

Cystic Fibrosis Information Sheet

Cystic fibrosis (CF) is an inherited disorder that causes severe damage to the lungs and digestive system. Cystic fibrosis affects the cells that produce mucus, sweat and digestive juices. As a result, these fluids are thick and sticky, rather than thin and slippery. They plug tubes, ducts and passageways, especially in the lungs and pancreas. Although cystic fibrosis requires daily care, most people with the condition are able to attend school and work, and have a better quality of life than in previous decades. Recent improvements in screening and treatments mean that some are living into their 40s and 50s.

Symptoms

In some children, symptoms begin during infancy. Other people first experience symptoms in adolescence or adulthood. Symptoms may include:

- Higher-than-normal level of salt in sweat
- Persistent cough that produces thick spit (sputum) and mucus
- Wheezing
- Breathlessness
- Repeated lung infections
- Inflamed nasal passages or a stuffy nose
- Poor weight gain and growth
- Severe constipation

Treatment

The goals of treatment are preventing and controlling lung infections, loosening and removing mucus from the lungs, preventing and treating intestinal blockage and providing adequate nutrition. Methods include medications, chest physical therapy, pulmonary rehabilitation, lung transplant and feeding tube.

Educational Implications

Frequent and/or extended absences may require re-teaching, tutoring and/or homebound instruction. A student may need support in dealing with the chronic illness, acceptance by peers and self-image.

Educational Options

Those students whose cystic fibrosis adversely affects their educational performance may benefit from special education under the Individuals with Disabilities Education Act (IDEA). To qualify under IDEA, a student must meet eligibility criteria in one of thirteen specific disability categories. Under IDEA, a student with a disability is entitled to a free appropriate public education (FAPE) and an individualized education program, including individual goals, objectives, related services, accommodations and modifications.

Students that do not qualify for services under IDEA may qualify under Section 504 of the Rehabilitation Act. To qualify under Section 504, a student must have a physical or mental impairment that substantially limits one or more major life activities (for example learning, breathing, thinking, concentrating, walking, bodily functions). Under Section 504, a student is entitled to equal opportunity, and may qualify for a Section 504 plan that provides regular or special education and related aids and services.

A student with a health condition who does not require special instruction and related services can receive, as appropriate, a wide range of supports in the general education classroom, including accommodations, individualized health plans (IHP), emergency care plans (ECP) and local education agency supports.