

## **“A day in my life or my life in a day” .....**

A true story of disease management from a patients' perspective

### **Alison Sundset**

**6.29am** .....”*Bleep... bleep ...bleep*” the familiar yet undesired sound of the alarm clock. These days I am not sure that I need to even set the alarm as I am awake hours before the little clock wakes itself up! I have lain awake planning how to fit my day ahead into 24 hours.

.....Well, it's Monday morning and the start of another week in the Taylor household. The year is fast turning into “annus horribilis” for me and my family! Just at the moment, I can only manage myself and my immediate family through one day at a time.

I would like to share with you “a day in my life or my life in a day” depending how one looks at it, but I think however you look at it, my life just now is not one I would wish upon anyone! I will start with myself before I jump into the shower. ...

Well, I am happily married with two children, Evi, 16 and Wills 13. I work as a PA for the local bank manager, I am “49½”years old and here's the new part: I have breast cancer!! This has taken me many weeks to absorb, let alone write down on paper. It was actually 3 months ago today that I sat staring into the deep trusting eyes of “my Oncologist” to hear him say – the “C” word. As the words sank in slowly, I could only think of the journey ahead and what it would mean to the management of the “home” – how will they cope without me?? I have now lost the words “without me” and instead look at the management of fighting through this. I had the surgery to remove the sinister body from my breast, traumatic surgery for me, but according to the smiles of the surgeon, everything had gone according to plan. Today, my third round of chemotherapy is scheduled. I am on the “standard” treatment so I am just another case and nothing too challenging, it would seem! The treatment - there are no words that can prepare you for the effects of this – it just knocks me out!! I can only hope that my body has recovered enough to have my next round of treatment. If only there was a way of knowing if my white cells have recovered enough, well in advance of the treatment, so I can have my next dose.....

**7.00am** - Shower!! As the warm water pours over my thinning hair my thoughts drift over to my precious daughter. A big day in her life today, actually a day in which she starts to shape her

future pathway. It's Evi's first GCSE<sup>1</sup> and of course it would have to begin with maths, her worst and most feared subject. She has been a big worry to us and to get her to these examinations is in itself a victory! Evi was diagnosed with Crohn's disease when she was 12 years old. At first, we all thought it was the usual period pain cramps, but suddenly she started losing weight, dragging herself around and seemed to have a constant need for urgent toilet visits at the most inconvenient times. The poor girl had to go through batteries of tests until they finally diagnosed her by a very invasive scoping procedure of her intestine. The disease symptoms come and go but reappear in differing grades of immobilizing pain and unpleasantness. In between the flares, Evi is on what they call maintenance therapy, where the goal is to give potent therapy in such carefully calculated doses to suppress disease activity but avoid potential side effects. I just hope that the specialist adjusted the dose right after our last clinic visit as I am so concerned that the stress of the examinations will bring on a flare. Someone is already banging on the bathroom door, my few moments alone, reflecting on the the day ahead, are over and Wills is trying to hit the shower before Evi occupies the bathroom "for an hour", as he carefully overstates daily!!

**7.30am** Usual noisy family breakfast at 5, Ellerby Drive!! Wills is running in the county athletics trials this evening and this dominates the breakfast discussion, which is a relief I think for both Evi and myself, lifting us out of our own troubled day ahead. They both took many weeks to understand and digest that "Mum" was sick; Wills went really inside himself and it seemed that it was too difficult for him to discuss this with me! I think Wills represents my bad conscience. He seems a happy-go-lucky teenager, but he only gets the few remaining minutes of my day dedicated to him and that really isn't enough. Evi and her chronic illness have dominated my time after work.

**8.30am** They left for school, and again, I am left in my own thoughts, bathing in the short but direct shafts from the morning sun, showing me how little time I have had recently to clean, the sun happily highlighting the pathway of dust across the kitchen dresser. Oh well, it will have to wait.....

