

Born in Southampton in 1971, Tim has lived in South London for the last twenty years and is married to Katie with a son Felix. A first-time book writer, Tim is a full-time communications manager and has played field hockey all his life. His eyes and heart have been opened by his health struggle with cystic fibrosis which has been a huge factor in his life, but not one that defines it.

HOW HAVE I
CHEATED DEATH?

A SHORT AND MERRY LIFE
WITH CYSTIC FIBROSIS

For my parents Margaret and Douglas, brothers Chris
and Jez, wife Katie and son Felix.

Tim Wotton

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Foreword

I was touched to be asked by Tim Wotton to write an introduction to his book. He writes beautifully with such honesty, clarity and humour. His blogs marking the year leading to his 40th birthday have had a huge following. For those affected by cystic fibrosis (CF) he gives hope, and for those who don't know about CF his words are inspirational, making us aware how much we can achieve and enjoy whatever problems arise.

I first knew about CF 34 years ago when my niece Rachel was diagnosed with the disease. We discovered that my brother Jonathan and sister-in-law Caroline were both carriers of the CF gene. Rachel was their first child and it took a few months of tests to discover why she was not thriving and putting on weight as she should have been. It was a very worrying time. We were unaware of anyone in the family having CF so knew nothing about it, and were shocked to hear that Rachel had a genetic, life-threatening disease. Back then, few children with the condition survived into their teens.

I was living in the United States whilst Rachel was growing up, and was unaware of the day-to-day routine that Caroline and Jonathan went through to maintain Rachel's health. The daily physiotherapy, the mountain of pills, the constant nagging fear that a cold or flu or some virus that affected the lungs would take hold and reduce her ability to breathe. I have vivid memories of her long stretch in hospital when she was about nine years old (for someone with CF, going to hospital is hardly ever for a short period of time.) Rachel had a terror of needles so the intravenous medication was a nightmare for her. I am filled with admiration for the way that Jonathan and Caroline encompassed all that was necessary to keep Rachel healthy and still managed to maintain a normal family life. Rachel was followed by a brother and another daughter, neither of which have CF.

Watching Rachel grow up, it was obvious that being a teenager with CF was a huge burden and responsibility. Just when a young person wants to fit in with their peers and be accepted they have to acknowledge their frailty, take masses of medication and spend time doing physiotherapy to make sure that they are keeping their lungs as fit as possible. Motivating teenagers is not an easy task, so imagine trying to persuade a fifteen year old to get up early so that they can do a regime of exercise, take a cocktail of drugs, have their breakfast and then go off to school. Once home in the evening, homework has to be done, and there's no time to watch TV as more physiotherapy needs to be done. And this is not for a short period of time; this regime is necessary every day, for life. It's never-ending and relentless.

This all happens against a backdrop of misunderstanding about CF as it's not that well known to the general public. Anyone with the condition constantly has to interpret their symptoms to strangers – coughing fits in the public domain have to be explained, often using humour to dissolve difficult predicaments: “Yes sorry about the cough, it will be the death of me!”

Only half of those with CF will make it beyond thirty, so a 40th birthday is an enormous milestone. For most of us, it is impossible to understand what it must be like when you can't take life for granted. I gained some level of insight when I starred in the film ‘Logan's Run’, which portrayed a twenty third century world where no one was allowed to live beyond the age of thirty. Of course, it's real life that is perpetually put in doubt for the likes of my niece Rachel, and Tim, who have been told that they were unlikely to reach twenty, thirty or even forty years of age.

Reading this book brings us closer to understanding how precious each day is. Rather than looking too far into the future for our hopes, it's crucial to enjoy the here and now because life can so easily be cut short.

Tim Wotton's brilliant book follows his personal struggle with CF; the day-to-day frustrations and anxieties, alongside his survival strategies, all underpinned by the absolute joy of

defying the odds and living life to the full. For anyone affected by CF or facing any form of life challenge this is a compelling and heartening story. For everyone it offers hope and inspiration. I celebrate with Tim his unlikely but triumphant 40th birthday and wish him all the best for the next forty years!

