Cystic Fibrosis

Cystic fibrosis (CF) is Australia's most common life-shortening genetic condition, with one in 25 people being carriers. Thick mucus in the lungs and digestive system leads to infections, lung damage, and digestive issues. Daily physiotherapy and medications are vital. Cross-infection risks keep people with CF apart. While CF presents unique challenges, treatments offer hope, and students with CF show remarkable resilience and determination.

School absence patterns

- Four annual clinic visits require day-long appointments
- Hospital stays for IV antibiotics can last multiple weeks
- Frequent absences result from infection vulnerability and sick days
- Overall, children with CF have higher absence rates than their peers

Challenges for students

- Managing 1–2 hours daily of airway clearance and physiotherapy
- Avoiding school infections, which can lead to hospitalisations
- Limited ability to meet peers with CF due to cross-infection risks
- Self-advocacy across multiple teachers in high school
- Potential embarrassment around coughing
- Balancing social life and CF confidentiality

Challenges for families

- Extensive caring responsibilities and hospital admissions disrupt family life, also affecting siblings
- The cost of treatments, equipment, and time off work creates financial strain
- Studies link higher financial stress to poorer health outcomes
- Siblings may face anxiety or disrupted schooling

What schools should know

- Coughing is a vital part of clearing mucus and is not contagious
- CF is often invisible; respect privacy if students prefer not to disclose
- Cross infection is a real risk for people with CF, so two people with CF should not be in the same physical setting. Online interactions and resources can help reduce isolation
- Basic promotion of hygiene at school, like hand washing, coughing into elbows, and staying home if unwell, is essential for protecting vulnerable students
- Individual Learning Plans (ILP) help students manage absences, remote learning, and assignment flexibility
- Consider a health and safety plan alongside the ILP
- Pancreatic enzymes (Creon) may be kept with responsible students for self-administering, as they pose minimal harm to others

MISSING SCHOOL

Health condition

- Sticky mucus in lungs and digestive system causes infections, lung damage, and digestive problems
- Insufficient pancreatic enzymes hinder nutrient absorption, causing weight issues
- Fatigue, dehydration, high salt in sweat are common
- Cross-infection risk prevents contact among people with CF
- Reproductive issues may arise in adulthood

Student population

1,586 children under 18 live with CF, comprising **42% of Australia's CF population**

Among them, **1,137 are aged 6–17** as of 2023

Slightly **more than half of Australians with CF are now adults,** reflecting improved life expectancy

One in 25 Australians carry the CF gene

"For those who are really unwell, it can be really difficult to catch up on work and assignments. And even for those who haven't necessarily had as many absences, just managing their daily treatments on top of schoolwork can be really challenging."

CF Together

An Australian organisation supporting families affected by CF, providing advocacy, education, research funding, and services to improve treatments and quality of life.

www.cftogether.org.au