FEC-T and Me: One Woman's Experience of Chemotherapy

About Me

Everyone is unique, everyone's story is unique and everyone's experience of chemotherapy is unique. This is important to remember, because what I write might or might not be true for anyone else.

At the time of my diagnosis I was 47. I found a lump, saw my GP, had a 'rapid referral' to the breast clinic and two weeks later was diagnosed. My formal date of diagnosis is 30th August 2010, a week after I first saw the breast surgeon. I had a 'large' lump (it turned out to be 8cm and included some pre-cancer or DCIS) and one abnormal lymph node. My consultant recommended a course of neoadjuvant chemotherapy ahead of a mastectomy. He was very clear that my cancer was 'early' (primary) that treatment was 'therapeutic' and that 'we will talk about this in five years time.' My oncologist reiterated this.

At the time of my diagnosis I had almost waist length hair which had never been coloured. Losing my hair seemed worse than having cancer. Nuts, but that's how it was. I had just completed a long distance footpath across Scotland and was, so I thought, fighting fit: how could I have a life-threatening disease when I felt as if I could rule the world? Well, I could; I do.

At the time of writing this I am waiting for surgery - the chemo was very effective, significantly shrinking my tumour (my oncologist said it was 'difficult to measure accurately') and my lymph nodes 'felt normal.' I can no longer discern the lump which is great, but of course doesn't mean the cancer has gone, just that the tumour is very tiny.

Other stuff about me: I am a Baptist minister in Scotland, I love chocolate, walking long distance footpaths and cats. I am single (never married) and never had children. I have never smoked and am tee-total (because I don't like the taste; no great virtue). I have enjoyed good health all my life – until this happened it was over thirty years since I had any prescription drugs! All these factors shape who I am and how I react to stuff, spiritually, physically and emotionally.

Why Write This?

There are any number of places to find info about chemotherapy and its effects. My hospital gave me a copy of the fact sheet from MacMillan Cancer Care; I downloaded the leaflets from Breast Cancer Care(BCC) and I checked out Cancer Research UK. These are good websites, reasonably 'safe' in so far as they don't scare you too easily. Of the three I found BCC the most helpful and have, from time to time, 'lurked' on their forums when I wanted to check out things that were happening. The BCC forums are good and well moderated but of course they tend to be people who are having bad experiences seeking support advice and help. Whilst I found them useful, I needed to be careful not to gain new anxieties! MacMillan also has forums and clearly some people find them helpful too.

Beyond the 'official' stuff there is any number of blogs where people tell their stories – many are incredibly inspiring as very brave women tell their stories, often very openly sharing the struggles they face. Some, like me, have an active religious faith, others don't. Sadly a lot of the dedicated blogs, especially of younger women, stop suddenly when the writer dies; this can be a distressing discovery. Other blogs move and change as the writer is declared No Evidence of Disease (NED) and moves on into a new phase of her life; these can both encourage and discourage (the danger of what I have come to call the 'what if fairy': what if I live, what if I don't, etc.?).

And books – endless books: some happy, some sad, some factual, some sensational (in any meaning of the word); I haven't read any, though have used Amazon 'search inside' to look at a few contents lists. You could buy lots of books on all sorts of views about breast cancer. If they help you that's great; I felt it would all be too confusing and potentially too demoralising (again much of the biographical stuff ends in death).

So, given all the stuff that's out there, why I am writing this? Basically because I seem to have had a mainly good experience of chemotherapy, which I am sure is largely down to good advice followed closely, along with good support networks, a willingness to be open about what was happening and possibly a bit of 'luck' (if a Christian is allowed to use such a word!). Just maybe by sharing the advice I was given and some of my experiences, someone, somewhere, might find it vaguely useful. *I would stress, though, listen to your own oncologists and your own body – you are unique and precious and my experiences may not be anything like yours.*

General Advice I've Found Helpful

The old saying: all advice is bad advice and good advice is fatal. Well, I've never really subscribed to that viewpoint and I've certainly had lots of helpful advice which I'd like to share. Use or ignore as works for you.

