Well I’m Accustomed to a Smooth Ride



Or maybe I’m a dog that lost his bite.

The first six weeks of chemo were relatively uninteresting. Fatigued, but not hammered in the fashion all those movies of the week and after school specials had me expecting. I thought I was special, that rare creature immune to the horrors. Everything would work exactly as planned, *mirabile dictu,* I am healed!

It seemed to be working, until it wasn’t, so the docs decided I needed to shift to another protocol.

May you live in interesting times.

First repercussion: Where my hopes for full remission via chemo were around 60%, the need to change protocols (due to aggressively resistant cells) means my chance of full remission via chemo are now around 40%. What that means is the marrow/stem cell transplantation is almost certainly going to be necessary.

Well fuck that. I followed my rules, all the precautions and shit. Whaddyamean that stuff isn’t working. I want to speak to your manager.

Second repercussion: The second line protocol is more systemically insulting, i.e., this shit is rough on the human body. Caustic. Fatigue and brain fog are way worse, and my

immune system collapse landed me in the ER with a near-shock condition sepsis event. Three days in hospital during my scheduled non-hospital time. Who is in charge here, and may I speak with her straight away?

I'm accustomed to a smooth ride, goddammit. I would like a word with your supervisor. My consumer rights are not being adequately met.

A week later, I am feeling relatively okay. Tomorrow, back to Gainesville for initial consult with the transplant team. I have a feeling I will own more information than I would care for by tomorrow afternoon. Kind of like when I found a British website focused on AITL that concluded with the following cheery thought:

> *It is important that you and your family recognize that you are dealing with a fatal disease.*

Well fuck me sideways and call me Shirley. The Brits, they can be overly direct, no?

I am not quite prepared to accept that as definitive, and besides, life itself is a fatal condition, but I must admit that my thinking has had more than its share of morbid consideration since I saw this on the eve of my last treatment. The new one, because the first one was not working. That.

We keep plugging. Our oncology pharmacist – our favorite member of the care team – says this: You keep going, even one more day, in hopes that they find the cure for this thing.

Also too: There are dogs and music and books in my day-to-day, and though reading is iffy with the chemo brain (It took me a full week to read *The Watchmen*, fer crying out loud), still, I persist.

Monday was our 35th wedding anniversary, me and Stanwyck. What

an amazement this is, the rich history, the shared life. I really want to celebrate many more. So much more to say about this, but alas, the brain resists the intentional sequencing of words to create something whatever etc.

Greatest gratitude to all who send messages and love and books. It means more than you can imagine. Truth.

So as my bracelet says…Keep Fucking Going.

What else is there? Oh yeah…

LOVE EACH OTHER, MOTHERFUCKERS.

It matters a difference.