

Confessions of a FLOT patient

Introduction

This information sheet is about my personal experience of FLOT (fluorouracil, leucovorin, oxaliplatin and taxotere [AKA docetaxel]), a chemotherapy regimen for oesophageal cancer.

I had the four main 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.

You can read as much as you can to try to be prepared for chemotherapy and its side effects but nothing prepares you more than the first cycle. Without doubt, the treatment affected all parts of the body from nerve endings in the feet to hair follicles on the head. These are outlined below as follows:-

- Digestive system
- Nervous System
- Nose and mouth
- Hair loss
- Neutropenia and infections
- Hormones
- Detox Day (Day 4)

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 largely responsible and you are damned if you do and damned if you don't take it. It required the most intervention and so on my fourth cycle, to nudge my large intestine into life, I decided to halve the dose of ondansetron and 'tough out' the nausea.

If you read some of the online forums for women with hyperemesis gravidarum, who are prescribed ondansetron, constipation is a major problem. So if you have this drug and are already prone to constipation, be careful when eating high fibre foods even with plenty of water as this could cause further issues! Prune juice can help but I personally can't look a glass in the face now without feeling queasy. It's worth noting here that many people suffer the other way, with diarrhoea.

Nausea

Intra-venous ondansetron was given on the day of treatment and in tablet form for 2 days after. Notwithstanding constipation, this kept nausea at bay but it did creep in and by day 4, it was quite marked. I was also given metoclopramide to take as needed but didn't in the end, as I couldn't face further side effects and the nausea was only bad for a 48 hour period.

Having something in your stomach definitely helps as does relaxing and distracting yourself as much as possible. 'Queasy drops' (www.notanotherbunchofflowers.com/products/queasy-drops)

helped as did crystallised ginger. I also used sickness bands, which I found effective in pregnancy for morning sickness. It is possible to eat with the nausea but food does not taste great and I temporarily went off a lot of foods that I ate during this period.

I tended to eat what I fancied which was mainly comfort, easy to digest foods 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 between treatments my appetite was pretty good.

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, it was like a 'pseudo' or 'phantom hunger' maybe 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.

Heartburn

Heartburn is what led to my diagnosis and it had not gone away, so controlling it was a challenge. During chemo, I suffered from bouts of heartburn and these were particularly bad the week after treatment. Even with PPIs and Gaviscon chasers, it was still there. Eating high fat dairy to gain/maintain weight also did not help.

Cramping and diarrhoea

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

Nervous system

I had my treatment in the winter at the time of the Beast from the East and it was bitterly cold outside. You are warned when leaving the hospital 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 thick scarf over my face and 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 could have been due to sensitised nerve endings. In addition, the cool air outside felt like light rain on the face even in the absence of any rain. This was really odd but again probably due to sensitive nerve endings and stopped the following day.

In the week after treatment, drinking cool liquids or those at room temperature, made my lips go numb for a short while and gave me an uncomfortable feeling in the throat. I made sure 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 them under warm water a lot during treatment week. I used to wear gloves when in the chiller section of the supermarket. Thankfully, the numbness went as soon as hands were warmed up. My feet were the same so I didn't walk on any cold floors without socks or shoes.

Muscle cramps

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 continued to keep my 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 eyebrow and lid. Really annoying but it does stop eventually.

After the second cycle, the nerve endings in my legs were sensitive and buzzy - like a form or restless legs from which I do not normally suffer and that went away after a few days. I had it in my feet on the third cycle but had no issues in cycle 4.

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 and sleeping too long although the latter helped to stave off nausea. Horses for courses I guess.

Chemo-apathy (chemo-brain)

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 and haven't had it since. 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.

Nose and mouth

The inside of my nose was sore from the first cycle and although there were neither obvious lesions nor heavy bleeding, my nose bled every day. The 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. Some people also get nasty mouth ulcers but thankfully I didn't get those.

Hair loss

Hair fall started quite significantly after cycle 2. Initially the scalp and hair follicles were very sensitive and tingly. 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 felt detached even when it was still attached. It seemed that all the hair in its resting phase fell out leaving actively growing but very fine hair.