1 Accompanying, Accountability and Boundaries

My first bit of helpful advice is this: find someone who can walk this path with you. On the day I met the surgeon who would make my diagnosis, the first thing he asked me was 'is there someone with you today?' To which the answer was 'no.' When he came to do my biopsy he brought a nurse to hold my hand (literally) and they both said very clearly, 'bring someone with you when you come for the formal results.' (They did a fine needle aspiration which showed it was cancer but formal diagnosis needed the results of the core biopsy). One of the things that struck me especially is that most women had another woman with them – sister, mother, daughter, friend – it may be that your partner can fulfil this role but it's OK if he/she can't.

Choose your accompanier carefully and decide what their role will entail. I chose someone who I trusted to take good notes of consultations, and who could ask questions if I clammed up or missed something. This meant that she would inevitably get to know a lot about my body and how it works as the questions you get asked are inevitably pretty personal. So, imagine if you will, a minister discussing her menstrual cycle in the presence of a member of her church...! The notes my friend took have been invaluable – not least because she heard the positives when I couldn't.

Linked to accompaniment is accountability. For me this was important as I live alone and am very independent. Having someone who expected to hear from me after treatment, who knew where I would be and when, far from being a hindrance was quite liberating. If you live with others this may seem redundant but having someone with permission to hold you accountable is helpful – whether that is your need to rest, reminding you to take your drugs or someone to say 'no' to banned foods.

The hospital where I was treated allowed you to take someone with you for your first treatment only, other hospitals will vary. This was really useful as it meant someone else knew firsthand what was involved and could explain to other people that it really was 'ok'.

The flip side of having someone to walk with you is the risk of 'invasion' of personal space by well-meaning people who want to help and support you but who inadvertently cross a 'line' into your personal world in a way that's unhelpful. Everyone needs to define their own boundaries – and be willing to defend them either personally or by appointing what I termed 'Rottweilers' who will step in if need be. Answerphones are a great intermediary in screening phone calls, email allows you to read things only when you are up to it; 'no' is a word some of us have to learn to say! For all that, there is a balance to be found because times may come when you want/need those same people around... it's not easy but awareness is probably the key to getting it 'right enough.'

2 Symptom Diary

I was advised to keep a symptom diary on a daily basis – which sounded like a chore but turned out to be very helpful. During the first cycle of each part of the regime it was all 'unknown' so I wrote quite a lot about what I experienced – from itchy skin to foods that disagreed to how I felt. What I discovered, and my oncologist affirmed, is that experience in the first cycle usually sets the pattern so as treatment progressed I could look back and see what had happened (I didn't remember everything!). Knowing what was likely to come also helped me plan my days and to spot any differences.

One real concern during chemotherapy is infection – this can be fatal so it is really important to take it seriously. I was advised to buy a digital ear thermometer, which although expensive is easy to use and avoids putting things into a mouth that may be sore. I chose to monitor on a daily basis, recording the results in my diary. Once or twice my temperature rose to 37.5C which is the 'trigger' for concern, once it hit 38C which is the trigger for immediate action **(go to hospital)** which would have been impossible to discern otherwise. My infection occurred in week 2 of my final cycle and was probably a bad cold, however I was given high dose, broad spectrum antibiotics... do not ignore sniffles! I know this sounds scary – and three hours in A&E wasn't pleasant – but it could save your life.

3 Diet

There is all manner of weird and wonderful advice on diet out there, so listen carefully to your oncologist or specialist Breast Cancer Nurse (BCN). This was where having my friend with me was handy as we were inundated with advice!

Basically the advice is to eat a balanced diet and to accept the fact that you will probably gain weight due to the steroids you will be prescribed. However, due to the side effects of the drugs you will be probably be advised to avoid certain foods – what I term the 'banned list.' I avoided all of these and it seemed to pay off.

Avoid acidic food, especially anything citrus (look out for citric acid in drinks and processed foods), pineapple and cranberry.

Avoid anything that is 'live' (risk of food poisoning) , so no pate, soft cheese, raw egg etc. Also no yogurts as these are 'live' – those friendly bacteria may not be when your immune system is compromised.

