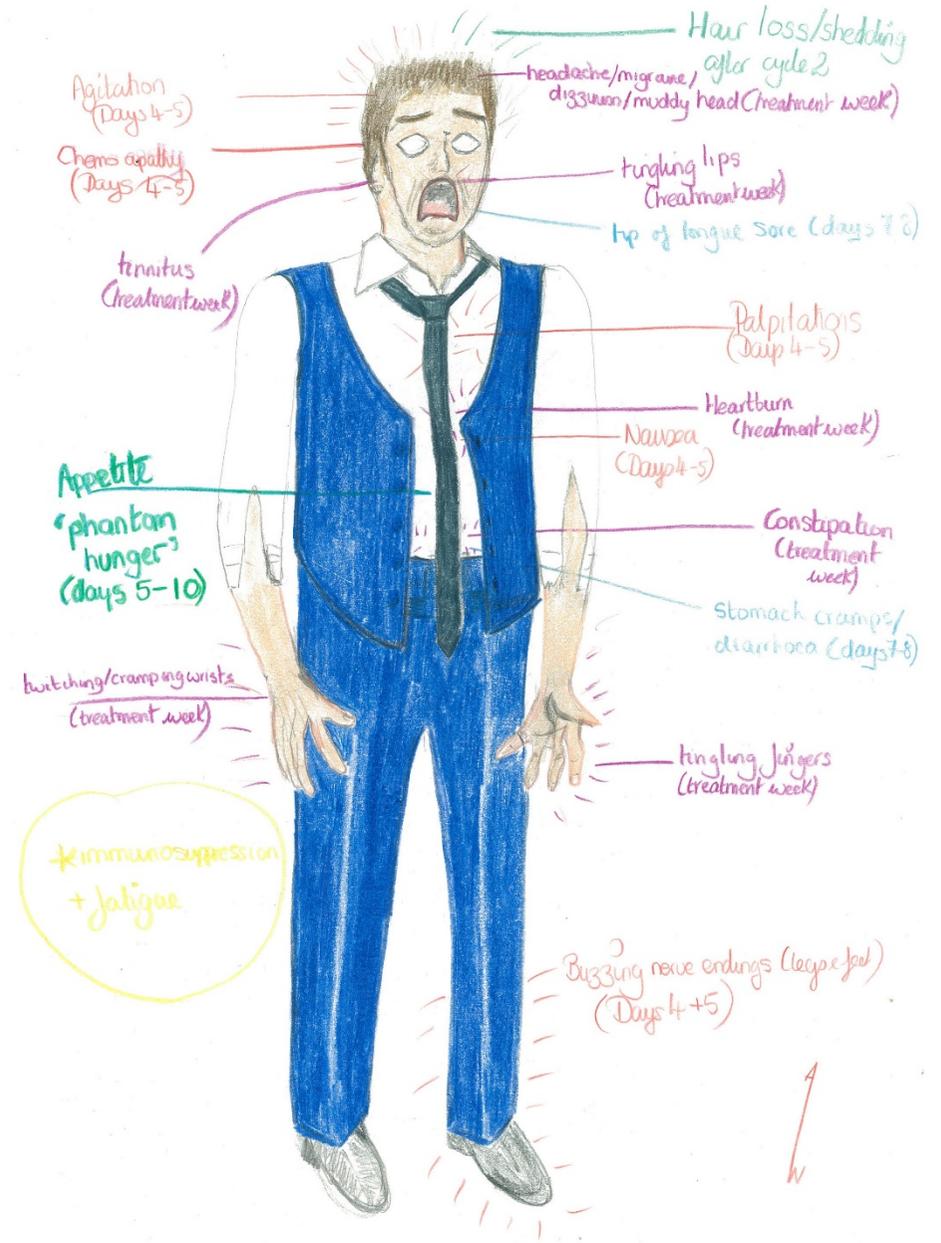


# Confessions of a FLOT patient

April 2018

FLOT Man – showing a summary of side effects and timings



10. I always had a bag packed with essential items, eg nightwear, underwear, towel and toiletries when I was undergoing treatment as you never know when you may need to be admitted and it saves your loved ones the aggravation of going through your drawers.
11. FLOT takes a minimum of 4 hours to infuse and with blood tests on top, you could be there 6 hours or more. Make sure you have something to eat and do to pass the time. I took a book, an art pad, my journal and my phone with plenty of music and programmes downloaded. There was Wi-Fi in the chemo suite so remember to ask for the code as it probably changes each visit.
12. I was told to live as much of a normal life as possible while receiving treatment. I did try to do this and went to all but two live concerts that I had booked prior to diagnosis. When out in busy places I tended to cover my mouth with a scarf and put Vaseline on my nose and mouth in an attempt to trap any viruses. I don't know if this works but anything is worth a try.

FLOT is a chemotherapy regimen for oesophageal cancer. I had four components plus add-ons as follows:-

- Docetaxel (1 hour infusion)
- Oxaliplatin/leucovorin (2 hour infusion)
- Fluorouracil (24 hour infusion at home)
- Dexamethasone (day of treatment and day before and after)
- Ondansetron (iv on the day and tablets 2 days after treatment)
- Granulocyte Colony Stimulating Factor (GCSF daily injections x5 starting 24 hours after treatment).

All chemotherapy produces side effects but it is difficult to predict how an individual will fare. You can read as much bump as you want to try to be prepared but nothing prepares you more than the first cycle. Hopefully you will fare OK. This leaflet sets out my experience of four cycles and things I did and wished I'd done before starting FLOT. It is worth noting that four days after treatment (detox day) was my worst day and then things improved so by 7-10 days following treatment, I felt reasonably human again.

### **Digestive system**

#### ***Constipation***

This was without doubt the most hideous side effect and brought a whole new meaning to being anally retentive. The anti-emetic ondansetron is probably responsible and you are damned if you do and damned if you don't take it. For me this required the most intervention and on my fourth cycle I decided to half the dose of ondansetron and 'tough out' the nausea.