Brows and eyelashes also thinned but were OK and a lot of body hair vanished, which was a positive. The only exception was for nose hair as this resulted in a runny nose, almost all the time!

It is worth noting here that my finger nails continued to grow normally and looked pretty good during FLOT.

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.

GCSF injections for 5 days starting 24 hours after my chemo helped to keep my white blood cells up. During the first cycle, the injections caused achy bones 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.

Hormones

Being perimenopausal, I was still having periods when I started chemotherapy and my period coincided with my first cycle. Although this only lasted 4 days, bleeding started again 4 days later for a few days and then 14 days later, again for 4 days. Essentially I bled 3 times within cycles 1-3. The bleeding was not heavy but was a nuisance so it is something to watch out for if you are a woman of a certain age. I have no idea behind the mechanism for this bleeding nor did I get a satisfactory answer from any health professional, other than 'chemo messes with your hormones'. What I did notice was the hot flashes really kicked in after this point.

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. 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.

Top tips prior to starting FLOT

1. Buy a digital thermometer as you will need this to monitor your temperature twice a day.
2. 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 set, once treatment is complete so you can address any deficiencies.
3. Get as fit as you can prior to starting treatment. Staying active definitely helps to counteract 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. Complan or Meritene shakes (available online or from Boots) are good supplies to have in to boost your calories, vitamins and minerals.
4. If you have any issues with constipation, ensure you get your bowels moving prior to treatment and drink plenty of water. OTC laxatives, prune or beetroot juice, dried mango, Vaseline and Anusol suppositories and Imodium in case of diarrhoea are all useful purchases.
5. 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 wig 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. Read up on fasting and chemo in relation to reducing side effects. I tried fasting 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 but other people can benefit.
9. Make sure you take 1-2 litres of water to the hospital and make sure you drink most of it. Apart from keeping your kidneys active to flush out the meds, it can be really hot on the chemo-suites and you need to keep your fluids up.
10. Always have a bag packed with essential items, eg nightwear, underwear, towel and toiletries when undergoing treatment as you never know when you may need to be admitted for monitoring and it saves your loved ones the aggravation of packing for you.
11. FLOT takes a minimum of 4 hours to infuse and with blood tests on top, you could be there 6 hours or more (my record was 9 hours). Make sure you have something to eat or something to 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 booked prior to diagnosis. When out in busy places I covered my mouth with a scarf and put Vaseline on my nose and mouth in an attempt to trap any bugs. I don't know if this works but anything is worth a try.

Chemo-legacy - 3 years post-treatment

While rehashing this leaflet, it got me thinking about whether I still live with any physical affects of chemotherapy so here are a few reflective points, three years on.

1. **Nervous system:** The nerve agents have definitely affected my hands and feet. I can not carry very cold items for long before the ends of my fingers become painful. Similarly I can not tolerate cold hands. I also do not like walking barefooted on cold floors and wear socks or shoes around the house even in summer.
2. **Migraine:** I do not know whether it was the chemo or the cocktail of drugs used in surgery but I no longer get the migraines I used to get. The only time I get headaches now, is if I do not drink enough water and I usually wake up with one.
3. **Hair:** I noticed my hair starting to grow back 12 weeks after the last cycle. It grew back thick, curly, course and grey. My husband said I resembled a fox terrier. I've lost count of the number of haircuts I have had since it got more establish and my hair is as long now as it was before I was diagnosed. It has also gone back to its original texture ie no longer curly and I have coloured it again, although I waited a year after chemo to do this to protect new growth. Hair grew back elsewhere too but I noticed my nose ran for months after chemo stopped probably due to hair loss in the nasal cavity. Although a kind of rhinitis persisted for a few months, I can not remember when it stopped being a problem.
4. **Hormones:** My ovaries put up a fight at the time but chemotherapy definitely signalled the start of menopause. Whether it would have happened anyway, who knows?
5. **Hygiene behaviour:** I was very careful about touching surfaces when I was out and keeping my nose and mouth covered all through treatment and this has been great training for dealing with the coronavirus pandemic as you easily slip back into these learned behaviours. The sterile gloves I bought at the time have also come in very useful.