

Liz - in her own words

July 28, 2021

At the moment I am having radiation once daily Mon-Fri and chemo on Wednesdays as well. They say you feel worse later in the timetable but for now it's not bad, because I have no nausea. The usual maddening things happen, e.g. they said I had to have a port, which turns out to be not a boat-shelter but a hole in your shoulder they can pull blood out of and pour chemo into and it saves all sorts of anguish. The forked tongue reality is that they can't do it until *after* the first chemo session and then the day after it's in, another lump swells up and feels quite uncomfortable so the radiation people see it and say better have it checked, it takes a million phone calls to get to the doc who put it in (by a miracle I had jotted his name on another page in my diary) and he says don't use the port yet so I am livid but have to smile it off and act like a jolly good sport while dreading the next time -- chemo nurse has to find an unused vein to enter for a makeshift port. Oh these things happen I say achieving the reputation of being a sweet goood-tempered old lady, However Murphy's Law (that which can go wrong, will do so) missed the boat and instead of my expected agony the nurse found a good place and stabbed it in at the first go (this morning) so I was assuaged and unsurprised that my blood pressure (which they take about four times a session) remained within the realms of my daily pill! The best is that they dose you with some benedril before doing anything else so you are half asleep and can vaguely listen to them saying now we are going to put in toxin a or b or words to that effect, without turning a hair.

I am thinking of writing and illustrating a book on how to go through lung cancer treatments but it would be better not to publish until *apres la mort* in case you need any of your doctors to help you out of a new phase! In fact I am incredibly lucky, they are so very nice, everybody from the receptionists on, and the treatments can be done at eight minutes from my house in a new blood and guts place opened on East Main in Patchogue I go up to Mather for procedures and a couple of medical centers on Rte 112 and Belle Terre Rd, so everything is local, a great boon.

I joined another French -interest group when ours lapsed a bit, I had a friend who bought into the Amsterdam, a place much like Port Jefferson Ferry, and we meet on Zoom Thursdays 11-12 noon. We translate sometimes Fr articles (politics) into English, or reverse Eng to Fr, and also discuss art with pics, the latest we did was the Cezanne article written in the NYT, a terrific article we all thought and if any of us could rise above our various medical "challenges" we would skip into MOMA like lightning to see the exhibit. We also studied other Fr. artists, musicians, etc. It's fun. Only 5 belong at the moment, people fall out and rejoin. Colleen also is in it, although not at the Amsterdam. If you saw the Newsday article about the A being about to go bankrupt you will understand my concern for friends there, I do hope someone rescues it. It is so elegant and luxurious, with great food and many clubs, e.g. you could grow plants, join a poetry group, etc. Also the corridors are wide enough to take two rather wobbly wheelchair trajectories without the risk of a crash in midstream!

I'd love to stay in tough and even hope we can restart our group although for the moment I couldn't attend in person.

All the best, Liz

September 14, 2021

You're right about this being a rougher patch. Apparently after they stop the radiation and chemo is when the side effects really kick in -- nausea, extreme pain in windpipe if you eat or drink, feet swelling to a point when you wonder if they'll pop but at least you can't feel them..... etc! I can only eat the strangest medley of things: boiled egg, saltines, cooked chopped spinach, mashed potato, Hot Dogs!!! and not much more. Water is hard to take, but with about an eighth of orange juice in the glass and using a straw, it's better. You are supposed to drink 64 ozs a day, this is a goal that I am never achieving.

One funny episode happened before I was into these effects -- my hair having fallen out, I went with Ali and the girls to buy a wig at the place suggested by the oncology office. Instead of what I'd expected, a

shop with lots of fake hair you could try on and get advice from your family on how horrendous you looked, it was a small private house which only took people by special appointment, and no family or friends allowed (they had to stay in the parking lot) because of Covid. Luckily for us, since it was a 35-min drive to get there, someone had just cancelled so I was allowed in. Each client was ushered to a minute cubicle that they had just sprayed with marvellous germ-killers to obliterate most of the natural air in the place, and you sat in front of a mirror as if at the hairdresser while your personal handler dashed off to get several glorious mops of hair it was hoped you would like. The very nice and helpful assistant in charge of me evidently assessed my taste far from where it actually was and arrived with several tousled curly creations that made me look like a version of Groucho Marx.

