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Today we are sharing Ross' story about his experience living with cystic fibrosis (CF). Our thanks to Ross for boldly sharing this with us.

My name is Ross. I was 30 years old when I was first diagnosed with CF. Prior to my diagnosis, I did not lead the typical life of a person with CF. I didn't feel any effect from CF in my early life. I did not have any lung capacity or gut issues. The only clues were some sinus issues in my late teens and a couple of chest infections in college that took me a couple of weeks on antibiotics to recover from. Even after diagnosis, I went along feeling "like a normal non-CFer" until I was around 51, and then my lung capacity fell off a cliff and gut issues kicked in - too late.

Don't get me wrong, I was doing most things right. I have been active as a plumber and played sports all my life, along with following prescribed medications and treatments since I was diagnosed, even though I often thought all this was overkill for me. Fast forward to the present day, I find myself in my early 60s, having been reliant on oxygen to exercise for 2 years and now fully reliant on oxygen and on the wait list for a lung transplant.



I don't have a F508del mutation, so I am ineligible for Trikafta, and I figured it probably wouldn't work for me anyway. Fortunately, however, my clinical team worked hard to gain me access, and the hospital has compassionately funded my access to Trikafta, it has turned my life upside down over the past 7 weeks.

I honestly can't believe Trikafta works as well as it does for me; I would love to meet and shake the hands of the scientists who created Trikafta. Thanks to their dedication to finding this treatment, I can walk around without being tight in the chest, I can exercise without coughing as much, I have a better appetite, I am working out harder in the gym and gaining muscle mass. I am happier and healthier in my own mind because the steady decline in lung capacity has been stopped for now, and I feel like I can build up strength for recovery from a lung transplant.

If I could go back, I would tell my former self to get onto Trikafta if you possibly can, because you don't know what is going to happen in the future. My advice would be to ask for access to Trikafta, even if you have a rare gene type and are currently considered ineligible. By the current guidelines, I am ineligible, but I am taking it, and it is positively changing my life.

Also, remember to follow the guidance provided by your clinical team to ensure you are taking care of your health. I have learnt the hard way, but keeping on top of your maintenance really does help keep you feeling your best, even when you're fortunate enough to be taking Trikafta.

I am told I may play squash again after transplant, and I can't wait to get my bike back on the road. Who knows, we "CFers" may live until 81! So, we should start planning our lives like everyone else would!