Jenny Agutter
Cystic Fibrosis UK Patron

Preface

At birth in March 1971, I was diagnosed with the life-threatening illness cystic fibrosis (CF) and not expected to live much past my teens.

CF is a serious genetic disorder with reduced life expectancy. It is caused by mutations in the cystic fibrosis trans-membrane conductance regulator (CFTR) gene, which regulates the production of mucus, sweat and digestive enzymes. For a person to have CF, both his or her parents have to be carriers of this mutated CFTR gene. The name cystic fibrosis refers to the characteristic scarring (fibrosis) and cyst formation within the pancreas, first recognized in the 1930s.

It is one of the UK's most common life threatening inherited diseases, affecting over 9,000 people. In the United States, approximately 30,000 people have CF. Around 1,000 new cases of CF are diagnosed each year.

Not such a long time ago, the diagnosis of CF meant an early death. Germanic folklore has a saying: "A child who tastes like salt when kissed on the forehead will soon die." Before the 1950s, the prognosis on CF was so negative that doctors hardly believed that a child with this condition could live beyond seven years of age. The life expectancy of CF patients has been increasing over the past 40 years.

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. Difficulty breathing is the most serious symptom and results from frequent lung infections that are treated with, though not cured by, antibiotics and other medications. A multitude of other symptoms, including sinus infections, poor growth, diarrhoea, and infertility result from the effects of CF on other parts of the body.

Each week in the UK, five babies are born with the condition; however, each week, three young lives are also lost to it. Vast improvements in treatment have increased the life expectancy of patients, but currently there's no cure for CF.

As my longevity in this world was perpetually in doubt, it had a dramatic effect on what I did, how I felt and my priorities in life.

This book depicts the countdown to my landmark 40th year in diary format with the clock ticking from the day I turned 39 to the day I reach 40, as I unpick how I've cheated death for so long and lay out my formula for survival. This is the first book written by anyone with CF who has reached this significant age milestone.

When people look at me, they see a married man with a gorgeous wife and son, working full-time in London and playing regular sports. What they don't see is my chronic illness, which clogs up my lungs and digestive system with a thick, sticky mucus. It makes it hard to breathe, exercise and digest food.

All my life – every day – has been a battle to defy the odds around my life expectancy, currently set at 42 years – though for a long time it was fixed at 30. I knew that life was likely to be short, and having my own property, wife and child seemed unattainable. My very existence has always seemed held in an hourglass with the grains of sand running out fast. Every hour of every day is important as I never know when my hourglass will run out of time.

I undertake heavy and demoralising daily medication which brings regular dark, sad and fraught moments. I cannot afford to let up or cut any corners medically, as any big lapse could be my undoing. It is relentless – like having a heavy chest cold every day of your life – and unforgiving, killing many sufferers early. Throughout my life, I've had the misfortune to see many of my contemporary fellow sufferers pass away in adulthood, teens or early twenties.

To compound the problems of my life, CF is not that well known, understood, and cannot be easily seen or ever properly

imagined by most people. It's like a form of 'locked-in syndrome' as all the damage is on the inside and not very obvious to the naked eye.

Historically, I tended to suppress all my emotions about CF and be very guarded about disclosing it to strangers. I never wanted to be viewed as the 'ill person' and be defined by my condition and I certainly never wanted anyone to feel sorry for me or pity me. But after so many years of secrecy and protection, there was a huge amount of unresolved sadness and emotion under the surface.

As I defied the odds to approach this milestone, I had an epiphany that surviving CF has been the biggest achievement in my life, but it was hidden away and I wasn't talking about it or using it for my own or others' benefit. The addition of diabetes to my medical regime reinforced the feeling that my survival was something to be celebrated and shared. Now I wanted to speak up...

