



My first thought when I wake in the morning is “I have cancer”. The second is “well you’d better make the most the day ahead then!” And I get up. TKI’s have let me think like this. And so, for me, that acronym TKI it summons up positivity and hope. That is an amazing thing - not least because I can’t really tell you what a TKI, a Trans Kinase Inhibitor actually is! But I can tell you that TKIs have let me live a huge amount longer than I was ever expected to live. ‘Live’ in both the sense of not dying but also in the sense of living my life in as normal a way, as happy a way as possible. I am seven years into my adventure with cancer. I wouldn’t be if TKI’s hadn’t kept me on this road.

So by way of background: I was diagnosed with stage 4 NSCLC in Sept 2011. At the time I was living in the Middle East with my wife and two children. I had spent much of my life travelling the world, keeping fit and healthy. I didn’t smoke - indeed a few months before it all began I took part in a race from the dead sea to the red sea. So when, during a routine ultrasound for an unrelated ailment, a radiographer noticed some water on my lungs and around my heart, it was a huge surprise. I had had no side effects apart from a dull backache which I’d put down to overexertion in the swimming pool. The working assumption was that the specks in my lungs were signs of Tuberculosis and I was told to come back home to UK. I thought it’d be a short trip, a short fuss and that I’d be back at work in a week or so with some medication or another. For my first two weeks back in UK I was confined to the infectious disease ward where they tried to work out what weird and wonderful disease I might have contracted.

Eventually a biopsy confirmed lung cancer. Stage 4 Non-small cell lung cancer. I was given 6 months to live. 18 if I was fortunate. My world, my wife’s world was turned upside down in that moment. From building our family, building a career,

planning holidays, ambitions - our life, our future suddenly changed direction. The hour glass was running out fast - ticking clocks began to worry me. Friends packed up our house, other friends here in London gave us a room to sleep in. And slowly but surely we started dealing with it. I was angry, I was sad, I was scared - not for myself but at the thought of putting my wife, my parents, my children through the pain of my dying. It was not fair. It made no sense. Daydreaming over and over about my own funeral, whether I'd be conscious til the last, whether my cognitive function would be the same, whether there'd be pain. This was not how I'd envisaged spending my 30s.

I didn't have private cover. I'd reasoned, wrongly, that I was a fairly invincible young man. Fortunate Brit that I am, I didn't need it. The NHS took me under its wing and has kept me going ever since. Evidently, writing here as I am 7 years later, I am extraordinarily lucky man. In very large part because of the treatment that I have received. But also, and like it not medical folk, because my wife, my family, my fixation on wellness have kept me going.

That said, the luck took a few months to materialise. I was immediately started on the standard treatment for patients with stage 4 NSC lung cancer; cisplatin-pemetrexed chemotherapy. 6 cycles of that. Hours of watching the poison drip into my veins, anticipating what it would bring. It was miserable - it sapped my life. I quickly became so weak that I couldn't even lift my 1 year old daughter, walking the stairs was a marathon - even reading a book was draining. The dull pain, sickness, nausea, acid, weakness and exhaustion felt like experiences en route to an obvious ending. Being neutropenic, on another antibiotic drip. Neuropathy in my fingers meant lego with my son was an ordeal, buttons impossible. And my mood; low, stressed, scared. My wife, miracle lady that she is, kindled the fight in me, force fed me amazing concoctions that kept me going. Soon enough I became utterly determined to fight. Some folk don't like that word 'fight' but, like it or not, the mental battle that rages in my mind is a vital element of my survival. I challenged myself every day to walk - sometimes this only meant to the end of the street. Sometimes it resulted in a trip to hospital, to the Clinical assessment unit at the Marsden, and a lecture that I was overdoing it. But I am quite sure that throughout this adventure, positivity, diet and exercise have been such important allies to my treatment.

