

# No day off from CF

## Report

May 2024

**Cystic fibrosis is a life-limiting, genetic condition without a cure. It dominates thousands of lives every day. You never get a day off when you have CF.**

In order to stay well, people with cystic fibrosis face a relentless treatment burden, from taking up to 150 tablets every day, monthly hospital check-ups to following special high-calorie diets and daily exercise and respiratory physiotherapy.

This is alongside any hospital admissions or routine appointments. Failure to maintain this rigorous daily routine can lead to serious health declines.

### **Preliminary data from our 2024 'Your Life and CF' report**

This early data from our latest 'Your Life and CF' report reveals the stark burden that people with CF are facing on a daily basis. The physical and mental burden of living with a chronic condition can take a large toll.

**Most people with CF take more than 30 tablets a day, the most tablets reported per day was 150.**

Despite advances in care for many the burden of care remains high, people with CF and their families have to manage a complex regime of medications and therapies every single day. Recent surveys of the CF community have identified simplification of treatment burden as a key research priority, despite this many people with CF are still experiencing a high level of daily burden. This burden can extend to caregivers, resulting in stress for the whole family.

**1 in 3 worried about their physical health every day.**

And

**79% said in the last 12 months their physical health had prevented them living life to the fullest.**

Physical health is an ever-present worry for people with CF. Effectively managing it requires daily intervention and can prevent day to day activities.

This has a knock-on effect for people with CF and their families mental health.

**90% of respondents were worried about the future, 43% were worried every day.**

**Improvements over the past 60 years have made life better for many, but as old problems diminish, they can bring new challenges and fears.**

**And there's still no cure. That's why we won't stop until CF does.**

[cysticfibrosis.org.uk](https://cysticfibrosis.org.uk)

"I struggle with having an active social life, I work really hard to maintain a good job and all of my treatments that I'm exhausted by the weekend."

Person with CF

"I don't really have any hopes for the future at the moment it's borderline constant panic/worry about my health and the effect on my loved ones."

Person with CF