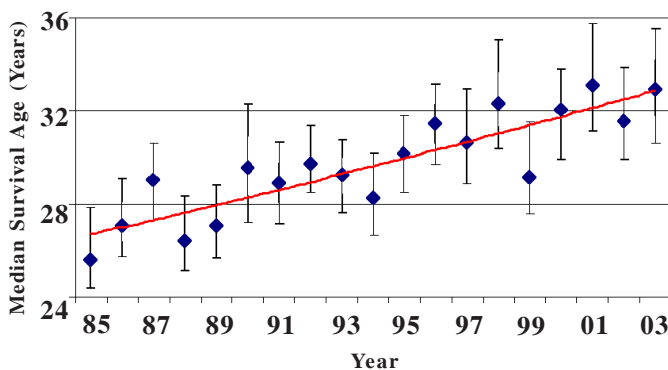


## It's All About Suzy: Quality Improvement in CF Care

It is all about Suzy. She has many friends, is active in sports and dreams of being an astronomer. She gets up in the morning, takes her aerosol treatment, does airway clearance, eats a high-calorie breakfast, takes her medicine and leaves for school. Suzy represents every person with cystic fibrosis (CF). We want Suzy to achieve her life goals: an education, career, a family, and a long and healthy life.

Since the 1950s, CF care has continually improved. In the 1960s, the CF Foundation started its Care Center Network to provide the framework for consistent standards of care for people with CF across the United States. Advances in the formulation of pancreatic enzymes, the change to high-fat diets, new pulmonary treatments, screening and treatment for CF-related diabetes, and many other changes in clinical care, have improved life expectancy and quality of life for people with CF. Despite these successes, much work still needs to be done. The CF Foundation is committed to the vision of *exemplary* care at all CF care centers to further extend quality and length of life. *Concepts* of *quality improvement* are being applied to reach this vision of exemplary CF care.

**Median Predicted Survival Age, 1985-2003**  
(with 95 percent confidence bounds)



What is quality improvement (QI)? What does it mean for Suzy? In 2001, the Institute of Medicine published a report on how to improve the quality of healthcare in the United States. Brent James, M.D., M.Stat, a professor at University of Utah and co-author of the report, defines quality improvement as “the science of *process* management.”

Process management involves knowing what happens in each step of the process, how the steps *interrelate*, the *human factors* - including normal *variation* - and a way for learning to continue. In simple terms, QI is using a scientific approach to look at and improve the process of clinical care using teamwork and leadership. For Suzy, QI may be working with her care center to better organize clinic visits. So, Suzy would come to clinic ready to ask her questions and the care team would meet before clinic so they know what is to be done for her. Both Suzy and the care team would work together to make sure she gets the care she needs.

### THE GOOD NEWS ABOUT CF CARE

The good news is that CF care is always improving. The increasing life span from the CF Foundation’s Patient Registry is proof of consistent improvement. However, in 2002, the CF Foundation began work to speed-up the rate of improvement. It started with goals being set and a plan of how to reach them being developed. All seven QI goals, set by the CF Foundation, are listed in the box titled “CF Foundation’s Goals for Quality Improvement” at the end of this section. Also, you can read the *CF Foundation Patient Registry Annual Data Report* on the CF Foundation’s Web site ([www.cff.org](http://www.cff.org)) for more information.

### Goals & Plan:

1. *People with CF and their families are full members of the care team.*

Communication is a two-way street. The doctors, nurses and the rest of the care team listen to Suzy’s concerns and answer questions. She and her family need to openly communicate with her CF care team. This includes information about what care Suzy receives at home. In return, her care team must clearly tell Suzy what her treatment options are and make sure she understands the benefits and risks of each option. It is important that Suzy and her family actively participate in healthcare decisions based on the healthcare team’s recommendations. This sharing and discussion of treatment options with the CF care team creates a plan that everyone agrees to for Suzy’s CF care.

Since the early 1990s, the CF Foundation has developed

- Words that appear in *bold italic* are defined at the end.
- All referenced Web sites are at the end.

care guidelines for people with CF (see Table 1). These guidelines for CF care include four or more clinic visits and at least two pulmonary function tests (PFTs) per year. According to the 2003 *CF Foundation Patient Registry Annual Data Report*, only 64.2 percent of children and 49.5 percent of adults had four or more clinic visits in 2003. A first step in improving care is to make sure you or your child visit the CF care center four times a year and get the recommended tests.

