

Tim Wotton

Gone but not forgotten

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Occasionally something will come from leftfield, stop you in your tracks and cause deep emotion and reflection. I had one such moment recently which I want to share with you...

I was in St. James Park, London, relaxing in the autumnal sunshine during a break from work, when I noticed on a Facebook forum a trailer for a film documentary about the amazing Mallory Smith, who lived life to the fullest while battling cystic fibrosis (CF)*.

Before she died, aged only 25, Mallory gave her mum the password to her video journals chronicling how she felt during her life-long struggle with the condition. A film has been produced from these journals, called 'Salt in my Soul'.

I sat there watching and re-watching this short trailer with tears running down my face, seemingly frozen in time, with flashbacks of how I felt on many occasions battling the same illness for 50 years.

It brought back some dormant feelings that I had not properly felt for the last 15 months due to the positive impact of the ground-breaking drug Kaftrio.

Before starting Kaftrio in September 2020, I really was on a steep health decline with failing lung function and reduced energy. My quality of health was very poor.

I have little doubt that I would've started using oxygen and been added to the lung transplant list, with all the risks of finding a donor, organ rejection and death.

Back then, I was up for at least an hour every night coughing like a demon, using a towel across my mouth to suppress the barbaric noise, so as not to wake my wife Katie and son Felix.

The 'end' was on my mind more often than not; magnified by the huge dip in my health in early 2020 and the deaths of other CF friends around the world.

Thinking about how I would say goodbye to my family and loved ones was too tough to imagine so I fought it off with positive thinking, mindfulness, meditation practices and clinging onto hope for a new drug to 'rescue me' from the hell that was enveloping me.

In the sporting world, it's common to say that it's 'the hope that kills you' but in my worrying situation, it was 'the hope that kept me alive'!

Since taking Kaftrio and having gone through the purge (of clearing the mucus from my lungs for a few months), I now hardly cough at all, which is amazing and surreal. Plus, I have more energy. I can play my beloved field hockey again and now play in a team at weekends with my son Felix!

My sleep is better (despite snoring, which is a side effect of Kaftrio) and I have no more need for that towel by my pillow at night to suppress the coughing fits. Indeed, my quality of life has improved beyond expectation.

The drug cannot fix all the years of lung damage but what its given me is worth its weight in gold.



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The person I was before Kaftrio and the very real concerns of my impending demise are currently out of sight but they are most definitely not out of mind. Watching that film trailer reminded me of that in no uncertain terms.

My feet are staying firmly on the ground. I don't take any of the recent days of better health for granted.

More than ever, I know that life is impermanent. My health could still revert back to how it was because we don't know how long the positive effects of this new drug will last.

I want to honour the memories of my CF friends and angels like Mallory who sadly were unable to benefit from Kaftrio but deserved to, just as much as me.

I appreciate that every single day is a blessing – a gift with abundant possibilities. I'll make sure to make the most of this new beginning, however long it lasts.

This post is dedicated to my CF friends who have passed away who are also gone but not forgotten.

Wishing you all a wonderful festive holiday and healthy 2022!

If you watch one thing today > [‘Salt in my Soul’ film trailer](#). The film will be available on streaming services from late January 2022.

I will keep you posted on my life-affirming moments, trials and tribulations as and when they happen. Please keep reading and sharing my blog and sign-up (on the right-hand side tab) if you have not already done so.

Yours cup half full.

Tim

Tim Wotton (author of Award-Winning CF Memoir [‘How have I cheated death?’](#))

* Cystic Fibrosis is one of the UK's most common life-threatening inherited diseases, affecting over 10,500 people. The condition affects the internal organs, especially the lungs and digestive system, by clogging them with thick sticky mucus. This makes it hard to breathe and digest food. Each week, five babies are born with the condition, however, each week, three young lives are also lost to it. There is currently no cure for CF. However, existing gene therapy trials in the UK are bringing people with the illness closer to a form of cure but CF is not that well known and would benefit from more public donations. For more information and to find out more view the [CF Trust Website](#).