"Have you anything straighter?" I asked, "and not necessarily all grey or white." "Of course, I'll be right back" she said with beaming smile and could be heard opening cupboards or boxes in the storage area of this minuscule space that could have been a model for those tiny houses that people are supposed to want to buy on Channel 30. After what seemed like hours she came back with several pretty awful possibilities. One was fairly straight, more like my hair than others, but a bit too brown. No, we haven't got any more of the ones like that tinged with gray. I looked at it and it certainly wasn't as bad as the Groucho lot. It feels as if it will come off I said. Oh that's because you need the special wig holder she replied and scampered off again to return with a long piece of velcro embroidered enough to be able to charge \$25 for it, which she wrapped around my head then replaced the wig. (I forgot to say I had already turned down the best specimens that cost about \$400 up, either because "hand woven" or because real hair). Nothing over \$185 I said firmly (having found out from Blue Cross Blue Shield previously that because this was my first wig they would allow up to \$300, but I didn't trust them for the whole amount). By this time I was not feeling so great partly from lack of air and partly because I was soon to pass into the next chemo phase of feeling nauseated all the time, so I peered through the front and said But I can't see out. Oh I can style it for you she said. Can you cut it? Yes. So she started on the front and after some tryouts had the resultant bangs at a level that allowed fairly good vision from the face they had concealed. I guess that's all right, I say and allow her to help me out onto the small back porch from which one's family could view the results. What do you think? It looks fine Granny said the girls. I totter back to the cubicle and get the now hairdresser to cut off a bit more. Thanks, that's fine I say. She puts the nylon turban thing Ali had got me as a first-step camouflage from Amazon into a posh box and shows me what to do to get all the medical insurance done. By now I am a puppet ready for the car and nothing matters much. Thank you so much I say as she tenderly escorts me down the ramp and while I am getting into the car, explains carefully to Ali (who never ever does anything about filling in forms unless she is positively driven by a court case) just how to get our \$235 or so back from the insurance, and we set sail.

At home I take off the wig and headband and lose part of the incipient headache I'd developed. I toss them on a pile of books in my room. Since then, when not wanting to shock people by baldness, I wear the turban, which is not so bad if put on back-to-front so you don't see the tasteful rose embellishment that made me dislike it so much at first. Soon I will summon the energy to undo the posh box and tackle the Blue Cross Blue Shield medical forms.

Rather a long story but it's really your fault for having been so encouraging about my previous letter. Since then I haven't felt like writing much, you evidently inspired me!

Jan 20, 2022

Every Brit who attended the coronation of Elizabeth II (my aunt got us seats in the sort of football banks of seats along the way and my whole family was there, starting at 5:30 a.m. as was the rule for watchers) will never forget one of the highest points of the magnificent procession of guests going to the event some six hours later. The one that caught everyone's attention the most was a glorious golden open carriage, barely containing a huge, superbly robed lady seated by a tiny little man covered in medals, who both ignored the drizzly rain and waved with great enthusiasm to the crowd, which responded with roars of delight and took the lady immediately to their hearts. It was Queen Salote of Tonga and her husband. Later, in a book by David Niven, who was with a group of actors in another part of the viewing seats, he

recalled how someone of their party had asked who was the little man beside Queen Salote, and Noel Coward (always known for quick though not necessarily kind wit), said immediately "Lunch!"

I thought you might enjoy that story!

Things are rolling along here. I am still doing the immunotherapy every two weeks, and taking pills that don't work to improve the neuropathy caused by the chemo of August. But I am so lucky to have dear family so close, and since I have never been one for extreme (or any other) sports, a life of crosswords, reading, writing, TV, and putting off sorting through old useless papers that clutter many drawers and cupboards, suits me quite well!

Feb 13, 2022

Dear Ludmila Anita et al.

lovely to hear from you re the French group re-start-up. I can come on Mondays. Right now it has to be zoom for me. I was doing okay on immunotherapy but with side effect from chemo: neuropathy but then a week or so back I got pneumonia. After a week or so not too well in Mather I am in a what we were told is a five star second tier rehab which should not get one star on a starry night. So I would be a zoomer for sure. But looking forward to seeing nous les autres so much xxxxxx

Liz

May 11, 2022

Hello Marie,

How very nice to hear from you and I'm sorry to have somewhat dropped the email ball though I hear about the meetings and long to be there. I hope your San Francisco journey goes wonderfully, I'm sure it will.

I've been filling in time with a pneumonic stop in Mather, a useful stay in a rehab called Oasis that had excellent rehab and in most other ways was better qualified to be renamed Mirage. Then a stay at home with many therapists — I first refused the occupational one thinking they taught you to make baskets ! But found my error and they were very useful too.

Felt I should be more Samsonish especially since hair (now silvery grey and extremely curly) growing apace — but no luck. Suddenly could hardly make it across the house even with walker completely breathless. Now back in Mather while they check out new cloud in lungs. This is my first (and I hope last) experience on oxygen but when you have very nice staff to deal with the tanks tubes etc it's much easier than I ever thought it could be. I am in a great room by the window that is such a pleasure. Trees right outside, birds, sky and wind.

Do you know a marvelous poem very short I once used to explain detecting high energy particles to non-scientists:

Oh who can see the wind?

Neither I nor you —

But when the trees bow down their heads—

The wind is passing through.

There is one more verse but that's enough to get the picture.

Much love Marie to you and all.

Liz