I decided to take the lid off of my own Pandora's Box and keep a diary in the year leading to my 40th to properly reflect, for the first time on my life – past, present and future – my trials and tribulations, happy times and what it has taken for me to survive this chronic illness for 40 years. I chose not to look back in anger but to look forward with positivity.

As I stirred my conscience, I began a journey of discovery that awakened my soul to the overriding desire to share my hard-fought but enriching life-lessons of hope as a form of cathartic process for myself and also to help others. At the same time, I wanted to increase the awareness and understanding of CF and share my bigger picture of life perspective, perseverance and optimism with a wider audience. One prime driver was to inspire people that even at your lowest ebb with the odds stacked against you, that there is usually a way to overcome.

There's a saying that 'what can't be cured, needs to be endured'. By enduring all my life, I realised I had some extraordinary stories to share and some unique life insights. I wanted to highlight the approach I have honed over the years that keeps me alive and kicking, where CF does not define me

but is just something I have to ‘get on with’ to lead my busy life.

Each chapter is a diary extract which covers the full spectrum of my daily life with flashbacks to my past and survival secrets – how have I cheated death?

Tim Wotton

1. Living the Dream

Early March 2010

I've been having the same recurring dream for nearly 40 years. Actually, it feels more like a nightmare than a dream. It's pretty damn frightening and I wouldn't wish it on my worst enemy.

In this ever-repeating dream, I'm held prisoner in my own version of Groundhog Day where it appears I have such a ferocious illness that I have to be taking a multitude of medication from the instant I wake to the moment I put my head down at night. I am always coughing and it feels like having the effects of a heavy chest cold every single day, so it must be some form of lung condition that never goes away.

In my dream, as soon as I wake up, I reach into my bedside drawer, which is like a mini chemist's shop, and I pick up the first of many drugs. The drugs don't seem to be recreational. I really seem to need them. Where a smoker's initial instinct on waking is to grab their packet of cigarettes, mine is to start taking a colourful mix of antibiotics-all different shapes and sizes.

Before I even make myself a cup of tea in the morning I've taken 15 tablets. Then I have to use a whirring nebulizer device containing a medicine. This produces a fine mist through a mouthpiece which I breathe in for 10 minutes.

Following this activity I lie back down on my bed. Not for a rest but so that I can pat my chest with my hands to bring up mucus which seems to be waiting to be coughed up – it's always lurking there, just waiting to come up.

It's pretty disgusting really to be producing such phlegm so early each morning but in my dream it seems perfectly normal to me. Curiously, I get the feeling that I've never smoked one cigarette in my life so this lung-related condition

has not been brought on by my own actions – it’s just there, is part of me and my DNA.

Occasionally, I cough so hard that I’m sick on myself, mainly just liquid but nonetheless pretty awful and a grim start to my day. Imagine it... you wake up and within 20 minutes you’re sick on yourself – not an inspiring thought really and an utterly depressing opening to anyone’s day.

Both up and down my house there are drawers and areas full of drugs and medical equipment – some are stashed away and some are on show for ease of use. Like an alcoholic with secret stashes of vodka dotted around the house, I have medication hiding places spread everywhere. Maybe I live in a show home for a pharmaceutical company and I’m their medication guinea pig?

I’m still not finished with this crazy clinical schedule as next up I’m pricking my finger with a sharp lancet in order to check my blood sugar levels via this little gadget. This gives me a score that I need to take time to register and jot down in a notebook.

At last, I can have some breakfast but that is accompanied by even more tablets and an insulin injection into my stomach, which tends to be a bit painful if I get the angle of the needle wrong. Sometimes when I withdraw the needle, I bleed from the point of injection which if not wiped up invariably ends up on my clothing. The drama never ceases with this condition...

On the worst mornings, I’ve been both sick and bled on myself and I’ve not even got showered, changed or even left my house yet. Managing this illness is non-stop and I seem to need the most amazing patience not to get wound up or annoyed by the whole thing. I seem to do all this so systematically as if it is a chore like brushing one’s teeth.