The sun feels comforting; we have talked about planning a holiday in the south this summer. It would be good for all of us and I would have a milestone to look forward to beyond chemotherapy. The reason why we have delayed is the challenge of forward planning with Evi's condition. It is difficult to manage her abroad with the unfamiliar locations of the lady's rooms etc. The flight itself stresses Evi; just the embarrassment factor alone of the very public toilet facilities etc.

---

<sup>1</sup> The General Certificate of Secondary Education (**GCSE**) is an academic qualification awarded in a specified subject, generally taken in a number of subjects by students aged 15–16 in secondary education in England, Wales, and Northern Ireland

It would make a huge difference to us as a family if there was a way of predicting Evi's relapses of remission, then we could plan holidays, a trip to the West End and the world of the theatre – imagine that?.....

**9.30 am** Household chores done and now just enough time to time to pop into Mum and Dad's on my way to the out-patients clinic. I usually use the excuse that I am just popping to the shops and should I pick something up for them, but these days I really need to check up on Dad. My father is your typical retired 67 year old, worked hard all his life in the restaurant business and planned for a long and well deserved retirement, together with Mum! Last winter, he was diagnosed with diabetes and it would appear after that he gave up on life. It was as if he had been given a label on his forehead "I have a chronic disease and therefore I am sick". It was diagnosed in a routine visit to the GP when getting his flu injection. It would seem he is a victim of the restaurant industry social eating and drinking, no exercise ...and smoking! A walking time bomb, my Mum calls him. The GP requested that he lost weight and Mum immediately put him on a "healthy diet" but he is still hugely overweight and seems to be glued to the armchair. He was diagnosed with type 2 diabetes - the common one! It has been a difficult time for Mum, I know, although she never complains. Because he has done little to nothing to change his life style, I have understood that his condition is not under control. He has moments where he really is almost in a type of trance and not with us. They have a GP appointment later today to see what the next steps are, so I guess I will hear ALL about it from Mum tonight. When I called the nurse at our GP's for Evi's repeat prescription I asked her for advice about how to move forward with my Dad and she was really helpful , although couldn't give me too much confidential information. She advised that Mum made a new appointment for Dad as it would seem that he wasn't responding to the new combi-medication either! Maybe in the end it would be best for him to go on insulin and to control his blood glucose level. Sounds simple, but how on earth are they going to monitor his glucose levels? It is a bus journey of 20 minutes to the GP's.... no car and yet another worry for Mum!

That's all I need! I haven't moved a yard in the traffic since I started telling you about Dad and time is ticking by. I think I will have to cancel my parents "drop in visit" and catch them on the phone later this evening.

**10.30am** An hour has passed, and I finally see the red brick Victorian building housing the oncology clinic. The journey always seems so long, an extra long hour as my thoughts drift to "what if" I don't get through this. I almost wish myself into a negative spiral on each journey up to the clinic. I enter the hospital car park. I am supposed to be at the out-patients clinic to take a blood test at 10.30 but I am going to be a few minutes late. Up and up I go in the car park; now at level 10 and still no parking space! It is OK now that I have to conquer 9 floors and a 10 minute walk to the outpatients, but in 6 hours post therapy I can assure you the return journey will be like facing the last 100 metres at the top of Mount Everest, and I will be using the lift!!

**10.45am** The phlebotomist had three attempts at hitting my vein, poor girl. I felt bad for her, but it was really painful! I look like I have been in the boxing ring, as the bruising is dreadful. It seems more and more difficult each visit. I must remember to ask my oncologist if that's normal, perhaps something to do with the therapy as I have always been a blood donor and it has never been an issue!

**11.00am** .....and now I play the long waiting game: wait for the blood to be analyzed; wait to be weighed; wait for the blood test result to be assessed by my oncologist; wait for the therapy cocktail to be mixed at the pharmacy; wait for the porter to transport my cocktail up to the ward; wait to see my oncologist for a review of my treatment plan; and then the infusion itself – endless!! However, on the bright side, I have met the most fantastic group of women. We seem like we have known each other for years, but I guess we are all on the same uncertain pathway and we are acting as our own support network. We all have the same treatment plan and therefore the treatment cycles all fall on the same date. It was a blow to our group when one of us was unable to take the therapy as her blood had not recovered from the last time and she was sent home. I feel my mobile phone vibrate in my pocket, indicating I have a message; here they have a relaxed view of the mobile phone, thankfully; otherwise I would be lost, trying to plan for my family. It was James of course! James is my husband; he works managing the workforce for Off-Shore, an oil-rig company, so by definition off shore means he is often away from home - in effect at sea! He remembered of course where I was today and told me he was holding my hand long distance!

