



Cystic fibrosis care is complex and often requires intensive daily treatments, as well as regular visits to an accredited specialized CF care center to maintain health and well-being. **MAINTAINING AFFORDABLE, ADEQUATE, AND ACCESSIBLE HEALTH COVERAGE IS CRITICAL TO LIFE WITH CF.**

COST CHALLENGES

OUT-OF-POCKET COSTS

45% of people with CF spend **\$5,000 or more** annually in out-of-pocket costs for copayments, coinsurance, and non-covered services

PREMIUMS

About **a third** of people with CF pay **\$10,500 or more** a year for premium expenses.

HOSPITALIZATIONS

45% of people with CF have experienced **two or more hospitalizations in the past 12 months**, compared to 1% of the U.S. population

DELAYS IN CF CARE

Over a 12-month period, **58%** of people with CF reported delaying or forgoing care due to cost

COVERAGE

Because of health care reform, health insurers cannot:

- Deny coverage of a pre-existing condition
- Exclude services related to a pre-existing condition
- Charge more for a pre-existing condition
- Impose annual and lifetime limits

Medicaid

More than half of children and a third of adults living with CF rely on Medicaid coverage for some or all of their health care needs.

- Medicaid serves as a payer of last resort
- Medicaid fills important gaps in private health insurance plans



CONGRESS MUST ENSURE:

- *Pre-existing conditions protections remain intact*
- *Medicaid eligibility and benefits are protected for people with CF*