I found that I couldn't cope with tuna, hard cheese, mayonnaise or anything highly flavoured. For large parts of the treatment I couldn't taste much and what I could taste seemed horrible, so it's basically a case of finding what works for you. I was advised to stick with 'soups and smoothies' but a lot of shop-bought smoothies break the rules so it's not that easy. I got very fed up with soup and in the end I ate a lot of pasta with tomato based sauces, some chicken, lots of fresh vegetables and fruit, porridge and cereal. I drank gallons of water (good for many reasons) tea, coffee and occasional milkshakes.

By the end of my treatment I'd gained about half a stone – and this continued to rise for a week or two: perhaps once my taste-buds recovered I ate a few too many treats! The hospital did not see this as any cause for concern (I was at the upper end of healthy weight before I began treatment, so am now only a little overweight).

4 Hair

Chemotherapy drugs attack all cells that are growing. Among these are hair.

I was advised to have my hair cut before beginning treatment and to have my head shaved once the hair fell out. There are practical and psychological reasons for this.

The official guidelines tell you that hair loss is likely to begin in two to three weeks; my hair began to fall out ten days after I began treatment and was almost complete within another four days. Other people's may take longer or be more patchy. Watching hair wash off your head in the shower, leaving your hands looking like a gorilla, is at best weird and at worst traumatic. Having had my hair cut meant the hair that fell was shorter and so less distressing (I'd already dealt with the worst sense of 'loss' having it cut from long to short). When it started to come out my scalp became very sore and itchy; brushing was painful. Some people say they can't stand the feel of wind in their hair at this stage because it hurts; I actually didn't mind it, but it was sore. Maybe this is fanciful, but I thought I could almost hear the hairs break off, and certainly felt some of them break off. By the time I had my head shaved I was actually glad to see the back of what was left – it looked a mess and my scalp hurt. By making my own decisions to have my hair cut and to have my head shaved I regained a bit of control; many other people also say this. Surprisingly I found I looked quite good bald!

It's not just head hair that is affected; it is every hair on your body – pubic hair, underarm hair, leg hair, eyebrows, eye lashes, nasal hair. Everyone is different and there is some variation: at the end of FEC I still had eyebrows and eyelashes, within a week of Docetaxel (Taxotere) my eyelashes fell out and my eyebrows thinned dramatically. Not having to shave my legs or under my arms was a minor consolation, but not everyone experiences this.

I'd never thought about the function of hair until I lost it – body hair soaks up perspiration so I had to keep an eye on the skin in some areas as it sometimes got chafed and sore. Sudocrem and E45 were part of my daily routine!

The NHS supplies (Scotland) or subsidises (England and Wales) wigs and I have a lovely wig hanging on a stand in my bedroom. Alas my scalp was so sensitive I never did get to the point of being able to wear it, but some people find them great. I used a lot of scarves and hats in public but was (and at the time of writing still am) mostly bareheaded at home. I think you have to work out what works for you and allows you to live life your way. My lovely church people embraced my headscarves (chosen to match my outfits) and the hospital was a place where you can be free to be bald if that is more comfortable.

A quick word on scalp cooling. I opted not to use this as my research indicated it is ineffective for most people. I have no regrets. Another woman on the same treatment tried scalp cooling and found it slowed down her hair-loss but after two treatments reached a point where she had her head shaved. It bought her more time to come to terms with the treatment and might have worked; she had no regrets either. She told me it was uncomfortable but tolerable. You have to decide before the first treatment whether or not to try scalp cooling and should not be pressurised either way.

5 Skin

Like hair, skin grows and regenerates quite quickly. Chemotherapy can affect skin, and certainly if you have sensitive skin to start with (as I do) you need to take care of it.

One shock to the system, which doesn't appear in any of the official guidance, was that I got acne after each dose of drugs – to have teenage spots at the same time as a chemical menopause felt a little unfair. My chin, my nose and my scalp all feel prey to 'zits.'