This dream carries on throughout my day where there’s a similarly rigorous routine at lunchtime and in the evening. At work, I usually conceal my medication – blood test, pills and injection – from those around me as I don’t want to draw too much attention to the whole process.

In the evening, the patting on my chest takes longer and I have even more secretions to cough up. Also, over the years, there have been many people (male and female) who have helped me with this evening physiotherapy – for the last decade, it’s been my wife who feels functional and not at all romantic. Annoyingly, this task often means that the food we are cooking that night is over-cooked or burnt and we eat later than we would like.

Before I know it, I’m back at my bedside popping pills from my chemist’s drawer before I turn the light out. Most days are completely exhausting as a result of the continuous coughing.

I have a sense that I want to be more spontaneous and break free from this serial drug-taking but my conscience won’t let me forget any of my treatments and the regime is adhered to religiously, like clock-work every day. I’m on some kind of crazy medical merry-go-round and there’s no way to climb off.

Then I wake up from my dream...

The realisation dawns on me that this is not actually a dream, but it is in fact my harsh reality living with and coping with cystic fibrosis (CF) and CF-related type 1 diabetes. It’s always been thus.

I am quite literally ‘living my dream’.

My Groundhog Day starts and ends with pills and I can only survive by being utterly committed to this punishing daily routine. In essence, my existence on this planet is governed by the necessity of a cocktail of around 40 tablets each day, intravenous treatments for three weeks at a time (the CF version of chemotherapy), nebulisers, long physiotherapy sessions, asthma inhalers and regular visits to hospitals and the pharmacist.

A knock-on effect of a lifetime of medication is that nearly half of my drugs regime is needed to counter the side effects of the antibiotics and 20 years of steroids has led to the development of my diabetes and osteoporosis.

For the first time in my life I feel the desire to take stock. It got me thinking about my overall intake of drugs during my life, so I got a pen and paper and started to work out the CF numbers.

As a rough calculation over just the last 25 years, I have swallowed **280** tablets every week, which equates to **14,560** a year and **364,000** for the whole period.

So it's clear I'm very good at taking pills and I've got my technique all locked down. Indeed, I might well be a human rattle. I wonder what the world record is for the number of tablets taken in one mouthful. It's probably held by one of us CF guys. OK, I know it's not something that I can add to my CV, but if there's an English team for pill popping, my name would be in that squad.

I do have to bite my tongue not to laugh when people tell me that they suffered taking a few tablets in a day or when they struggle to remember their one tablet a day of prescribed medication. The most illuminating are those that choose not to use antibiotics as they want their body to fight the infection. What luxury it is that they can be so dogmatic.

Do I think about anything when I'm taking my medication? Not really, I just do it. I've had to put aside any ethical barriers, though I will question and challenge my doctor and I won't add to my regime without good reason.

Also during this time, I have had **10,000** nebuliser sessions, **18,200** physiotherapy sessions, over **50** IV treatments, **600** visits to my chemist and **250** appointments at Frimley Park hospital.

CRICKEY! When I look at my CF in plain numbers, it's shockingly daunting and surreal. Have I really taken all those tablets? Have I had that many physiotherapies, IVs and trips to medical centres? Was that all me? I expect for someone who doesn't visit a doctor or take a pill that often, those rare occasions are quite memorable and challenging... and worth griping about.

As I've spent so many hours of my life cocooned in this CF hell, only the really shocking moments stand out. I think by

default, I block out the majority of my suffering as a way of protection from the daily grind of it all. I think if I dwelled upon every moment where my illness has to take centre stage in my life, I would come undone very quickly.

All this merely maintains my current state of health as there is no cure yet for CF. I cannot afford to let up on it or cut any corners medically, as any big lapse could be the end for me. This condition is completely unforgiving and relentless – like an incoming tide battering against a sandcastle.