TABLE 1

Guidelines for CF Care and Percentage of Children and Adults Who Meet Guidelines		
Clinic Visits — 4 or More Per Year	(C) 64.2	(A) 49.5
Pulmonary Function Tests — (PFT) 2 or More Per Year	(C) 82.6	(A) 76.8
Respiratory Cultures — At Least 1 Per Year	(C) 94.4	(A) 87.7
Glucose — Every Year if ≥14 Years	(C) 77.6	(A) 70.9

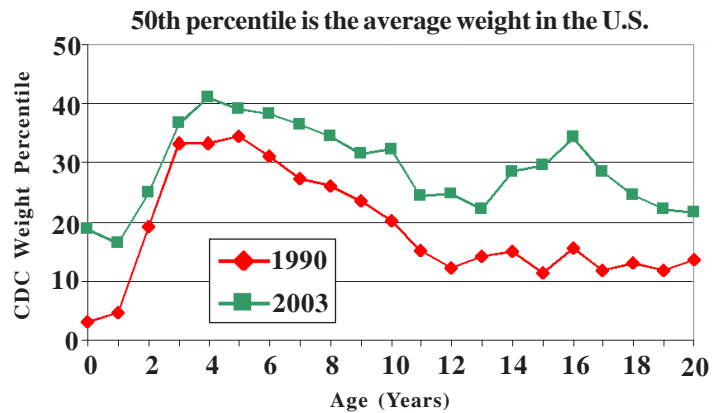
Ongoing learning about CF is also important. As Suzy gets older, she will need to take more responsibility for her care. Learning more about CF and her increasing responsibility will help prepare Suzy to move away from home. Her doctors, nurses, dietitian, therapist and social worker also need to learn more about the latest therapies and research, then decide if this information might help Suzy. This learning will help Suzy, her family and CF care team talk about, and agree on, her CF healthcare. This and other written information, Virtual Patient Education Day Web casts and the yearly medical CF conference are examples of how the CF Foundation is working to support ongoing learning in the CF community.

2. *Children and teens will have normal growth and good nutrition. Adults' nutrition will be maintained as near to "normal" as possible.*

There is a link between good nutrition and survival. Progress has been steady in improving the nutrition of children with CF. However, according to the 2003 CF Foundation Patient Registry, the weight of children with CF is still below the average U.S. population. For Suzy, we want her to grow at the same rate as others her age.

To help Suzy, the CF Foundation is working to provide guidelines to the care center teams so that they can continue to improve nutrition care in CF. One part of this work is a regular review of new information published in the medical literature. This information will be put into easy-to-use guidelines for CF care centers and the CF community.

### Median CDC Weight Percentiles vs. Age, 1990 and 2003



3. *Everyone with CF will receive the right therapies to keep lung function steady and to decrease the number of pulmonary exacerbations or respiratory infections.*

The goal of every person with CF and their healthcare team is to keep the lungs as healthy as possible. There are a number of therapies now available. Some care centers use these therapies differently than others. For example, one care center may recommend chest physical therapy, sometimes called “clapping,” for airway clearance. Another center may recommend a mechanical device such as a vest. There are many reasons for these variations between care centers. The CF Foundation is working to find out if these variations in practice make a difference in the *clinical outcomes*. However, just doing airway clearance regularly may be more important than exactly how or what device is used. For Suzy, her family and CF care team, they need to work together to find a way that she will do airway clearance every day and fit it into her busy life. This simple therapy may help Suzy avoid pulmonary exacerbations, improve her health and clinical outcomes.

You can learn more about the CF Foundation’s goals for quality improvement by reading the *CF Foundation Patient Registry Annual Data Report*, available in the publication section of the CF Foundation’s Web site ([www.cff.org](http://www.cff.org)).

**CF Foundation's  
Goals for Quality Improvement:**

- People with CF and their families are full members of the care team. Communication will be open so everyone can be involved in decisions about care. Care will be respectful of patients' needs, preferences and values.
- Children and teens will have normal growth and good nutrition. Adults' nutrition will be maintained as near to "normal" as possible.
- Everyone with CF will receive the right therapies to keep lung function steady and to decrease the number of pulmonary exacerbations or respiratory infections. Exacerbations will be diagnosed early and treated appropriately.
- People with CF and care teams will work together to eliminate the chances of patients getting respiratory pathogens or germs, particularly *Pseudomonas aeruginosa* and *Burkholderia cepacia*, in the hospital, clinic and home.
- People with CF will be closely monitored for complications of CF, especially CF-related diabetes (CFRD). For any complication, prevention and early treatment when possible should be the approach.
- Everyone with CF will be able to receive appropriate therapies, treatments and support regardless of race, age, education or insurance coverage.
- Everyone with CF will be supported by their CF team when making decisions about transplantation and end-of-life care.