If you read some of the online forums for ladies with hyperemesis gravidarum, who also are prescribed ondansetron, constipation is a major problem. If you have this drug, be careful eating high fibre foods even with plenty of water as without your knowledge, all digested food may end up turning into concrete in your lower intestine - the lines of communication are well and truly down! Prune juice helped the first time but I can't look a glass in the face now without feeling queasy. It's worth noting here that many people suffer the other extreme.

## ***Nausea***

I was given intra-venous ondansetron on the day of treatment and tablets for 2 days after. These kept nausea at bay but even with medication, the nausea did creep in and by day 4, it was quite marked. I was also given metoclopramide to take as needed but I didn't take any as I couldn't face any more side effects and the nausea was only bad for 48 hours. Having something in your stomach definitely helps as does relaxing as much as possible. 'Queasy drops' were helpful and also crystallised ginger. I also used sickness bands which worked when I was pregnant. It is possible to eat with the nausea but food does not taste great and I went off food I ate during this period. During the week of treatment, I ate what I fancied which was mainly comfort, easy to digest food in the form of shepherd's pies, pancakes and home-made trifle. During the second week I defaulted back to eating my usual fruit and veg heavy diet. It is also worth noting that during my good week, my appetite was pretty good (see Appetite and cravings).

## ***Heartburn***

Heartburn is what led to my diagnosis so controlling it has been a challenge. During chemo, I suffered from bouts of heartburn which were particularly bad the week after treatment. Even with PPIs and Gaviscon chasers, I still felt hollow. I was also eating high fat dairy to gain weight which often did not help.

## ***Cramping and diarrhoea***

The anti-sickness meds caused some cramping at the start of treatment, however I also got some on day 7-8 and during cycles 1 and 4, this was accompanied by a bout of diarrhoea. The good news is, except for some residual fatigue, this signalled the end of the side effects. Whoopee!