At the same time my skin became very dry. I switched to E45 shower and bath products which smell like copydex glue (yuk!) but are kind to dry skin. I moisturised all over (including my scalp) daily with E45 cream and used Sudocrem on the creases when they got sore. Keeping skin intact is really important in avoiding infection. Using unscented, hypo-allegenic products is best – and there are a few to choose from.

Skin rashes are also quite common (I had a bit of a rash on my face with the Docetaxel) so it is really important not to change any laundry products which may affect your skin adversely and mask drug induced effects. If you do get significant rashes do tell your oncologist, they can prescribe suitable creams etc.

Some people continue to use make-up but it is generally discouraged.

Skin care is obviously more than just your face; you need to be very careful with any minor injuries – nicks, cuts and burns especially as broken skin can be a route for infection. Wash any broken skin injuries with Dettol or TCP and cover with a clean, dry plaster.

6 Nails

Both drug regimes affect your nails, as can be seen by the horizontal lines or ridges that appear at three weekly intervals – a bit like tree rings! The effect on nails of FEC is fairly minor but the Docetaxel can cause them to fall off . I was advised by the BCN to use dark nail varnish on all my nails (fingers and toes) throughout the treatment and for a few months afterwards until the damaged nails have grown out. You need to go right to the edges of the nails and importantly right down to the 'quick.' I have not lost any nails (yet) but have noticed that they are very soft and horribly discoloured (like smokers nails). The drugs apparently increase photosensitivity of your nails as well as weakening them. I found that my nails grew more slowly than usual during both drug regimes.

Manicures are 'out' during chemo as damage to cuticles must be avoided and you are advised to keep your nails very short as this reduces the risk of them getting broken or splitting. As a clue to how soft my nails became, even peeling a label caused them to break.

7 Mouth

The mouth is another part of the body that regenerates very rapidly – as we all know form when we burn it by heating very hot food. As a result of the chemotherapy drugs this ability is compromised and the effects can vary from dryness to mouth ulcers; for some people this can be truly horrendous.

I was advised to switch to biotene toothpaste, which is a specialist dry mouth formula. It tastes pretty grim (no minty flavour) and does not 'foam' but it is very kind to mouths. I drank gallons of water, sucked boiled sweets (beware crunching them as the rough edges can cut your mouth) to promote saliva and 'strepsils' if my throat felt sore. I also let my food and drink cool a little and avoided anything very cold. I kept some alcohol free mouthwash on hand (check labels, various ones are suitable) which I used periodically if my mouth felt a bit sore.

My mouth became very rough and dry in the first week or so of each cycle, but I escaped without any ulcers. I had a 'tickly' throat at some point in each cycle which is why I used strepsils – rough or sore throats are more easily infected; something to be avoided if at all possible.

Vaseline was useful to protect my lips when they became dry.

8 Digestive Tract

The digestive tract extends from mouth to anus, and every part of it gets affects by the drugs. As already noted, I found that my digestive system became very sensitive during treatment and there were things I couldn't eat without upsetting my stomach. I was warned that both diarrhoea and constipation can result, and kept 'over the counter' medication for both on hand. As a precaution, I took an odd diarrhoea tablet if I ate something that upset my stomach, but otherwise was fine provided I stuck with my restrictions. My stomach was at its most sensitive about a week into the cycle. Thankfully I had no constipation.

There were two other effects, both very 'normal' but not so well documented in official guidelines.

The first was acid indigestion (heartburn) which occurred in the first part of each cycle. I was advised to buy Gaviscon but found it didn't 'touch' the pain. My oncologist prescribed Losec which was like magic, and I had pain-free experiences thereafter. An important tip: do tell your oncologist of any unpleasant side effects – they can help.

The second effect is what many people call (indecorously) chemo-farts. Flatulence seems to be an inevitability – lots of it and sometimes very smelly! It is nothing to be worried about but it helps to know it might occur.

