan to make an exception for drugs that are not usually covered (a non-formulary request). Many employers also offer an option to get drugs from a mail order company that gives a discount for a 3-month supply. There are several CF specific pharmacies that may offer better pricing.

Other Services

- Is there a dental or vision plan?
- Is Life Insurance or Disability Insurance offered? What is the cost?
- Are dependents covered? What is the cost?
- What is the phone number for the benefits specialist at this employer should additional questions arise?
- Does the insurance offer **case management**?

Section 5: Legal Protection

Since 1985 there have been many legislative changes that assist people with CF in the workplace. As you begin your career, it is important for you to know these laws and how they impact you. The following is a brief description of some of these laws. For more detailed information, talk to your CF center social worker.

- Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1986 – This law allows you to continue your insurance coverage for up to 18 months through your employer if your job is terminated or your hours are reduced. For more information on COBRA go to www.cobrainsurance.com.
- Americans with Disabilities Act (ADA) of 1990 – ADA requires that employers provide reasonable accommodations for people with disabilities who can perform the essential functions of the job. This means they must provide modifications that will enable you to perform your job functions. Some accommodations you may need to consider are a laptop computer to work while in the hospital, flexible working hours to accommodate your daily medical regimen, and disabled parking. If you are employed by a private employer who has less than 15 employees, you will not be protected from discrimination by the ADA. For more information about ADA visit www.ada.gov.

- Family and Medical Leave Act (FMLA) of 1993 – This act permits employees to take up to 12 weeks of unpaid leave during a 12 month work period for an illness or to care for a spouse or child with an illness. During this 12-week period the employer must continue insurance benefits. If you know you will be out for an extended period of time, you should contact your human resource manager or CF social worker to apply for short or long term disability. You may also be eligible for social security disability benefits or Supplemental Security Income. Your CF care center or social worker has The Advocacy Manual, A Clinician’s Guide to the Legal Rights of People with Cystic Fibrosis that has detailed information about these programs. For more information visit the Department of Labor website at www.dol.gov.
- Health Insurance Portability and Accountability Act (HIPAA) of 1996 – HIPAA ensures that you can change insurance plans when you have a change in employment. Also, with continuous coverage (no more than a 63 day lapse in coverage), it ensures that you will not have a waiting period for pre-existing conditions. For more information on HIPAA visit www.cms.hhs.gov.
- Ticket to Work and Work Incentives Improvement Act of 1999 – If you receive Social Security Income or Social Security Disability benefits, this law may allow you to work and continue some of your insurance benefits. It will also create a voucher, or ticket system, where you can gain rehabilitation and other services that will assist you in obtaining employment. Visit the Social Security Administration’s website at www.ssa.gov to see when your state began or will begin this program.



Section 6: Resources

Here are a few resources that we recommend:

Day-to-Day, Know Your Health Insurance Coverage.

Pamphlet published by the Cystic Fibrosis Foundation.
www.cff.org, 800-FIGHTCF.

The Advocacy Manual, A Clinician's Guide to the Legal Rights of People with Cystic Fibrosis. A guide for CF care centers.

Cystic Fibrosis Foundation: Visit their website at: www.cff.org, 800-FIGHTCF

A Consumer Guide for Getting and Keeping Health

Insurance. Information from the Institute for Health Care Policy and Research.
www.healthinsuranceinfo.net

The Human Resources benefits specialist at your place of employment.

Catch All The Sites. A comprehensive listing of important web sites related to CF.
www.digestivecare.com.

Cobra Insurance: www.cobrainurance.com

Americans with Disabilities Act: www.ada.gov

Health Insurance Portability and Accountability Act (HIPAA): www.cms.hhs.gov

Department of Labor: www.dol.gov, 866-4-USA-DOL

Social Security Administration: www.ssa.gov, 800-772-1213

Equal Employment Opportunity Commission: www.eeoc.gov, 800-669-4000

If you need more information about these resources, see your
CF care center social worker.

If your employer requests information about CF, refer them to the Cystic Fibrosis Foundation website at www.cff.org and check out the "Living with CF" and "About CF" links.

Section 7: Glossary of Terms

- **Accommodations** - Changes in your work environment, schedule or role that allow you to fulfill your job responsibilities.
- **Bleb** - An air bubble or cyst in the lung.
- **Case Management** - The coordination and facilitation of all aspects of your healthcare program.
- **Co-pay** - A cost sharing arrangement when you pay a specific charge for a specific insurance.
- **Deductible** - The annual amount you have to pay before insurance pays your healthcare costs.
- **“In Network”** - Services covered by your insurance policy.
- **OSHA** - Occupational Safety and Health Administration – a Federal government agency. www.osha.gov, 1-800-321-6742
- **“Out of Network”** - Services partially or not covered by your insurance and which may need special approval.
- **Vocational Rehabilitation** - A government program that assists in guiding people with disabilities in obtaining employment. They can help with training or funding for college.

NOTES



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