## **Top tips prior to starting FLOT**

1. Buy a digital thermometer as this will be required for taking your temperature twice a day.
2. If you are interested in keeping an eye on your lab results, ask your GP for a full blood count, liver and kidney function and nutritional status re B12, iron, magnesium before starting treatment. Ask for a print out so you can use this to monitor any changes or deterioration. Request another once treatment is complete so you can address any deficiencies.
3. Get as fit as you can prior to starting treatment. Staying active helps to counteract the side effects. If you have lost weight prior to diagnosis – try to gain a few pounds. This is incredibly hard but will help if you have a few days when you don't fancy eating much. Complian or Meritene shakes are good supplies to have in to boost your calories, vitamins and minerals.
4. If you have any issues at all with your bowels, ensure you get them moving prior to treatment and drink plenty of water. Get in some OTC laxatives (particularly glycerine suppositories), prune juice, beetroot juice, a precautionary tub of Vaseline and Anusol suppositories or Imodium if the other way.
5. Your hair is likely to fall out or thin so it is a good idea to acquire either a few chemo hats or a wig. You can get a free one if you speak to Macmillan at your cancer centre.
6. Buy either some latex free or sterile gloves – you will never know when these might come in.
7. Warm gloves – you will need these to protect your hands.
8. I read up on evidence of fasting during chemo to reduce side effects. I tried this on cycle 1 and 2 but by cycle 3 I couldn't be fuffed and just ate what I felt like. I personally did not notice a difference.
9. On treatment days, I took 1-2 litres of water to the hospital and made sure I drank most of it. Apart from keeping your kidneys going, it can be really hot on the chemo-suites and you need to keep your fluids up. Bottled water is getting bad press at the moment but it is handy to know the volume you are drinking.

## **Migraine**

I am very migraine prone and suffered a lot from a swimming, whoozy, muddy head during my chemo cycles. This was not helped by staying in bed too long and sleeping too long although the latter helped to stave off nausea. Horses for courses I guess.

## **Neutropenia and infections**

Neutropenia is a terrifying concept, however I was reliably informed that there was no way to predict it and going out or being with people makes no difference. I was extra careful to not expose myself to people with colds but could not avoid getting my husband's flu virus.

GCSF injections for 5 days starting 24 hours after my chemo helped to keep my white blood cells up. During the first cycle, my bones did ache after the injections but I had no side effects during the remaining cycles. I asked for a copy of my blood results a week after each treatment so that I could monitor any changes in white cells and this gave me more confidence to go out.

## **For the ladies.....**

Being perimenopausal, I was still having periods. My period coincided with my first chemo session and although this only lasted 4 days, bleeding started again 4 days later for a few days and then 14 days after again for 4 days. Essentially I bled 3 times within cycles 1-3. The bleeding was not heavy but was a real nuisance and would not have helped haemoglobin levels so it is something to watch out for. I have no idea what the mechanism for this bleeding is nor did I get a satisfactory answer from any health professional other than 'chemo messes with your hormones'. What I did notice was hot flashes really kicked in so whether I have gone straight to menopause without passing Go, is yet to be seen.

## ***Appetite and cravings***

Once the nausea had worn off at day 4-5, my appetite came back but this was in the form of insatiable hunger. The hunger sensation was so strong, I am not sure if this was a 'pseudo' or 'phantom hunger' caused by the chemo affecting gastro intestinal nerves but it did calm down. I just went with it and ate what I fancied to get the calories in.

After treatment, my GI tract felt like it was recovering from the mother of all hangovers. I felt as though all nutrients had been washed out and I needed to rebuild them. I craved meat and salt really badly and could not get enough of it. I am not sure if this is a sign of low iron but I just went with it and looked forward to the time when I could have a rare steak.

## ***Nose and mouth***

The inside of my nose was sore from the first cycle and although there were neither obvious lesions nor heavy bleeding, there was always some blood every day. My tip of my tongue was also tender a week after treatment – this took a couple of days to clear up and again signalled the end of the array of side effects for the cycle. I was lucky in that I did not suffer from any nasty mouth ulcers.