9 Take-home Drugs

Modern chemotherapy is incredible well-managed and the hospitals do everything they can to keep you well throughout. It is really important to take your 'take-home' drugs exactly as prescribed and to tell your oncologist or BCN if you have any adverse effects. The drugs are of two main types – steroids and anti-emetics. For a few people there is a need for stronger anti-sickness medication and this can be done, if needed.

Another undocumented (so far as I can discover) effect is the impact of steroids on sleep – almost everyone seems to find that they don't sleep whilst taking their steroids. Sleeping pills can be prescribed if loss of sleep is a real problem, but most people seem to put up with it, as it is usually only a few days of each cycle.

Do not wait to see if you are sick! Evidently it is harder to stop sickness than to prevent it. I was not sick at all but was sometimes conscious of a very slight 'seasickness' sensation so I am sure the drugs worked.

About FEC – My Experience

FEC – Flourouracil, Epirubicin and Cyclophosphamide– is a well tested and trusted chemotherapy 'cocktail.' There are two ways it can be delivered; mine was the one where they inject all the drugs on day one.

Having FEC is quite a personal and intimate experience as the nurse has to sit beside you and inject the drugs (via a canula in your hand/wrist) over about an hour.

The process begins with the insertion of the canula and then some saline is used (via a drip) to 'flush' the canula before the drugs are given by injection. The nurse explains any possible side-effects and you must tell them if these occur; one of the drugs can make you feel woozy, fortunately I was fine. Towards the end of the session you are given some anti-sickness drugs via an injection into the canula – the one they used at my hospital can (and did!) cause an itchy bottom, but this passed very quickly. Finally you have some more saline to flush the vein after the drugs. The whole process takes about an hour to an hour and a half.

It is essential to drink lots of water in the first day after FEC to flush through the aggressive effects of the drugs which can, evidently, cause a form of cystitis. I used bottled water with 'sports' caps which had the advantage that you can open them 'one handed' and they don't spill if you knock them over – handy when you are being injected. I felt quite thirsty anyway, so drinking plenty of fluid was no hardship (though it meant extra loo trips!). I had no problems, so assume the drinking helped.

My main effect was what I referred to as my 'floppy' phase. This began about five hours after the infusion and I felt my energy drain away as if someone was turning down a dimmer switch. I could function normally for about three to four hours a day but had to rest after that. During that time I found my senses (except taste which vanished) very heightened – smells were stronger (and unpleasant), sounds louder etc. For me, watching television was too noisy and high energy – even daytime drivel! I preferred to be quiet and sprawl on the settee. After about five days the effect reversed as quickly as it came, my energy levels rose and I could enjoy the remainder of the cycle with a near-normal life.

I did experience one adverse effect that forced me to see my GP. This was vein pain. Phlebitis (inflamed veins) is a well documented side effect of FEC, and which my oncologist told me is caused by the Epirubicn (E, the red liquid). Because I was neoadjuvant (pre-surgery) , I could switch arms between cycles; for adjuvant (post surgery) this will not be possible. The vein pain began as a sense of bruising close to the injection site; within about 24 hours the pain spread along the vein, on one side as far as the elbow and on the other into the upper arm. At the same time the vein 'tightened' (shrank) and it became very sore to straighten my arm. Having been checked to ensure there was no infection, I was advised by my oncologist to try to use the arm(s) as much as possible to avoid permanent damage. This is like advice for sprains. It seemed to work as I recovered full movement in both arms and within a few weeks the pain abated. Believe me it hurt a lot to stretch my arms but it was worth the pain. Use of over the counter painkillers is permitted (after checking) if it is vein pain, but you need to be sure there is no infection first.

About Docetaxel – My Experience

Docetaxel is the 'T' because the brand name before it came out of patent was Taxotere; some hospitals use this brand, others (like mine) use generic forms.

Administration of Docetaxel is by drip, so is a less intimate experience than FEC, so it's useful to take a book or to hope the person in the next chair is chatty. Including the before/after infusions it takes about two hours.