Still sat waiting, all the other ladies have actually started with the infusion, but I haven't seen my oncologist yet. The nurse comes and sits next to me and says they are just reviewing my blood work and I will see the doctor soon - and not to worry. I always have a bad feeling when a nurse says "Not to worry Mrs Taylor. I am sure everything is OK" with an angelic smile. Another, 30 minutes and the doctor's office door opens and I am invited in for a chat. I sit shaking as he delivers the news to me that they have to delay my treatment for a few days as my white cells are too low and they are afraid to give me any chemotherapy today. They would give me something to help boost my white cells so I wasn't to worry. I felt like I was in a tunnel and his voice just echoed around me, I was shaking and couldn't think straight, I had a million questions to ask but couldn't formulate them; was this what they meant by 'chemo-fog'!!!! He continued to explain to me that I would need to come back to the hospital in the morning for another test, and again on Wednesday, and then see if they could schedule me sometime this week to have my infusion. I just sat nodding but I think I only absorbed half of what he was actually saying. So now my 6 hour visit to the hospital today is going to turn into a whole week of visits. I am not sure how I got up and out of his office but I did. Then my entire world seems to fall apart, and the tears spilt over. Suddenly, in the middle of a huge hospital bustling with people I have never felt more alone.

**1.00pm.** My "silent world" was thankfully interrupted by the phone; it was Mum to remind me that she needed running up to the specialists to get a new prescription of anti-inflammatory's

and had I remembered her appointment was 10am now and not 9am, would that still be OK with me and my work? Mum asks for so little help and she, of all of us, is perhaps the one who needs the most help but she just gets on with it. Actually, that is not so true; she doesn't only just get on with it, she hits it straight on! She has rheumatoid arthritis (RA) and is the secretary at the local RA patient support group. I am so proud of her! She has had 12 operations in total and now waiting for her second hip replacement, all due to the horrific lapses of remissions and disease progression. Now she seems more stable but the consequences of the swellings have damaged both cartilage and bones. This damage is irreversible. Her hands and wrist are twisted and bent like the drawings of the witch in the Hansel and Gretel fairy story, but for Mum this is not a fairy story, and will have no happy ending! I am lucky that she is so strong. I have not yet "unloaded" my burden upon her. How do you tell your already troubled Mum that you have breast cancer?

**2.00 pm** OK, got my "super booster drug-shot to stimulate my white blood cells, said a tearful goodbye to the ladies in the infusion group and head back to the car park. As I walked my mind wandered over to Evi, half way through her maths final by now; hope she is OK and most of all pain-free to concentrate! Three hours parking at the hospital has just cost a hungry £6 on my VISA card as the ticket popped out of the machine – with a friendly "*Thank you and see you soon again*" I guess it's just a standard car park pay machine but the words "*see you soon again*" hit like a knife in my chest. "Yep, see you again tomorrow", I thought, but next time just for a blood test! How was I going to manage both myself and Mum's appointment without alarming her to my truth! I wonder if I could have just taken a blood sample at the GP's, after all it is a simple test surely? It seems a waste of everyone's time that I have to use the oncologist clinic for a cell count?! They know best, I guess. Actually, the real reason my Mum has to trail out to the hospital is for the same reason that I do; she needs to have a blood test to get her next two months of medication. The GP can't write Mum a repeat prescription until he has looked at her blood test results. As far as we have understood, this is to check the toxic side effects of the anti-inflammatory drugs. She doesn't actually even see the specialist, only his nurse.