## **Hair loss**

Hair fall started quite significantly after cycle 2. Initially the scalp and hair follicles become quite sensitive and started to tingle. It was very uncomfortable especially at night when my head touched the pillow and after this, hair started to fall out in handfuls and the pain went away. My hair also started behaving differently and did not feel as though it belonged to me but then seemed to stabilise. It seemed that all the hair in its resting phase fell out leaving actively growing but very fine hair. Brows and eyelashes thinned but were OK and a lot of body hair vanished, which for ladies is a positive! It is worth noting here that my finger nails continued to grow normally and looked pretty good during FLOT.

## **Nervous system**

Lots to say here and it is mainly around keeping warm in every possible way. After treatment, I kept my hands warm all the time. If I took something out of the fridge or put my hands under cold water, they went numb/tingly for a while so I wore gloves or ran water warm during treatment week. I even wore gloves when in the chiller section of the supermarket. However I found the numbness went if I warmed up my hands. My feet were the same so I didn't walk on any cold floors without socks or shoes.

In the week after treatment, if I drank something cool or even at room temperature, it made my lips go numb for a short while and gave me an uncomfortable feeling in the throat. I was warned when leaving the hospital after treatment to not inhale the cold air as this can give the sensation of not being able to breath. I didn't suffer from this as I had a scarf over my face and also my husband got the car really warm before I got in.

I noted that on the day after treatment, if air passed over any skin it felt like shivers down the spine. It did not indicate a fever as temperatures were normal but I think it was overly sensitised nerve endings. In addition, when outside in the cool air, it felt like light rain on my face even in the absence of any rain. This was really odd but again I will put it down to sensitive nerve endings and it only occurred the day after treatment.

Hands and wrists after the second and third treatment had a habit of locking up/cramping – I tried home remedies for cramp, adequate salt intake, calcium, pumpkin seeds (or supplement for magnesium) or tonic water. Failing that I just kept the hands and wrists warm. This problem did subside during the second week and wasn't a problem during cycle 4.

Muscles in the wrist twitched as did my eye brow and lid. Really annoying but it does stop eventually.

I suffered from sensitive, buzzy nerve endings on my legs a week after the second cycle – it could have been like a form or restless legs from which I do not normally suffer. This did go away after a few days. I had it in my feet on the third cycle but had no issues in cycle 4.

## **Chemo-apathy**

This symptom is quite distressing and difficult to describe. It is real and is definitely the chemo as I didn't have it before treatment and it went away during my good week. I can only describe it as follows – you think the thought around wanting to do a particular task, eg I need to have a drink of water. However there is something keeping you from doing this, be it a lack of motivation or inertia or being in a stupor and just wanting to stay where you are. It is neither depression nor fatigue. You can physically do something but it seems easier and preferable to stay sitting and staring into space. Everything feels too much trouble and you just can not be bothered. For someone who is quite busy, I found this quite unnerving but I forced myself to do things and my normal motivation soon came back.

## **Detox day (Day 4)**

This is the day when I felt my most toxic and unwell– it was like the hangover from hell with bells on. Detox day was characterised by nausea, dizziness, palpitations, breathlessness, agitation and chemo-apathy. Prior to treatment, my resting heart rate was 65-70 bpm however on day 4-5, this could be >90 bpm and was accompanied by breathlessness and tinnitus (pulsatile, ie sound of pulse in your ears and the white noise kind) - really horrible but again it does all calm down after a few days. I suppose this could be fatigue as energy levels were also compromised due to the detox going on. I had extreme agitation during cycle 2 where I felt as though I did not want to be in my own body. It was nasty and I likened it to the 1980s horror sci fi movie Scanners as I felt as though my whole body was about to explode (see picture of FLOT man). There is no way of getting away from it. I tried to drink water by the gallon, ate what I could get down and tried distractions like the tv, computer games, listening to music and mindfulness. I also took up drawing in a big way which carried on throughout recovery from surgery.