The ordeal of standard chemo got me through the first 6 months of my prognosis. But it was during this 6 months that my consultant threw the first grain of hope my way. From first meeting me he was struck by the fact that, for a lung cancer patient, I was relatively young and that I was a non smoker. These facts suggested to him that I likely had a genetic mutation. His best guess was that I was Alk positive. Initial tests conducted in a different hospital had said otherwise. But when I came under his care he followed his instinct and tested again. On his second attempt, using a different method (FISH) his hypothesis was proven correct. And so, when the cancer progressed after my initial chemo, he managed to secure access to Crizotinib, my first TKI. I stopped circling the drain. I

regained strength, energy and hope. Yes I had side effects but these were negligible and allowed me a far better quality of life than that which I had previously had on standard chemo. Unlike the last ordeal the nausea this time round was manageable with only small doses of anti-emetics. My liver complained (elevated ALT and bilirubin) but altered doses soon limited its whining. Similarly the diarrhoea was manageable. I did suffer from lymphedema and the water retained in my legs added about 10 kg to my weight - a fairly exhausting weight at first but one which, with exercise, got me fitter and reduced. The upside of lymphedema was that my children enjoyed making patterns in the putty that was my ankles. The management of my lymphedema is one good example of where the team at the Marsden went the extra mile to make my life with cancer easier. I was referred to the lymphoma team and advised to exercise often ( working my lower leg muscles squeezed the water away from my ankles), get my feet up often ( a rest is always welcome but gravity helped drain the fluid) and wear tight stockings (not something my father would have approved of!). From a clinical perspective Crizotinib gave me life. It took me over the best case 18 month prognosis line. The cancer shrunk a lot - initially.

I was on Crizotinib for 18 months and by the time the cancer found a way round it my son was 6, my daughter was 3. I figured that aged 6 my son might actually remember me now - a good thing I reasoned. What's more (and never forget the importance of this) my wife and I had had time to get our life in order with finances, conversations and plans for this uncertain future. We had accepted that I will die. I am gutted that I shall miss so many parts of my children lives. But I am also delighted that I will experience so many before that. Crucially, I don't take the joys for granted any longer. And I know now where my priorities really are in the time that I have left.

In late 2013, I was told that the cancer was progressing again and that this time it had found its way into my brain. I was whisked into neurosurgery to get the big occipital tumour out. I was then brought back for stereotactic radiotherapy on the temporal lobe tumour. Again the quick thinking, keep going approach of my medical team gave me some hope. There were some hiccups - suspected meningitis was one - my wife driving me through rush hour traffic as my head leaked cerebral brain fluid was another. But the main downside was for my children who were very disappointed not to be able to shave my head before I lost my hair. I shan't go on about the neurosurgery excitements, not least because they aren't immediately relevant to being Alk positive, but I do understand that I wouldn't have had surgery at all if the cancer had spread in the brain as it might normally have been expected to do. Two tumours made it operable, 10 would not have. TKIs should take credit there. My family obviously deserve credit here too. Their stoicism and positivity throughout the surgeries was extraordinarily uplifting. And the children took it in their stride too. My son horrified his primary school teacher by taking my brain surgery staples in for 'show and tell'. My daughter proudly told her little friends who, on seeing the huge scars, asked 'what wrong with your Daddy's head; " He's got cancer" - 'Oh'.

And joy of joys, I walked back into the Marsden to be told that I had been granted a place on another TKI trial; this time for Alectinib. I really did like Alectinib, The side effects were minimal (honestly I can't even remember any) and, crucially, it immediately shrank the cancer. Unfortunately my liver didn't like it. Bilirubin and ALT went sky high and the drug company took me off the trial just as I began to reap its benefits.

At this point we all began to worry. To prepare for a final deterioration. At this point, in mid 2014, there weren't any other drugs in the cabinet for me to try. So first it was back into St Georges for another tumour to be cut out of my head. And then nothing. Nothing. No cancer treatment. We were waiting for the next TKI to become available on trial.

Now this is when the pain, mainly back pain from pleurisy, really reached new heights and when I really began to understand what the higher numbers on the 1-10 pain scale really mean. It was also when I began to love morphine. Once again the Marsden were there to rescue me - the pain management team made sure my love of Morphine remained respectful not addictive. Despite knowing that the cancer was spreading, that I was slowly dying, I was able to carry on with some vestige of normality. Yes I was weak, exhausted and at times a grumpy Dad. But I was alive.