## WHAT YOU CAN DO!

The CF Foundation and care centers are working hard to improve healthcare quality. You can help too. You can take steps to improve the quality of your or your child's healthcare. Research has shown that if you are more involved in your healthcare, you can get better results and feel more satisfied with that care. Here are some simple things you can do:

- **Ask questions**, and keep asking them until you understand the answers. Many people are involved in your or your child's care. So, talk with your CF care team often and get your questions answered.
- **Tell your CF care team about all of the medicines you take.** Be sure to include nutritional supplements, herbal supplements, over-the-counter drugs, vitamins and prescription drugs from other doctors or previously prescribed at your care center.

- **Read the label on your prescription** when you get your medicine. Make sure you are getting what your doctor ordered. For example, is it the right brand of enzymes?
- **Work with** your CF healthcare team to make decisions about your or your child's healthcare.
- **Know that "more is not always better."** Be sure to find out why you need a test or treatment and how it can help you.
- **When you or your child has an X-ray or laboratory test**, do not assume that "no news is good news." Ask when and how you will receive the results. Will it be in person, by mail or by phone? If you do not receive the results when you expect them, contact your CF care team and ask for them.
- **Ask your CF care team what the *scientific evidence* has to say** about CF and treatment options. You can find more information on the CF Foundation's Web site ([www.cff.org](http://www.cff.org)) or from PubMed, a service of the National Library of Medicine with more than 15 million medical and research documents ([www.ncbi.nlm.nih.gov/entrez/query.fcgi](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi)).

## QUALITY OF CARE

More public and private groups are developing and using *quality measures* and reports. One quality measure is *accreditation*. This is a "seal of approval" given by a private, independent group. CF care centers are accredited when they meet the standards of clinical care, research and teaching as set by the CF Foundation. To learn more about these standards, ask your CF care team or contact the CF Foundation.

The CF Foundation also has a plan to measure how well the QI goals (see box in left hand column) are being met at CF care centers. The CF Foundation's Patient Registry is one way the goals are being measured and reported. These goals are not just words or ideas; rather, they are real and measurable.

The resources section of this pamphlet has more information about accreditation and quality measures. You can also ask your CF care center, hospitals, or home care companies about their quality improvement work.

## CHOOSING QUALITY HEALTHCARE

Here are some tips for including quality in your healthcare decisions. Such decisions involve CF care centers, treatments, health plans and you.

### Look for a CF care team who:

- Has received accreditation by the CF Foundation;
- Is working to improve the quality of care they provide;
- Has the training and experience to meet your needs;
- Takes steps to prevent illness — for example, will talk to you about getting the screening tests or is working to avoid the spread of germs;
- Will work with you to make decisions about your or your child's healthcare;
- Can get you or your child admitted to, or treated at, a hospital with experience in caring for CF;
- Will partner and communicate with your primary healthcare provider;
- Is part of your health plan.

### When choosing a treatment, make sure you understand:

- When and how soon problems need to be treated;
- Your treatment options;
- The benefits and risks of each treatment;
- The costs of each treatment;
- Whether the treatments are based on the latest scientific evidence.

### Make sure you have a health plan that:

- Allows you to use an accredited CF care center;
- Allows you to use a pharmacy and hospital familiar with CF care;
- Provides the benefits (CF medicines and covered services) you need;
- Provides services where and when you need them;
- Does a good job of helping people stay well and get better;
- Has been given high ratings by its members on the things that are important to you.

To learn more about choosing a health plan or insurance, read “Day-to-Day: Know Your Health Insurance Coverage” available from your CF care center or on the CF Foundation's Web site.

The CF Foundation's mission is to find a cure and improve the quality of life for people with CF. Quality improvement is all about Suzy and keeping her healthy so she can reach her life goals. It will take everyone working as a team to improve her CF healthcare and quality of life.

## GLOSSARY

**Accreditation:** A “seal of approval” that shows an organization meets national standards.

**Clinical outcomes:** Results of a person or group's health based on a measurement. For example, gaining weight is a clinical outcome of eating.