Trapped by treatment just to stay alive, I'm quite literally trapped in my own Groundhog Day. I've not had a day off from this illness in nearly 40 years – fitting in my life, work, family, sport around this daunting and incessant routine. By sticking to this endless regime, I'm just about staying afloat – constantly treading water – I daren't stop swimming for a second in case I go under the surface, never to return.

While thinking about the relentless nature of my illness, I had the most shocking thought based on the CF version of the film 'Two Weeks' Notice' – what would happen to me if I stopped my treatments for just two weeks? How ill would I become? Even when I miss the odd treatment the effect on my health is pretty noticeable. I'm pretty sure that after two weeks of living without due diligence, I'd be in hospital and really struggling.

With such a condition to contend with, in every way, I firmly believe that I'm only as healthy as my last treatment.

It is against this daily backdrop that I survive each day, battling against the odds that this horrible illness heaps on me. People across the world aspire and strive to 'live the dream'. Unfortunately I'm living mine! I can only hope that one day when my morning alarm goes off, that something would have changed and the nightmare Groundhog Day spell will have been broken; and I can live a normal life untouched by medication and clinical regime.

Until that day arrives, on hearing that alarm, I'll keep reaching into my bedside drugs drawer...

2. Countdown Begins

Wednesday 17 March 2010

It's my 39th birthday today. I took the day off work to have an excursion with Katie in London. It was one of those lovely and rare days out together now that we are parents. We enjoyed a pleasant walk whilst holding hands in St. James Park, remembering again what being a couple is all about. This was followed by watching the pelicans flirt with tourists while eating our picnic on a park bench.

The highlight of the day was the matinee performance of 'Les Miserables' at a Shaftsbury Avenue theatre – my first time and I loved it, like so many before me. After clapping to a standstill at the finale, Katie and I made our way out of the theatre into a bustling Piccadilly Circus with the curious delight of an evening stretching ahead with no need to rush. An aperitif at the Opera Bar in Covent Garden preceded a delicious Thai meal. What a lovely day – a perfect day.

I also made a phone call to my twin brother, Jez, with whom I share my special day. Obviously, this is the person I've known all my life since we first met 39 years ago across a crowded womb! My twin looks nothing like me – he is tall, dark and handsome and looks more like my elder brother Chris. So what happened to me? I'm short and blonde! If I wasn't a twin there might be some serious questions to be asked! I do bear a resemblance to my mum's father so I know I'm safe in that respect...

Most people view their birthdays as special and enjoy the attention that they bring from family and friends. I'm no different in this respect. My birthdays mean a great deal to me as each one signifies a glorious achievement. Each one celebrates the simple fact that I'm still here.

All my life – every day – has been a battle to stay alive and keep defying the odds around my life expectancy (currently set at late thirties for CF sufferers, although for a long time it was fixed at thirty).

How does that feel to have one's very existence always in doubt? Consider one's life expectancy being held in an hourglass. Now imagine that the grains of sand in your glass appear to be running out very quickly... How would that feel? What would you do differently or prioritise before *your* sand ran out?

In my twenties I saw only a hopeless end. An early death seemed inevitable. I made the most of today because tomorrow might never have arrived.

This always reminded me of the 1976 film 'Logan's Run' which depicts a future society in which the population is maintained in equilibrium by requiring the death of everyone reaching a particular age. When the palm flower crystal embedded in the palm of everyone's right hand changes colour from red to black, people have reached the '*Lastday*' and are executed.

In my real-life version of the film, how long can I keep running away from the CF grim reaper?

For most of my life, thirty seemed unachievable and forty felt an impossible age to reach. This concern and fixation over my life expectancy was exacerbated after the sad deaths of certain CF friends leading up to my 30th birthday. With each departure, I questioned why I was still alive when they were not.

How had I cheated death? How many more birthdays would I have? Would I ever live long enough to feel over the hill rather than six feet under it?

