

The cruelty of chemo and the kindness of strangers

Lying on the kitchen floor, gasping for breath, it occurred to me that Wendy might have a point. Severe anaemia, as it turned out. Plus dehydration, adrenal suppression and probably an opportunist infection.

Chemo kicks the crap out of you.

I was fairing well, or so I thought. Yes I'd hit the 'fatigue wall' a few days after they injected me with heavy-metal compounds designed to poison every dividing cell in my body (more so Sneaky Bastard tumour, that's the idea), and the complete loss of appetite for anything kicked in about the same time.

But for the past two treatments, I'd recover, finding I could get up, then walk the dogs again, then start to find food at least mainly palatable again, over the coming week or two. But not this time…

Week 1: as expected. Bed ridden for a couple of days, then starting to move around. Only this time that's as far as it got. A phone call. It was the Cancer Nurses. My last CT scan report (2 weeks prior) had picked up … a pulmonary embolism (PE)…

… and I was doing so well.

They were surprisingly calm. 'Could you come into the Hot Clinic on the Ward? We need to give you drugs for that?' No, I'd rather sit at home and wait to die … of course I could. 'It's a tiny one', the on-duty Reg said, 'We're giving you Apixoban [blood thinning meds] so nothing else forms while it naturally dissolves'.

Out again in the hour. Down to the bustling pharmacy. Don't cut

yourself, don't walk into anything. Sorted.

Only it wasn't. Weaker and weaker. Eating and drinking nothing. Then the need to go up and down stairs twice. Then the kitchen floor.

Red Card back into the ward. Those four malevolent companions, confusing the signs for each other. For example: we use an IR thermometer to keep track of my temperature. Relies on gauging the temperature of the blood just below the skin. Which is great.

Unless you happen to have severe anaemia, in which case the peripheral circulation shuts down to protect the vital organs. Your skin temperature *drops*. 'Oh great', thought ignorant I, 'at least I don't have an infection …'. Oops.

'What's the normal range for blood Hb?' I asked the on-duty doc, 'Around 130'. 'What's mine?' '85'. I was surprised I was still standing.

A massive (for me) dose of steroid, to kick my adrenal glands back to life. Antibiotics, since an infection seemed plausible. And one unit of red blood cells. My first transfusion. I watched it go in, like magical claret wine.

Had my headphones on, barely moving I felt so crap. Do you know how I knew it was working? ZZ Top's 'Gimme all your Lovin''. My feet started tapping.

Might that be because of the raging privatisation devouring ophthalmology, I wondered?

Motionless up to then. I almost skipped down the corridor on the way out, having had to stop twice on the way in just to get my breath. The altruistic kindness of a stranger gave me instant energy. That should be rated as highly as costs and outcomes.

Was there more? Yes, as it turned out. I have only one 'good eye' (the result of a squint that was not picked up until I was 6 years old, way too late). So I'm twitchy about eyesight. I read chemo could affect that, 'in rare cases'. I booked an appointment, one of the all-singing ones which measure your intraocular pressure and take a good look at your retinas.

I was ushered in to see the optician after all the tests. The good news? My pressure was normal, the steroid jolt hadn't given me glaucoma. My vision was normal, far as they could tell.

But those retinal scans. 'You see those?', the optician said. What looked to be fluffy white clouds dotted over a river delta. '*They are cotton-wool spots, a sign of retinal damage'*.

Oh FFS. What else?

Could have been the chemo. More likely, the bout of anaemia that was

enough to put me on the floor. Retinas are very sensitive to low oxygen. ‘We’ll send off the letter to the local Eye Centre today’, she said, ‘could you go there to their A&E and wait?’.

No, I can’t.

Chemo leaves you immunocompromised. Sitting in a crowded area full of people who could well be coughing viruses far and wide for hours is not a wise move.

Then the fun really started. We tried ringing them. All their numbers. Repeatedly. ALL of them rang out. No one home.

Wendy contacted PALS, ‘who would ring the Eye Centre and get back to us’. Nope.

Wendy rang PALS back and said she was going to mail the Chief Exec.

A promise to contact the Eye Centre. Nothing.

To be plain, unlike the cancer centre, this is a service that is obviously on its knees, understaffed and overstretched to the point of systematic silence.

Now why might that be? The only recourse people have with an acute eye emergency is to turn up and wait hours.

We never got a response. Cotton-wool spots are, I gather, usually not a sign of permanent damage – but they can be. The opticians picked up no visual deterioration. But I wanted an expert opinion. Someone to say ‘It’s ok, we’re going to watch this, you are in safe hands’.

Nothing.

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Giving us exactly what we’ve seen for NHS dentistry? I could have seen an ophthalmologist privately the next day – for several hundred quid.

And, don’t even look at the price list for treatments.

Eyes are expensive. Inequality and injustice follow privatisation, that is something I’ve learned. Is this what people want?

But the outcome of all that chemo?

Costing me absolutely nothing.

Brilliant.

The tumour had shrunk to under half its size on diagnosis, and now I get immunotherapy to keep kicking it. ‘*Median survival for people on this is 3-4 years’* my Consultant said.

YEARS…

… for lung cancer….

… astonishing.

Alan Taman