**3.15pm** The mug of tea at the kitchen table at Mum's tastes like Krug champagne! I can hear her talking but it seems like I am in a glass bubble. My headache which started in the car is now splitting my right and left brain apart! She is actually trying to whisper to me about the trip to the GP's with Dad! I shake myself together and come back to Mum's kitchen and into her world. It sounded like there had been a "Nobel Prize" medical breakthrough at the GP's today as Mum relayed her experience of events. She has even written down the highlights in Dad's monitoring diary. Monitoring diary? Since when has Dad had a monitoring diary?? She informed me it was all part of a new lease of life for Dad; he had been given a second chance to get up and lead a normal and happy retirement and, she added triumphantly, he actually now understands what is wrong with him! She reads from the little book, that he had a test called HbA1c and this gave us a good overall picture of situation. It was not a good picture obviously, so now he is going to have to take control himself using this device. A device looking like a pen in a case was thrust in my direction accompanied by a folder called "I am in control". Well, the title alone made me bite

my lip! I could feel the sting of the salt from tears welling up! In control; Oh, I wish, I thought. Luckily, Mum was so excited about this that she didn't notice the tears in my eyes. This was Dad's insulin and he was to monitor his blood 4-5 times a day. I saw for me a continual bus journey to the GP's. No, Mum informed me that they were to do this test at home. Then I was witnessing the unpacking of yet another device! The size of a Nano I-Pod I think! Mum explained that this was the thing he tested his blood on and without delay showed me how she performed this task. She did it with all the confidence of a professional but her own diseased hands challenged the overall outcome! She told me the nurse had spent ages training with Dad and telling him how the injection worked in his body, how he had to watch what he ate and then how he used the measuring device. Mum added, "It all seems so simple now, I'll show you!" As she continued chatting to me, her testing performance carried on, there appeared a spot of blood on her finger tip and she applied this to a bit of thin plastic and then stuck it in the black I-Pod thing!! In a few moments, there appeared a figure and Mum smiled with self admiration! I was amazed, Wow, this really could transform their life!! As I absorbed what I had just witnessed on the kitchen table, Dad rolled in to join us. The pathetic facial expression of self pity, I had grown to see over the last few months, had disappeared and a beaming smile appeared, along with a hug for me! Dad sat down and explained all that had happened at the GP's and occasionally Mum chipped in ...

**4.00pm** I looked at the kitchen clock; I want to be at home when Evi comes in from school. I have to hear how it had all gone. I am praying she is OK. I wanted to confirm with Mum that she had to be ready at 9.30am sharp tomorrow, so I could drive her to the hospital, and I wondered if I got Betty to drive her home that would be all right? She looked at first a bit put out but then said "Of course you will have to get to work won't you?" Work! Oh, I have still to call in to inform them I might be late in tomorrow as well! They have been so understanding at the office through this period! Mum still had the device in her hand and looking at it and said that she wished she had one of these to control her and then laughed loud at the her stupid wishful thinking. At the front door, we said our goodbyes, and she shouted after me, that she wasn't so sure if she liked my new hairstyle, as it looked a bit lifeless! I laughed back and said OK!! She added it was all those modern products that we put on our hair these days."It wasn't natural!" I just agreed with her!

As I drove away, I pulled the wig off and smiled to myself and placed it like a soft toy pet on the passenger seat and stroked the "lifeless" hair! Will I make it through this week without James at my side!

**5.30pm** I heard a car pulling up outside and as I looked through a gap in the kitchen blind I see the grey face of my precious Evi walking down the path with her best friend's mother in tow, carrying Evi's school bag! It can't be happening, is she sick? Not now please!

Evi explained that the examination has gone OK but was really difficult but she promised me she had done more than her best to answer all she could! What more could an anxious parent wish.

