Symphony 9 and the Chalk Lion: legacy and hope

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If you travel on the West Coast Mainline to Euston, and sit facing forwards on the left of the carriage, look to your 10 o'clock just south of Leighton Buzzard in daylight. There, carved into the chalk hills in the distance, is a lion, one of its paws forever raised Eastwards. The boundary to Whipsnade Zoo.

I pointed this out to my sister Pam recently, as we travelled South, as it was pointed out to me decades ago by another commuter.

She excitedly said she would tell my niece, who often makes that trip for work. Legacy. A small one, to be sure, but it still felt right.

As did the point of the journey. Hearing Beethoven's Ninth Symphony (the 'choral') performed by the Royal Philharmonic at the Royal Festival Hall on the South Bank. A glorious evening, in brilliant sunshine, next to the Thames.

Something I'd done dozens of times before, only this time with a deeper purpose. A bitter-sweet thought, that this could be the last time I would hear it live.

I discovered the Beethoven symphonies in my teen years, a nerdy lad walking the streets near his home blasting out Radio 3 on his Grundig 'Elite Boy' radio (the height of technical sophistication back then, predating even the 'ghetto blaster') and they've been a source of comfort ever since.

Pam had never heard it, and I'm delighted she was impressed. I'm glad I passed that on too - something I would not have done, ironically, had I not been diagnosed with stage 4 lung cancer.

One of the most important phrases I've read about this

Sneaky Bastard of a disease is, ‘don’t let your diagnosis define you’. Which is a rabbit hole I’ve managed to avoid, mostly. But it does change you. Wanting to pass things on becomes more important.

Part of wanting to leave behind something more lasting than you are.

Which has become more pronounced lately, as I go through repeated cycles of chemo and immunotherapy.

My Sneaky Bastard isn’t one of the more obliging ones, with targeted mutations that the latest immunotherapy alone can hit, leaving the rest of me relatively untouched. Which means the systemic poison of chemotherapy is used, with a broader immunotherapy thrown in. Heavy-metal poisoning (platinum) delivered to EVERY dividing cell. The Sneaky Bastard ones, being greedier, get hit harder, and cancer cells can’t heal as well as the orderly ones. That’s the theory.

But it’s harsh. It hits about 3 days after infusion: total wipe-out. Weak as a kitten and perpetually tired, for around 7-8 days further. Your appetite goes. That is the weirdest thing, for me. Not just reduced, or an altered sense of taste (which are both true), but it just GOES. I smell food, want it, then the slightest morsel in my mouth instantly removes any wish to keep eating. No nausea as such, thankfully. Just the certain knowledge that I CANNOT EAT - or I would be ill, violently. Even water becomes a challenge for a few days, which is potentially dangerous so I do force myself to drink what I can.

Weight slips off me. Then, slowly, things start to return. I stop needing to sleep constantly. I am able to get further than the bathroom and back, though not all at once.

My strength edges upwards. The last to return is the appetite, still far from normal but at least I can eat something.

After about 2 weeks I can start trying normal activity again. Just in time for the next chemo hit…

Three cycles I’ve been through. Another one due. The burning question: HAS IT WORKED? All that suffering, is there a pay-off? It’s a coin

toss with this Sneaky Bastard: around a 50:50 chance the tumour has shrunk.

The latest scan was taken a week before I saw my consultant to find out. Fear gripped me leading up to the day.

Which on the one hand is irrational.

I already know this thing will eventually kill me; surely I'd already had the worst possible news, and anything beyond that is only so much detail?

But, when you have a life-limiting disease, detail is everything.

No one can tell you where on that survival curve you are. You want to be well to the right, one of the luckier ones, the exception, not the average.

You don't want median, you want living extreme. The will to survive dominates everything if you let it, and waiting to hear that particular bit of news it's almost impossible not to.

The chemo worked.

Before and after CT scans. The lurking sub-continent of the Sneaky Bastard filling my left lower lobe on the before shot, a scattered Sneaky Bastard archipelago, much reduced, on the after.

Shrunken mets too. The best possible result.

My consultant's beaming smile. He must really relish those moments, given the awful news he often has to deliver.

But it worked…

Immunotherapy alone, which is next, is the real life extender, IF it works. It might not.

Sneaky Bastard islets could mutate and become immune to the immunotherapy, my immune system could stop responding and stop targeting what's left.

But, if that doesn't happen and the treatment works - and no one can say until you start it - then median survival times go to 3-4 YEARS.

Years!

Living with cancer, not dying from it.

Hope.

The NHS at its very best. That's what it can do.

Even if it doesn't, the consultant felt confident in reassuring me I'd still be here in a year's time (or not dead

from Sneaky Bastard,
at least; there's always
the proverbial or
actual bus...).

Well beyond the
initial dark diagnosis
before treatment.
More life.

More living.

Yes, eventually
Sneaky Bastard wins,
I get that.

But, every month of
victory is more time
to hope, and love, and
leave people with
memories they will
cherish.

**Even knowing where
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