Alive long enough for our consultant to sit us down 6 months later and tell us that yet another TKI had become available and that I had been granted access to it. LDK378 (that number is scored in my brain); Ceritinib. That was in late 2014 and here I am almost four years later still on it, still alive, and living an almost completely normal life. The cancer shrank hugely in the first year and is now stable (well - I hope it is - I'll find out next week what the MRI has said). Yes there are still side effects, the worst of which is awful diarrhoea (yes it's me running panic-stricken down the aisle on the commuter train trying to find a loo) and tiredness - plus a grumpy liver from time to time (again the raised ALT is an issue). But I have been able to get fit again, to enjoy family life to the full and to get back to work on a basis that better balances my priorities. Ironically I think the normality, the freedom that comes with energy and a lack of pain, gave my medical care team some headaches of their own; After 3 years of waiting to die, my wife and I started to look beyond the horizon and somehow she persuaded me that we should have that third child after all?! It's probably an unfair question to ask one's consultant, or one of his or her amazing registrars, but "do you think we are mad having another child?... oh and could you keep me around to see the birth please?". It certainly wasn't an easy decision; the odds remained, remain 50/50 that I shan't be here in a year's time. It was a crazy, illogical but wonderful, brave and positive decision. And it has changed our lives again. Our youngest arrived in May 2016. She has been a delightful distraction from so-called palliative care. More than that - she is, like brother and sister, the strongest argument for TKIs that I have. We have just finished potty training and she has



just had her first days in kindergarten. Wow. And so it is that TKIs have extended a possible 6 month prognosis to 7 years. Last night my eldest daughter, now 8, read me the first pages of her first proper book - no pictures! And, worse, Wilf beat me on a run at the weekend. TKIs have given me life and, crucially, a relatively normal life. And, lucky you, they are also an additional, albeit rare, positive to being Alk positive.

Tom

## Appendix:

If useful I have added below some of my personal experiences in managing the side effects of TKIs, and the symptoms of cancer.

### Side effects;

- TKIs have played havoc with my gut. The latest, Ceritinib has been the worst by far. But a few months trial and error have taught me how best to manage this. I now take them at least two hours after my last food of the day. Between meals was no good. I still ended up rushing to the loo. Fat makes it all so much worse. So I limit the amount of fat I eat. But, fortunately, without any I absorb too much of the drug and my liver gets sad. So its a balance, erring on the the side of less fat is best. The balance took some working out but once again thank you Marsden - the combined efforts of gastro enterologists and nutritionists (and lots of immodium) have given me control.
- My diet has changed hugely since diagnosis, not lease because my wife is an anti cancer diet preacher. I know that the Drs aren't convinced but we have little red meat, no processed pork and have reduced diary. We have loads and loads of veg. And reward the abstaining by eating whatever we wish when we are out. I am, as a result, in many ways (bar the obvious) healthier as a result
- Exercise; I'm sure that it has been vital throughout my various treatments. Getting up and moving even when my head told me otherwise has kept me going. Even a few steps when it was really bad. Right now I'm motivated to stay fit by the knowledge that I'll need the strength and endurance soon enough. There's an obvious physical upside in that I remain healthy. But, for me, its first and foremost about my head. Exercise increases endorphins which in turn make you more positive. My preferred exercise is swimming - I blame the Marsden here because I told myself that swimming the serpentine for the Marsden was a worthy cause. And I love it because, unlike running or football, my lungs can tolerate it.
- Rest / Sleep. I love sleep. And I really love my lunchtime granny nap. I need

it. That 30 minutes has kept me sane and given me the energy to see every day out. I now use any opportunity. Never use a commute for anything else (unless you're running for the loo).

- Balance: Living as long as I have with cancer I have still had to work. But it was exhausting trying to work all day every day and all too often what my family got back from work was an exhausted, grumpy, sick man. It took me too long to work out that I had to get the balance right and put my family first. I swallowed my pride and gave up the career I'd had for a more flexible, self employed existence where I had more control. It seems so logical now. It didn't at the time.
- Shock; Don't underestimate the shock of diagnosis and the time, the weeks and months that it takes to sink in. The hospital used to terrify me. Now it's familiar, friendly. But I've learnt the ropes and have my routines. I sleep in MRIs, bring good books, take lists of questions into clinic. I talk to friends, to family, I no longer bottle things up ,
- Family; Never ever forget its the spouse, the children, the parents that suffer the most. I can fight my fight but they are desperate to help and can only do so much. They are also left to pick up the pieces. They are as much a part

## Medical care

- Communication; The clinical nurse specialists are my lifeline. They have always been there at the end of the phone. And that is perhaps the very greatest thing about the Marsden. The familiar reassurance at the end of the phone, the guidance, the knowing that you're more than just a name.
- Comprehensive care; The pain management, the gut tests / nutritionist, lymphedema, CNS advice, - all of these additional areas of patient care have made my life with cancer so much easier to bear.
- And crucially for me the sense that my Drs have never given up, that they will always strive to find a way to keep me here so long as it exists. I want them to take a chance. I want this to continue. I don't take any of it for granted. And for that I am forever grateful.