She had studied together with Becky after school and felt sick and was in pain. Joyce, Becky's mother, told me that they had been testing each other in answering mock examination papers in Geography and that Evi had got flustered and then I saw she was clearly in pain. My poor Evi, would she ever lead a normal teenage life? It worried me! Evi and I discussed the symptoms and she said it was a 5 on the scale of 1 to 10 of pain and no urgent toilet visits. I thought I would call the gastroenterology unit to ask their advice! This was an important time in Evi's life and I had to help her get through it. They suggested on the phone to increase her maintenance dose in case there was a potential flare up of the disease, but they were not able to suggest anything else unless they could take a simple blood test to check for any signs of inflammation.

It seemed today that a simple blood test was the clue to controlling my whole family!

**6.00pm** To try to take my mind off my day and to get Evi out of her room and away from her books, we went off to cheer on Wills in the county trials! He was running in the 1500 metre race! We stood there in the pouring rain, hugging each other while Wills dipped over the finish line, second in his heat. We just crossed our fingers and hoped that his time gets him into the finals! He looked so amazing as he gave his all around the last bend! I felt so proud inside! The race track kept coming in and out of vision; it felt like all my energy was draining slowly from my body through my muddy wellington boots, and running across the field, just like I had unplugged a bath full of water! I fight to take control back. All my bones are screaming in pain at me! Wills comes bouncing over and I give him what seems like a very unstable hug! I wondered if it was the wonder drugs working overtime to make new white cells for me? I will have to wait until the morning to see! Another trip up to the hospital outpatients ahead of me!

**7.00pm** Another successful family effort to produce an old favourite "Spaghetti Bolognese" for supper. The supper table has always been the family's discussion platform! Here everything was taken up and an attempt at a solution was presented, and tonight was no exception to that rule! I told them about their grandfather's day and how he was able to test his own blood many times a day to control his diabetes. The children showed great interest, even Evi chipped in and said "I would even prick my finger several times a day if I could prevent my pain coming before it did, and I hate needles!" "Poor girl" I thought, although she seemed better than earlier this afternoon. Could the medication have kicked in so fast? Then I informed them about my day. I spoke slowly with the left side of my brain, holding to the facts and trying to put "on mute" the right side which was screaming inside me to pour out my real emotions to someone. I held back! I explained that I might have to take a lot of time off work, but try to catch up in the evenings, and to travel up to the hospital each day for a blood test to make sure that the drug is working and then hopefully I can have my therapy so I am still finished in time for the start of the school summer vacation. Oh, I just have to be! I can't stand the whole summer like this! Please no more delays now!

**Later .....**

Huddled over holiday catalogues – I noticed Evi was more interested in discussing the flight distance than the colour of the swimming pool water in the hotel adverts which seemed to be Wills main focus! Poor Evi, but we have no choice but to just go for it and hope that she is in a good pain free time! The family needs something to look forward to now!

So that rounds off my Monday and I am sure you are wondering why I am writing about my life in this chapter? Well, firstly I am not unique in this situation? Hundreds of families would be able to share a similar story with you but could the situation be made easier for us? None of my family are trying to find a cure for a rare genetic disease but just manage as best we can to cope, and get through our everyday, with a chronic illness. As the population grows older demands on the health care system will increase, but how will this be managed? It worries me, if I survive this round what is waiting for me? Chronic disease management needs re-addressing and a drive to move the management into the local community would be a possible approach that would certainly address my family's needs! I am not thinking only from a cost saving aspect but also to maintain a quality of life for patients dealing with disease on a daily basis, just like my family. Look at my situation, four of us dealing with the trauma's of chronic disease, we all accepted that we have the disease, we are dealing with it in our own way but is there a way forward to make it easier for us to manage away from the clinical setting, give us - the patient - some control of our own disease...and our own lives?

If such simple technology can give back control to my father, and give Mum her life and husband back, then it gives me hope of a brighter future! A future where patients with chronic diseases could predict a relapse in remission, and prevent pain and the effects a flare up has on the disease progression, as in the case of my Mum. Could we monitor the possible toxic side effects of the potent long term medication from the comfort of the armchair or at the high street pharmacy?

As a mother, a daughter and a cancer patient I certainly hope that at least Evi's future will give her the control of her own disease management .....