When I finally made it to thirty, it felt as if I'd reached the Holy Grail. It was certainly a tipping point in my life. I wanted to carry with me the spirit of my friends who had died, and make my longer life count for something. When so much of a CF life is not at all normal, living beyond thirty was extremely fulfilling. It's something that my healthy peers took for granted but for me it was breaking the CF boundaries.

There are not too many people with CF that I know in the UK who are over forty and it always felt inspirational when anyone reached this significant milestone.

Due to my life-long battle for survival, I am hugely sentimental and I particularly want to do something memorable on my birthday. I want to make each one count for me and those around me.

I see each birthday as a time of celebration for my family, friends, medical staff and complementary therapists who have supported me and have been such a valuable part of my prolonged existence.

As I look ahead to my 40th birthday, it feels natural to also look back and reflect on my previous birthdays and the journey I've been on.

One milestone that feels like a watershed was my 17th birthday when I was feeling unwell and undergoing a heavy intravenous treatment. This meant that I couldn't go out to party with Jez and our mutual best friends. Every fibre of my body was screaming with anger and frustration about the apparent unfairness of staying in while my friends partied. I vowed never to miss out on future birthdays.

My birthdays could never be just another day. Each one was going to be a celebration of my life – a life worth living and well-lived.

Rather fortuitously, my birthday, 17 March, coincides with the Irish national holiday St. Patrick's Day – a day to be jovial and to let one's hair down. For many of my birthday evenings, I have tried to out-drink the Irish... but it should be noted that I've always failed miserably.

As well as organising activities during the day, Jez and I have always been inclined to organise a party for the majority of our birthdays with extra big venues and wider invites for the key milestone ages of eighteen, twenty one, twenty five, thirty and thirty five. There's a saying that 'if you book them, they will come' and my friends have fed off my infectious desire to celebrate life to the full and have as much fun as possible.

When I invite them, people have tended to flock. I am fortunate to have very faithful and reliable friends.

I'd like to think that an abiding memory for most of my friends will be of me taking centre stage with a pint in one hand and a rum and coke in the other laughing and enjoying myself-literally squeezing every drop out of life!

There have been occasions when I've gone too far with my 'partying'. On my 24th birthday, I was so drunk that I was physically carried shoulder high by my flatmates out of a pub in Putney to a cacophony of hysterical cheers from the Irish throng. This was definitely an example of triumph of the spirit – unfortunately it was a pint of different spirits that did for me that night!

To make matters worse, I threw up in the taxi on the way home and was in a horrible state the next day when I played hockey in Maidenhead. I was still being sick during the pre-match team talk which consisted of the sound advice: "Don't pass the ball to Tim!" Having somehow got through the game, back in the opposition clubhouse canteen, I sat on my own meticulously eating a bowl of soup while the rest of the players cheered on England in a Five Nations rugby game next door.

Another time, following a drink-fuelled birthday bash on reaching twenty nine, I got extremely emotional and melancholic outside a Putney nightclub with Sasha, a hockey friend. Perhaps this could be attributed to the underlying sadness I felt that the 'unachievable' age of thirty was looming which could hasten my potential demise.

But as I approach the forty year milestone, in March 2011, something has changed in me... I have flipped my mindset from a fear of dying to a desire to live for much longer as there is so much I still want to see and do. This was immeasurably magnified when I became a husband to Katie in 2003 and a father to Felix in 2007.

I now view the future in a different way – welcoming each year. I mentally project and expect a longer life with my own family to live it with. I firmly believe that the best birthdays of all are those that haven't happened yet.

I see reaching forty as a celebration of my life to date and what it has taken for me to survive; but I also view it as a launchpad for the rest of my life – with my hourglass half full rather than half empty. I would certainly want to celebrate my 40th milestone with the mother of all parties.

If getting to forty was the equivalent of climbing Mount Everest then I'm on the ascent with the summit in sight – almost mystical through the clouds. But will I make it to the top?

For each of us, transitioning to a new decade is a reason for jubilation. For me, it is achieving the impossible. The countdown to my 40th officially begins and I've got to make it, especially now that I've started this journal!