The day before you have chemo, and again on the morning of treatment, you have to take a lot of steroids, this is really important as it is quite an aggressive drug. Like FEC, it begins with the insertion of a canula in your hand/wrist which is flushed with saline. You are given anti-sickness medicine (a tablet at my hospital) and then more steroids (by infusion) and your blood pressure checked before treatment. At my hospital they also gave you Piriton (anti-histamine) as an infusion because docetaxel can cause allergic reactions. The infusion lasts about an hour – time to read/chat – and you really must attract a nurse if your feel adverse reactions, described as like being kicked by a mule in the small of your back. After treatment you have more saline before you can go.

Doctaxel really hammers your blood so you have to have a special injection 24 hours later to help it recover, this is called neulasta and is usually administered by a district nurse.

I am not entirely sure which effects were Docetaxcel and which the neulasta, as they overlapped. I found I felt very stiff for about three days – as if I'd exercised really hard. After the neulasta I had bone pain, mostly in my lower spine but also on my jaw, skull and sternum! I was able to relieve the pain with ibuprofen, but some people need stronger painkillers.

During the first cycle the pain was worse than in subsequent cycles, partly because I had to learn how to manage it, and I had one evening when I simply could not get comfortable. What worked best for me was one ibuprofen every three hours – but everyone is different. Warm baths help ease the stiffness.

One side effect of Docetaxel can be mild peripheral neuropathy – loss of sensation in fingers or toes. I found I was more clumsy than usual in the first week of each cycle and still have reduced sensation on the tips of my right thumb and fore-finger. This may improve in time or it may not.

The good news was that I had no loss of energy. I was able to function pretty much as usual, although the cumulative effect of four month's treatment and sleep loss meant I was tired and ready for bed by 9 p.m. most days and 8 p.m. on occasion.

Chemical Menopause

At the time I started treatment I was not even peri-menopausal, everything was near text-book regular. I was told that the drugs would almost certainly stop my periods and that they would be unlikely to restart. As it happened, I continued to menstruate for two months before stopping. The second of these was the 'daddy' (or 'mother') of all periods – very painful and very heavy; this is evidently not unusual, but no-one thought to warn me. I was told retrospectively it is fine to take paracetamol or ibuprofen for this; I used hot water bottles!

Since then I've had lots of hot flushes and night sweats; again this seems to be quite common. I reckon I have about 10-12 hot flushes a day and 3-4 night sweats. Inevitably this takes its toll – interrupted sleep and general weariness. There isn't much that can be done about this during the treatment phase but I'm told longer term there are some herbal things that are safe to use (they don't like you taking ANYTHING they don't known about or approve during treatment).

Week 3, a Few Treats and Other Support

Week 3 is a special time during chemo – the side-effects of the drugs have abated and you tend to feel quite good. If it wasn’t for seeing your oncologist and having the next dose of drugs it'd be great. A few treats during that time are a good idea – food you can taste, a longer walk, visiting friends, whatever works for you and gives you a lift. Some people find alternative therapies to be helpful – massages, aromatherapy etc. Just a word of caution – check with your oncologist before doing any of these (unless they are offered by your hospital/cancer support centre) as it seems some oils can prove problematic. It is worth checking out any cancer support centres in your area which can offer practical advice, support groups, alternative therapies, counselling if you value, desire or need them.

There is no one size fits all - we all find our own way through.

Climbing Mount Chemo

My metaphor for chemo was an uphill climb on a zig-zag mountain path, each cycle being a new twist on the way. It was a long climb – lasting four months – and I was tired when I reached the 'top.' Getting an infection right at the end – fortunately only a minor one – was scary and disappointing and served to show me how much the process has taken out of me, yet overall I did really well and have emerged largely unscathed.   I have a couple of 'fibrous' veins but they have normal flexibility so I've got off lightly. The treatment was effective and I approach surgery with a tumour that has been significantly 'down-staged' – making that process easier and safer.

I know I've been fortunate not to suffer adverse side effects and that I have been very well supported. I hope that these ramblings might be of some help to someone else as they climb their own mountain with this regime.

If you've read all this stuff, thank you for doing so, and I pray that your, or your loved ones, chemo story will be a good one.

Catriona

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Sept 2010

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