**Concepts:** Ideas or abstract thoughts.

**Exemplary:** Excellent; worthy of confidence.

**Human factors:** What each person involved brings to a project or situation, which varies with each person.

**Interrelate:** To work together.

**Process:** A series of actions or steps that lead to an end point or conclusion.

**Pulmonary exacerbations:** Signs and symptoms of an infection in the lungs.

**Quality improvement:** Using a scientific approach to look at and improve the process of clinical care using teamwork and leadership.

**Quality measures:** How a person knows if healthcare is getting better, worse or remains the same.

**Scientific evidence:** Information that is proven through independent research and study.

**Variation:** The differences between items or measures.

## RESOURCES

The more you know about CF and its treatment, the more likely you are to get the best possible care and clinical outcomes. You can find more information on the Internet. Most local libraries have computers you can use and staff that can help you learn to search the Internet. The following are some resources:

### CF Care & Insurance:

- The CF Foundation has information about CF, how to find CF Foundation-accredited care centers, the latest in research and current clinical trials ([www.cff.org](http://www.cff.org) or **800 FIGHT CF**).
- *CF Foundation Patient Registry Annual Data Report* has information about current clinical outcomes in CF ([www.cff.org/publications](http://www.cff.org/publications)).

- CF Services, Inc., a national mail-order pharmacy and subsidiary of the CF Foundation, can help you get prescription drugs ([www.cfservicespharmacy.com/](http://www.cfservicespharmacy.com/) or **800-541-4959**).
- “Day-to-Day: Know Your Health Insurance Coverage.” Visit the CF Foundation’s Web site - [www.cff.org](http://www.cff.org) - or contact **800 FIGHT CF** or [info@cff.org](mailto:info@cff.org) to get a copy of this pamphlet.
- Institute for Family-Centered Care works with healthcare organizations to involve patients and families in healthcare ([www.familycenteredcare.org/homepage.html](http://www.familycenteredcare.org/homepage.html)).
- Medline Plus a service of the U.S. National Library of Medicine and the National Institutes of Health has information about CF ([www.nlm.nih.gov/medlineplus/cysticfibrosis.html](http://www.nlm.nih.gov/medlineplus/cysticfibrosis.html)).
- PubMed, a service of the National Library of Medicine, has more than 15 million medical and research documents ([www.ncbi.nlm.nih.gov/entrez/query.fcgi](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi)).

#### Accreditation:

- Joint Commission on Accreditation of Healthcare Organizations (JCAHO) evaluates and accredits hospitals, healthcare networks and managed care organizations. For information, visit Quality Check at [www.jcaho.org/qualitycheck/](http://www.jcaho.org/qualitycheck/) or call **(630) 792-5000**.
- Community Health Accreditation Program (CHAP) evaluates and accredits home healthcare organizations. To find out more, call CHAP at **800-669-9656, ext. 242**, or visit CHAP’s Web site ([www.chapinc.org/chap-consumer.htm](http://www.chapinc.org/chap-consumer.htm)).

#### Quality: Reports and Measures

- *Improving Health Care Quality: A Guide for Patients and Families* - [www.ahrq.gov/consumer/qntlite/](http://www.ahrq.gov/consumer/qntlite/).
- Institute of Medicine serves as an adviser to the nation to improve health. The IOM wrote Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century ([www.iom.edu](http://www.iom.edu)).
- For quality reports about Medicare managed care plans, call **800-MEDICARE**, or look for Medicare Compare at [www.medicare.gov](http://www.medicare.gov).
- Fact sheets and other information on healthcare quality are available in the “Quality Assessment” section of the Agency for Healthcare Research and Quality (AHRQ) Web site ([www.ahrq.gov/](http://www.ahrq.gov/)).

#### DISCLAIMER

We have listed several organizations, Web sites and phone numbers here to help you find out more about healthcare quality. This information is provided only as a service to readers and does not imply endorsement or promotion by the CF Foundation of these organizations, any products or services they offer, or any groups they may link with through their Web sites.

#### Internet References:

- *Improving Health Care Quality: A Guide for Patients and Families*. AHRQ Publication No. 01-0004, October 2000. Agency for Healthcare Research and Quality, Rockville, MD. [www.ahrq.gov/consumer/qntlite/](http://www.ahrq.gov/consumer/qntlite/)